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Validating the Resident VIEW in Long-Term Care Settings: Final Report to Oregon Department of Human Services, Aging & People with Disabilities Division

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2021

Validating the Resident VIEW in Long-Term Care Settings

Findings from Validating the Resident VIEW Instrument in Nursing Homes (IAA #155717-0) and

Validating the Resident VIEW Instrument in Community-Based Care (IAA #158501)

Final Report to Oregon Department of Human Services, Aging & People with Disabilities Division

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10/15/2021

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Acronyms

ADL	Activities of Daily Living
AFH	Adult foster home
AL/RC	Assisted living/residential care
CBC	Community-based care
CFA	Confirmatory Factor Analysis
DHS	Department of Human Services
EFA	Exploratory Factor Analysis
IADL	Instrumental Activities of Daily Living
IOA	Institute on Aging
LTC	Long-term care
MoCA	Montreal Cognitive Assessment
NH	Nursing home
PELI	Preferences of Everyday Living Inventory
PHQ	Patient Health Questionnaire
PSU	Portland State University
QOC	Quality of Care
QOL	Quality of Life
QoL-AD	Quality of Life in Alzheimer's Disease Scale
VIEW	Voicing Importance, Experience, and Well-being

Validating the Resident VIEW in Long-Term Care Settings[1]

Executive Summary

Introduction.

In 2015, Portland State University Institute on Aging (PSU/IOA) received a grant from the Quality Care Fund to develop the Resident VIEW (Voicing Importance, Experience, and Well-being), a measure of person-centered care (PCC) from the perspective of residents. Structured open-ended interviews were conducted with residents living in nursing homes (NH), assisted living (AL/RC), and adult foster homes (AFH) settings to learn more about their everyday concerns, values, and preferences. Each interview focused on one of eight domains of PCC. These domains had been identified from the literature and in prior research. *Personhood*, or as described by residents as being "treated as a person," is central. Then come five areas that directly affect the quality of daily life of residents: *opportunities for residents to engage in meaningful activity, relationships with staff, personalized care, staff knowing the person,* and *autonomy and choice*. The *organizational and physical environments* provide the immediate context in which residents live and people work. This framework recognizes the importance of the physical space and the culture of the organization.

This initial project resulted in 63 items, or close-ended statements, across the eight domains. These were tested with a small sample of residents in each type of setting (NH, AL/RC, AFH). This feasibility project indicated that a large-scale validation study was feasible. **The Resident VIEW is unique in that residents are asked about both the <u>importance</u> of an item as well as whether they <u>experience</u> the practice reflected by the item.** Understanding both what residents view as important as well as what they experience allows for more individualized planning and assessment of PCC

[1] Findings from *Validating the Resident VIEW Instrument in Nursing Homes* (IAA #155717-0) and *Validating the Resident VIEW Instrument in Community-Based Care* (IAA #158501). Final Report to Oregon Department of Human Services, Aging & People with Disabilities Division

services. As an example, an item from the physical environment domain asks: “how important is it that your room is arranged and decorated the way that you want it?” and “Is your room arranged and decorated the way that you want it?” In a person-centered environment, we would expect consistency between responses to these questions.

In 2017, PSU/IOA received funding through the Civil Money Penalties Fund to test the validity of the Resident VIEW in Nursing Homes. In 2018, the team was awarded funds from the Oregon Quality Care Fund to replicate the validity of the Resident VIEW in AL/RC and AFC settings. This report describes both validation projects, including the methods used to develop the samples and collect data, the analyses conducted with resident data, results, and the final Resident VIEW measure.

In addition to validating the Resident VIEW, a goal of the research was to reduce the length of the final measure by identifying the best items. A short form of the Resident VIEW is necessary to make it practical for use in quality improvement efforts and in research, and, importantly, to be less burdensome for residents and organizations to administer.

Research Questions

Analysis first addressed two questions related to the performance of the measure:

1. What are the best items for predicting key outcomes, including quality of life (QOL), quality of care (QOC), and resident satisfaction?
2. How do residents respond to individual items of the Resident VIEW? That is, which items appear to resonate most? Which items are confusing? Which items are difficult to answer?

The voices of residents are underrepresented in efforts to improve quality and PCC. This is especially true for residents living with dementia. To obtain as many of those voices as possible, we did not use cognitive assessments to eliminate residents from participation. However, we did administer a cognitive assessment to identify a level of cognitive functioning for participants who completed or nearly completed the Resident VIEW to answer this question:

3. How well does the Resident VIEW perform for people living with cognitive impairment?

Context is important in shaping long-term care and organizations vary in important ways. In addition to setting type, we collected data about geographical location, ownership type, and various administrative characteristics to address the following questions:

4. Is there a common measure that performs well in all settings or are separate measures needed for each LTC setting type? That is, which items, if any, perform well across all types of settings? Which items are unique to each setting?

5. What is the relationship between Resident VIEW ratings and facility characteristics (e.g., facility type, quality, size, Medicaid population), administrator (e.g., tenure, educational background), and staff (e.g., job satisfaction, assessment of person-directed care)?

6. How do Resident VIEW interviewer assessments of quality compare to other quality indicators (i.e., 5-star rating, number of deficiencies)? How can qualitative data reported by interviewers augment understanding of quality as measured by quality indicators?

Three open-ended questions were posed to residents to gather more detailed information about items related to feeling or not feeling like home, the most important decisions they made every day, and recommendations for improving the way the organization was run. This resulted in a rich data set that addressed the following questions:

7. What do residents say makes a residential setting feel like home? Not feel like home?
8. What are the most important decisions residents make on a daily basis?
9. How do residents feel the setting where they live could be run better?

Sample

The overall objective of the sampling design for this series of studies was two-fold. First was to ensure generalizability to a well-defined population of NH, AFH, and AL/RC residents. Second was to ensure adequate representation of *heterogeneity* among settings across Oregon, especially as it relates to regional variation. We excluded memory care communities in this validation study due to the length of the survey and the difficulty that people with cognitive impairment might have understanding and completing the interview. However, we did not exclude residents on the basis of cognitive status and strived to include all who could consent to participate and understand the questions. The table below shows the data sources and final resident sample for the study.

Table 1. Data source by setting type

	NH	AL/RC	AFH
Eligible number of settings at project start	93	535	1,483
Number of settings in the final sample	32	31	125
Resident interviews	258	241	220

Additional data were collected, including surveys of 215 direct care staff from NH and 84 staff from AL/RC; 252 interviews with administrators, nursing leaders, and owners/providers across setting, and administrative data from all settings. Analysis of these data have not been completed and are not described in this report.

Results – Final Selection of Items (Research Questions 1, 2, 4, 6)

Items were examined by domain and the strongest items from each domain were selected. This was done to ensure that the final measure represented the range of PCC practices. Each item was examined in terms of its overall importance rating by residents, presence of unmet need (measured by incongruence between very important and experience), its explanatory power within the domain, and for its association with four outcome measures. Except where noted, each item selected was significantly related to at least three of these factors. Spontaneous comments by residents in response to items were also examined. This process helped to determine how residents thought about the items and the relevance of the item to the measure. Detailed information about each item is presented in Part 1.B., which provides descriptions quantitative and qualitative findings for every item within each domain.

Analysis revealed that a core set of seven items met criteria for inclusion across all setting types (NH, AL/RC, and AFH). Some items met criteria for only one or two of the settings. Those working in a specific type of setting can use site-specific items along with the cross-setting items. This means that the NH Resident VIEW tool may include up to 18 items, the AFH Resident VIEW is a possible 13 items, and the AL/RC Resident VIEW contains up to 14 items. Below are lists of those items and the associated domains. They are phrased in terms of resident experiences rather than the importance of the items.

Cross-setting core items

1. Does this place feel like home? *(Physical environment)*
2. Do you do things you care about? *(Meaningful activity)*
3. Do the people who work here take the time with you that you need?[2] *(Personalized care)*
4. Do the people who work here make you feel comfortable asking for help?[1] *(Personalized care)*
5. Do the people who work here know how you like to spend your time? *(Knowing the person)*
6. Do the people who work here laugh with you? *(Relationship with staff)*
7. Do the people who work here have a good attitude? *(Organizational environment)*

Additional items for Nursing home residents

1. Is your room arranged and decorated the way you want it? *(Physical environment)*
2. Is it peaceful here? *(Physical environment)*
3. Do you feel you have a purpose? *(Meaningful activities)*
4. Do the people who work here know who is important to you? *(Knowing the person)*
5. Do you have privacy when you want it? *(Autonomy and choice)*
6. Do you do things for yourself when you want to? *(Autonomy and choice)*
7. Do you feel free to express your opinions about the things you do not like here? *(Autonomy and choice)*
8. Are the people who work here gentle when they are helping you? *(Personalized care)*
9. Do the people who work here show that your needs are important to them? *(Treated like a person)*
10. Do the people who work here answer your questions? *(Treated like a person)*

[2] Note: No items met criteria of sufficient evidence for inclusion for personalized care across all settings. However, these items had sufficient evidence for inclusion across two settings, and ambiguous support in one setting for personalized care. No items for the domain *autonomy and choice* met these standards for inclusion.

11. Do the people who work here have time to help you when you need it? *(Organizational environment)*

Additional items for Adult Foster Care Residents

1. Can you easily get around outside of your room? *(Physical environment)*
2. Do you spend your time the way you want to? *(Autonomy and choice)*
3. Do you feel you have a purpose? *(Meaningful activities)*
4. Do the people who work here take into account your health needs? *(Personalized care)*
5. Do the people who work here know the kinds of things you are interested in? *(Knowing the person)*
6. Do the people who work here know what makes a good day for you? *(Knowing the person)*

Additional items for Assisted Living and Residential Care Residents

1. Do you feel welcome in areas outside of your room? *(Physical environment)*
2. Do the people who work here know how you like to have things done? *(Knowing the person)*
3. Do the people who work here know who is important to you? *(Knowing the person)*
4. Do you spend your time the way you want to? *(Autonomy and choice)*
5. Do the people who work here show that your needs are important to them? *(Treated like a person)*
6. Can you talk to the administrator when you have a problem? *(Organizational environment)*
7. Do the people who work here have time to help you when you need it? *(Organizational environment)*

Results from Open-ended Questions (Research Questions 7, 8, 9)

Research Question 7. Feeling at Home.

Five overarching and overlapping themes emerged from the open-ended responses:

- Whom I'm with: Social Connection
- What I Can Do: Autonomy, Control, and Choice
- Where I Am: Engagement with the Physical Environment
- How I'm Treated and How Things Work: Organizational Environment
- How I Feel and What I Think: Perceptions and Coping

Overall, residents in AFH were most likely to report their living situation felt like home. They were more likely to have developed relationships with the providers, have access to common living areas, and more say in how they spent their time. They were more likely to be engaged in contributing to the community.

The qualitative comments regarding satisfaction with the setting are consistent with the quantitative data. Through the quantitative data, we know that the setting feeling like home is associated with the four outcomes that were measured in this study, including resident satisfaction. Qualitative comments provide important insights into what makes a setting feel like home or not feel like home. A substantial number of residents, including those who express satisfaction with the setting, suggest that a congregate care setting can never be home. For those individuals, optimizing the elements of home identified here are critical to make the experience the best it can be. With time, those individuals may also begin to feel their setting is home.

Research Question 8. Supporting Autonomy through Daily Decisions

After asking residents about the importance of each item in the *Autonomy and Choice* domain, our team asked residents in assisted living, residential care, and adult foster home settings, "what is the most important decision you make here?" Residents mostly make decisions about their daily lives – what to do, what to eat, and how to spend their time. This reinforces the importance of staff understanding the daily routines and ways that each resident finds as meaningful ways to live and spend their time. Decisions related to community life, such as contributing to the community, communication, and engaging with others, were most important to some, but account for only 15% of decisions described. About a quarter of the comments made were related to meaningful activities and how residents choose to spend their time. Nearly one-third (31%) of residents reported making no decisions, didn't know if they made decisions, or had relinquished decision making to others. These responses are consistent with different

domains of the Resident VIEW, suggesting that use of the short form may be a useful tool to chart progress toward PCC as experienced by residents.

Research Question 9. Improving Quality and the Organizational Environment

As a follow-up to the Resident VIEW item, “Do you feel this place is run well?” in the *Organizational Environment* domain, we asked participants the open-ended question, “How could this place be run better?” Responses were wide ranging and although many did not have specific suggestions for improvement, the key themes emerging among those that did included: staffing, staff responsiveness and quality care, administrator qualities and organizational factors, the physical environment, relationships and meaningful engagement, and food/dining.

Staffing is a major issue. Residents know it is a challenge to recruit and retain staff, but from their experiences, low staffing means long wait times, lack of follow-through, poorer care, and difficulty forming relationships. Some residents recognized systemic issues of direct care workers’ wages as a factor in recruitment and job turnover. Staffing issues are related to low expectations with respect to care, forming bonds, and, for those with physical disabilities, navigating their space and engaging in meaningful activities.

Low staffing was often coupled with concerns about quality of care – including the lack personalized care or even lack of care in general. Although AFH residents generally had fewer suggestions for improvement than residents in other settings, it is important to emphasize that residents in all settings made suggestions for improvement and even as other residents across those same settings expressed contentment with the organizational environment.

Validating the Resident VIEW in Long-Term Care Settings

Introduction

Background

For decades, advocates, consumers, family members, policy makers, researchers, and regulators have worked to improve the quality of residential long-term care (LTC). In Oregon, this care is provided in multiple settings, including nursing homes (NH), assisted living (AL), residential care (RC), and adult foster homes (AFH). Quality improvement efforts, often referred to as "culture change," emphasize person-centered care (PCC) and quality of life (QOL) as well as quality of care (QOC). Although definitions of these key concepts vary, there is growing consensus that these concepts are complex and multi-dimensional. A proliferation of research over the past 20 years has resulted in new ways of measuring PCC, QOL, and QOC. Despite the emphasis of the resident as a person at the center of care, however, residents' voices have rarely included as part of this work. Until resident voices are heard, it is not possible to know whether LTC organizations are truly person-centered and are supporting QOL as defined by the resident.

In 2015, Portland State University Institute on Aging (PSU/IOA) received a grant from the Quality Care Fund to develop the Resident VIEW (Voicing Importance, Experience, and Well-being), a measure of PCC from the perspective of residents. As described by White, Elliott, and Hasworth (2016), structured open-ended interviews were conducted with residents living in NH, AL/RC, and AFH settings to learn more about their everyday concerns, values, and preferences. Each interview focused on one of eight domains of PCC. These domains had been identified from the literature and in prior research (see Figure 1). Personhood, or as described by residents as being "treated as a person," is central. Then come five areas that directly affect the quality of daily life of residents: opportunities for residents to engage in meaningful activity, relationships with staff, personalized care, staff knowing the person, and autonomy and choice. The organizational and physical environments provided the immediate context in which

residents live and people work. This framework recognizes the importance of the physical space and the culture of the organization.

This initial project resulted in 63 items, or close-ended statements, across the eight domains. These items and other measures of interest were tested with a small sample of residents in each type of setting (NH, AL/RC, AFH). Results indicated that a large-scale validation study was feasible.

The Resident VIEW is unique in that residents are asked about both the <u>importance</u> of an item as well as whether they <u>experience</u> the practice reflected by the item. Understanding both what residents view as important as well as what they experience allows for more individualized planning and assessment of PCC services. As an example, an item from the physical environment domain asks: "How important is it that your room is arranged and decorated the way that you want it?" and "Is your room arranged and decorated the way that you want it?" In a person-centered environment we would expect consistency in responses to these items.

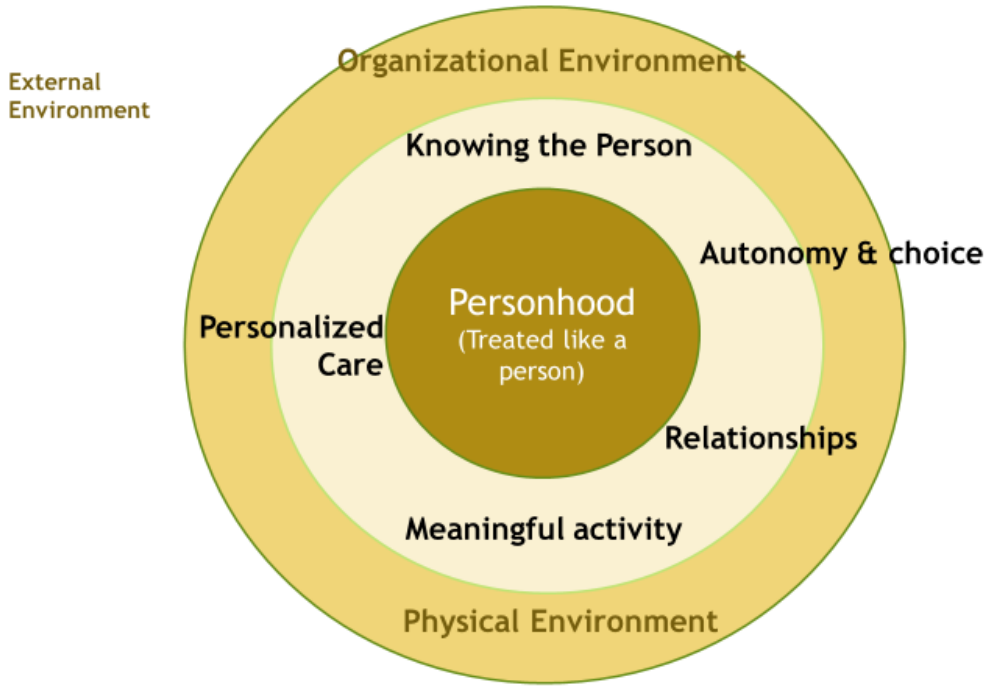


Figure I-1. Conceptual Framework for the Resident VIEW

In 2017, PSU/IOA received funding through the Civil Money Penalties Fund to test the validity of the Resident VIEW in Nursing Homes. The initial results of this study are presented in White, Tunalilar, Hasworth and Winfree (2019). In 2018, the team was

awarded funds from the Oregon Quality Care Fund to replicate the validity of the Resident VIEW in AL/RC and AFC settings. This report describes both validation projects, including the methods used to develop the samples and collect data, the analyses conducted, results, and the final Resident VIEW measure.

Research questions

In addition to validating the Resident VIEW, a goal was to reduce the number of items in the final measure by identifying the best items. A short form of the Resident VIEW is necessary to make the Resident VIEW practical for use in quality improvement efforts and in research by being less burdensome for residents and organizations to administer. With that end in mind, analysis first addressed two questions related to the performance of the measure:

1. What are the best items for predicting key outcomes, including QOL, QOC, and resident satisfaction?
2. How do residents respond to individual items of the Resident VIEW? That is, which items appear to resonate most? Which items are confusing? Which items are difficult to answer?

As described previously, the voices of residents are underrepresented in efforts to improve quality and PCC. This is especially true for residents living with dementia. To obtain as many of those voices as possible, we did not use cognitive assessments to exclude residents from participation. However, we did administer a cognitive assessment to identify a level of cognitive functioning for participants who completed or nearly completed the Resident VIEW to answer this question:

3. How well does the Resident VIEW perform for people living with cognitive impairment?

Context is important in shaping long term care and organizations vary in important ways. In addition to setting type, we collected data about geographic location, ownership type, and various administrative characteristics to address the following questions:

4. Is there a common measure that performs well in all settings or are separate measures needed for each LTC setting type? That is, which items, if any, perform well across all types of settings? Which items are unique to each setting?
5. What is the relationship between Resident VIEW ratings and facility characteristics (e.g., facility type, quality, size, Medicaid population), administrator characteristics (e.g., tenure, educational background), and staff characteristics (e.g., job satisfaction, assessment of person-directed care)?

6. How do Resident VIEW interviewer assessments of quality compare to other quality indicators (i.e., 5-star rating, number of deficiencies)? How can qualitative data reported by interviewers augment understanding of quality as measured by quality indicators?

Three open-ended questions were posed to residents to gather more detailed information about three topics: feeling or not feeling like home, the most important decisions they made every day, and recommendations for improving the way the organization was run. This resulted in a rich data set that addressed the following questions:

7. Feeling like home:
    a. What do residents say makes a residential setting feel like home? Not feel like home?
    b. What can residential settings do to help residents feel more like home?
    b. How is “feeling like home” related to facility, staff (e.g., job satisfaction, assessment of person-centered care), and administrative characteristics?
    c. How are qualitative responses to questions about “feeling like home” associated with different types of settings? (i.e., NH, AL/RCF, AFH)
8. Important decisions:
    a. What do residents say are the most important decisions they make at the facility?
    b. How do these responses relate to level of resident reported autonomy, quality indicators, overall satisfaction, and quality of life?
9. Improving organizations:
    d. What do residents suggest as ways for improving the way facilities are run?
    e. How do suggestions relate to characteristics of the facility (e.g., quality, size, Medicaid population), administrator (e.g., tenure, educational background), and staff (e.g., job satisfaction, assessment of person-directed care)?

Organization of the Report

Following this introduction, the report includes an overview of the sample and methods used in conducting the validation research. The results are presented in two parts. First are findings from analysis to validate the Resident VIEW, including the final measure. Second, we elevate resident voices by presenting findings from analysis of the three open-ended questions. We close with a discussion of findings, recommendations, and conclusions. Each component is described briefly below.

Sample and Methods. We describe the sampling processes used to identify long-term care communities and the procedures used to recruit communities and the residents who lived there. We describe the characteristics of the communities and residents who participated in the study. Overviews of other data included in analysis are presented, such as regulatory data and information collected from various providers. We describe the qualitative analyses used to capture resident voices. This included analysis of responses used to identify meaning attributed to items, relevance of items to residents, and areas of confusion. Open-coding and thematic analysis was used to examine responses to the open-ended questions regarding homeness, decision making, and recommendations for improvement.

Results, Part 1. Validation of The Resident VIEW. We address research questions 1-6 in this section of the report. We first present the final Resident VIEW measures. The measures include items that best predict outcomes of interest (i.e., QOL, QOC, resident satisfaction) and were identified through both quantitative and qualitative analysis. We found a core set of questions that were predictive of outcomes across all setting types. Each setting had an additional set of items unique to that setting. Second, we describe findings for each item by domain. These subsections include summaries of resident comments and all of the statistics associated with each item.

Results, Part 2. Elevating Resident's Voices. This part of the report addresses research questions 7-9 and is presented in three sections. Each corresponds to one of the open-ended questions: Creating a home environment, supporting resident daily decisions, and resident recommendations for improvement.

Discussion, Recommendations, and Conclusions. This final part of the report provides an overall summary of findings. Recommendations for use of the Resident VIEW moving forward are made as well as recommendations for quality improvement based on resident comments and observations. We conclude with suggestions for further examination of the Resident VIEW.

Methods

Sampling Design

The overall objective of the sampling design for this series of studies was two-fold. First was to ensure generalizability to a well-defined population of NH, AFH, and AL/RC residents. Second was to ensure adequate representation of *heterogeneity* among settings across Oregon – especially as it relates to regional variation. To achieve this objective, we used a two-stage stratified sampling design, separately for each setting type. These studies were approved by Portland State University's Institutional Review Board.

Table II-1 Information about data source by setting type

	Nursing Homes	Assisted Living	Adult Foster Homes
Eligible number of settings at project start	93	535	1,483
Number of settings in the final sample	32	31	125
(a) Resident interviews	258	241	220
(b) Direct-care staff surveys	215	84	Not applicable
(c) Administrator, nursing, and owner or provider interviews	55	47	150
(d) Interviewer observations	139	46	155
(e) Administrative data	32	31	125

The first stage for each setting involved recruiting a stratified random sample of facilities from a larger facility list. The target population at this stage included all licensed AL and AFH settings in Oregon. For NH study, it included all NH located within a 100-mile radius of Portland, Oregon or 70 percent of all licensed NH in Oregon (Table II-1). Data collection was separately conducted, and stratifying variables differed slightly by setting type due to differences in availability of information (NH=rurality, profit designation, and quality; AL=region and quality; AFH=region).

The second stage involved recruiting residents from participating NH, AL/RC, and AFH, using the resident census or a list of current residents provided by the setting. We considered all residents eligible except non-English speakers, those who were comatose or had altered levels of consciousness, those who were too ill to participate, or those who were nonverbal and unable to communicate. Although our initial strategy was to randomly select residents from each setting, we interviewed all eligible residents in many participating settings. Overall, due to this complex sampling design and potential differential selection into the sample, we constructed design and non-response weights to account for differences in probability of selection of settings and residents into the final sample.

Survey Process

We recruited settings into the study using multiple methods of contact. The Department of Human Services sent out multiple provider alerts to administrators across the state to inform them of the study. The project manager also attended meetings with partner organizations, such as the Oregon Health Care Association, to personally introduce the study and answer questions from providers. To increase participation among adult foster homeowners, we also met with union leaders and solicited their support.

All providers in the sample received a letter in the mail describing the study and informing them that they were randomly selected for participation. We then followed up by phone and email, with up to five outreach attempts. Some administrators and adult foster home providers received more than five outreach attempts if we had reached them and had a promise of recruiting them into the study. This was also the case when providers requested to reschedule our visit. Interviewers called and scheduled their own visits for adult foster homes. Facility visits were coordinated by the project manager to ensure adequate staffing appropriate to the size and location of the facility. We sent the administrator information about the study and a one-page description in plain language to distribute to residents in advance of the visit.

At the setting, the interview team obtained a list of residents from the provider and determined who met the inclusion and exclusion criteria for the study. All eligible residents were divided up amongst team members at facilities and interviewers then went in the order they were listed on their respective face sheets. We often returned to larger facilities in an attempt to interview more residents if there were a sufficient number remaining in the sample who were eligible to participate. All attempts to interview residents and outcomes were recorded. Upon meeting the residents, interviewers would introduce themselves and the study and gauge resident interest and ability to participate. If the person was interested, we would proceed with the informed consent and the interview.

When we wrapped up our site visits, we would meet with the administrator or AFH owner, or whomever was our point of contact, to obtain information from their records for residents who consented and participated in the study. This included move-in date, payment source, and birth date. We would also conduct the provider interview at this time if we had not done so already. Upon conclusion of the visit, the interview team also completed the sample cover page, which described the number of residents on the census, number and reasons for exclusions, and the number of interviews complete and incomplete (including cases and non-cases, as defined below). Our project team maintained records of all recruitment outreach attempts and all data from sample cover pages from each community we visited. Interviewers also recorded their observations about the setting.

Sample and Data

Table II-2. Descriptive statistics for settings by type

	NH		AFH		AL/RC	
	Target Population	Sample	Target Population	Sample	Target Population	Sample
Size						
Five beds (%)	X	X	72 [1,063]	79 [99]	X	X
Avg. licensed beds	81.4	78.7	X	X	51.1	60.1
Medicaid contract (%)	95 [88]	94 [31]	90 [1,341]	91 [115]	77 [284]	77 [24]
Non-profit (%)	19 [18]	21 [7]	X	X	5 [20]	7 [2]
Rural/Frontier (%)	28 [26]	33 [11]	25 [367]	21 [27]	41 [153]	45 [14]
Region						
Portland Metro	65 [60]	64 [21]	56 [828]	64 [81]	40 [147]	42 [13]
Willamette Valley	30 [28]	30 [10]	22 [327]	18 [22]	28 [102]	29 [9]
Southern Oregon	0 [0]	0 [0]	14 [204]	10 [13]	14 [53]	13 [4]
Eastern Oregon	5 [5]	6 [2]	8 [124]	8 [10]	18 [68]	16 [5]
Total	93	33	1,483	126	370	31

Notes: Totals may not add up to 100 percent due to rounding. X indicates that information is not available for that setting. Counts are reported in brackets. Information reported here are based on the largest sample size and might differ slightly across different analyses due to missing values.

Portland Metro = Clackamas, Columbia, Multnomah, Washington
Willamette Valley = Benton, Clatsop, Lane, Lincoln, Linn, Marion, Polk, Tillamook, Yamhill
Southern Oregon = Coos, Curry, Douglas, Jackson, Josephine
Eastern Oregon = Baker, Crook, Deschutes, Gilliam, Grant, Harney, Hood River, Jefferson, Klamath, Lake, Malheur, Morrow, Sherman, Umatilla, Union, Wallowa, Wasco, Wheeler

After data collection was finalized, data were checked for errors and each case was assessed using detailed information about the interviews – including interviewer notes as well as completion records (e.g., what percent of questions were answered before break-off). Overall, 105 cases in the NH data set, 25 cases in the AFH data set, and 15 cases from the AL/RC data set were removed prior to final analyses. NH cases had a higher rate of removal because we originally kept all break-off interviews for the NH study. Due to high rate of removal in the NH study, we switched to the practice of entering AFH and AL/RC cases only if they completed at least five domains of the Resident VIEW.

Settings that were visited. Table II-2 shows characteristics of NH, AFH, and AL/RC settings in the original target population and our sample. Overall, our sample was comparable (with ~5%) to the target population in terms of Medicaid contract, non-profit, and rurality. For NH and AL/RC, we were also able to mirror the distribution of capacity in the target population. For AFH and AL/RC, the settings among our respondents were slightly larger compared to the general population. For AFH, they were also slightly more likely to be located in the Portland Metro area.

Responding residents. Overall, responding residents in our samples mirrored characteristics of NH, AFH, and AL/RC residents in Oregon (see Table II-3 below). AL/RC residents were more likely to be female compared to NH and AL/RC residents. AL/RC residents were also significantly older compared to NH and AFH residents. AFH residents were slightly more diverse compared to NH and AL/RC residents. Both NH and AFH residents were significantly more likely to pay using Medicaid funds compared to AL/RC residents. NH residents were significantly more likely to share their rooms compared to AFH and AL/RC residents. Length of stay among AFH and AL/RC residents was similar and higher compared to NH residents. AFH and AL/RC residents had similar reported quality of life scores, and both AFH and AL/RC residents had significantly higher scores compared to their NH counterparts. Although PHQ-9 scores were slightly higher among NH residents compared to AL/RC residents, depressive symptoms did not differ significantly across different settings ($p > .05$).

Table II-3. Characteristics of residents in the analytic sample and comparisons to Oregon-wide studies

	NH (n=258)	OSU17 Data	AFH (n=195)	CBC18 Data	AL/RC (n=227)	CBC18 Data	Pooled (n=680)
Sex							
Male	42	42	47	38	31	30	39
Female	58	58	53	62	69	70	61
Median age	73	X	72	X	84	X	77
Age groups (years)							
<65	20	20	29	23	8	6	18
65-74	34	24	29	19	19	12	27
75-84	27	28	22	21	24	30	24
85 and over	20	28	20	38	49	51	30
Race/ethnicity							
Non-Hispanic White	93	83	87	86	97	90	93
Other	7	17	13	14	3	10	7
Medicaid receipt							
No	39	40	32	43	58	58	43
Yes	61	60	68	57	42	42	57
Room type							
Private	42	X	90	X	85	X	72
Shared	58	X	10	X	15	X	28
Length of stay							
<6 months	48	96	18	36	20	30	29
6-12 months	14	2	14	16	13	15	14
1-2 years	17	1	17	9	26	16	20
More than 2 years	21	1	51	41	42	38	37
QoL-AD (range=0-3)	1.63	X	1.83	X	1.81	X	1.75
PHQ-9 (range=0-3)	0.80	X	0.76	X	0.70	X	0.76

Notes: Only residents with non-missing, valid data were included for each statistic. X indicates a statistic is not available for that group. Totals may not add up to 100 percent due to rounding. Numbers highlighted show similarities between Resident VIEW sample and Oregon-wide studies.

Data. We collected information from multiple types of respondents, including residents, direct-care staff, administrators, nursing, and AFH owner/providers. Our interviewers also took notes of their observations. Finally, we retrieved administrative data about settings that we visited. Table 1 shows a detailed count for availability of data by setting type. Although all data gathered for this study are described below, this report includes findings only from resident interviews. The research team will continue to analyze and report on other data in the future.

Resident interviews.

These data were collected via face-to-face structured interviews using a structured questionnaire (see Appendix A and B for copies of NH and AFH/AL/RC questionnaires). The original questionnaire included 63 items across 8 domains from the Resident VIEW measure, asking about how important residents perceived each item and to what extent they experienced it. The questionnaire was revised after the NH study to include additional questions related to issues that came up during the NH study, such as those related to food (eating meals when the resident wants to; satisfaction with food), informal/family caregiving, social support, and certain demographic information (e.g., whether the resident had had any children). In addition, the Montreal Cognitive Assessment (MoCA) was moved from the middle of the questionnaire where it had been in the NH study, to the end of the Questionnaire, and the response categories for the Katz ADL scale were revised to better reflect the original scale. As such, AL/RC and AFH data sets include a larger number of questions compared to NH data set.
Table II-4 below shows names, number of items, and conceptual summary for each of the eight domains in the original Resident VIEW tool. The plus signs indicate items that were added after the NH study (a total of 3 items). Each domain was constructed to tap into different areas of practice that directly support and/or reinforce personhood – a concept that is the central focus of this tool – that is, each person has inherent value and is worthy of respect.

The questionnaire also included the Montreal Cognitive Assessment (MoCA; Nasreddine et al., 2005), the Quality of Life for Alzheimer's Disease (QOL-AD; Logsdon, Gibbons, McCurry, & Terri, 2002), Katz Index of Independence in Activities of Daily Living (Hartigen, 2007), Patient Health Questionnaire (PHQ-9; Saliba et al., 2012), and satisfaction items based on the work of Kane, Lum, Cutler, Degenholtz, and Yu (2007). Finally, we collected information about each resident's age, gender, race/ethnicity, room type (private or shared), move-in date, and primary method of payment (Medicaid or private).

Table II-4 Domain descriptions

Domain	# of Items	Concept
Physical Environment	7	Resident's perceived degree of control over, satisfaction with, and belonging to the physical environment
Meaningful Activity	10+1	Resident's perceived degree of engagement in various activities that have meaning to the person and provide a sense of purpose
Personalized Care	8	Resident's evaluation of the extent to which care provided accounts for and are catered to their wishes, needs, and skill set
Knowing the Person	7	Resident's evaluation of how well people who work at the setting know the resident beyond care needs
Autonomy/Choice	9+1	Resident's perceived degree of control over choices and decisions that affect them directly or indirectly
Treated Like a Person	8	Resident's evaluation of how well people who work at the setting relate to and treat the resident
Relationships with Staff	7	Resident's evaluation of how good their relationships are with people who work in the setting
Organizational Environment	7+1	Resident's evaluation of how the setting is run and resident's perceived degree of control over it

We also asked residents the following three open-ended questions:

- "What makes/would make [this setting] feel like home?"
- "What are the most important decisions you make?"
- "How could this place be run better?"

Resident responses to these three questions were coded and analyzed by our team members. These analyses constitute the qualitative findings section of this report, separately for each of the three concepts (home environment, decision-making, and organizational improvement). The sample varied somewhat by question. The “home environment” question excluded short-stay NH residents who were least likely to find this question important or the setting like home. The “important decisions” question focused only on CBC residents. Finally, the “organizational improvement” question included all residents who answered the question.

Analysis began with line-by-line open coding of the responses by a lead team member. Possible codes were discussed with at least one other team member to categorize codes and identify themes. Resident responses were then coded according to the categories and themes established. Coding was initially done with team members blinded to the setting. Once coding was done, responses were matched to resident setting. Comparing responses within and between settings allowed us to identify similarities and differences across settings.

Direct-care staff survey.

Direct-care staff in NH and AL were asked to fill out a brief questionnaire assessing PCC at their worksite measured by the Person-Directed Care – Staff Assessment (PDC-SA; White, Newton-Curtis, & Lyons, 2008). Like the Resident VIEW, the PDC-SA includes five PCC domains (i.e., personhood, comfort care, knowing the person, autonomy/choice, relationships) as well as three domains addressing the organizational environment (i.e., resident environment, management structures, work with residents). Staff also completed the Direct Care Worker Job Satisfaction Scale (Ejaz, Noelker, Menne, & Bagaka, 2008). In addition, we collected information about demographic characteristics (gender, race/ethnicity, education) and job characteristics and experiences (hours worked, tenure, job satisfaction, turnover intention).

Administrator, nursing, and AFH provider interviews.

In NH and AL, we asked administrators, directors of nursing, and RNs about their job responsibilities, previous work experience, and preparation for their role. In AFH, we asked the owner or manager these same questions as well as some questions specific to their setting. In AL and AFH, we asked these providers to define PCC, describe what they think residents care most about as it relates to quality of life, what they think matters most for residents’ quality of life, and what would allow them to provide more PCC.

Interviewer observations and comments.

At each setting, interviewers wrote field notes following resident interviews and used observation checklists about resident engagement. Based on NH interviewer field notes,

AL and AFH checklists were more specific with respect to physical environment, perceived strengths, and concerns about the setting. NH qualitative comments were recategorized using the checklists used in AL and AFH for comparability.

Administrative data about each setting.

Oregon DHS provided licensing information for all eligible settings, including size, address, ownership, whether the setting is licensed to provide dementia care, and whether the setting is contracted to serve residents paying primarily via Medicaid.

Missing values.

Missing values ranged from zero to 10 percent (Table II-5). Most missing values for NH residents' demographic information were due to lack of reporting by one facility. QoL-AD and PHQ-9 scores were calculated by averaging non-missing values unless all items in the scale were missing, in which case a missing value was assigned. For the Resident VIEW, QoL-AD, PHQ-9, and general satisfaction items, we used a simple imputation method to ensure we used all available data from responding residents.

Table II-5. Missing values

	NH % [n]	AFH % [n]	AL/RC % [n]
Sex	9 [22]	3 [5]	<1 [1]
Age	9 [24]	3 [6]	<1 [1]
Race/ethnicity	10 [25]	2 [4]	1 [2]
Medicaid	9 [24]	1 [2]	1 [3]
Room type	10 [25]	0 [0]	0 [0]
Length of stay	9 [22]	3 [5]	1 [2]
QoL-AD	<1 [2]	<1 [1]	<1 [3]
PHQ-9	<1 [1]	9 [18]	10 [22]

Quantitative Analyses

To evaluate the Resident VIEW tool as a measurement, we used multiple sources of quantitative evidence. These were descriptive statistics, bivariate statistics, and regression analysis. Each analysis was conducted separately by domain (as originally indicated in the questionnaire) and setting type (NH, AFH, and AL/RC).

Descriptive statistics.

For each item in each domain, we calculated percentage of residents who reported that item as being very important, those who reported experiencing or receiving an item, and those who reported an unmet need. We calculated unmet need as share of residents who received an item less than they reported it as important. For instance, if a resident

reported that they found an item very important, but also reported receiving it only to some extent or not at all, that resident was considered having an unmet need for that item.

Bivariate statistics.

We first examined associations of each item with four resident outcomes. These outcomes were selected because they are indicators of overall well-being of residents and the Resident VIEW tool is intended to be used to improve such indicators of well-being. These resident outcomes were likelihood of recommending the setting to someone else (1-item binary), general satisfaction with the setting (measured using 2-item sum score), the Quality of Life for Alzheimer's Disease as an indicator of subjective quality of life, and Patient Health Questionnaire as an indicator of depressive symptoms.

For each domain, we also examined inter-item correlations and Cronbach's alphas (ranges from 0 to 1) to understand agreement among items in the same domain. The latter is typically used as a measure of how well a group of items belong with each other. Higher Cronbach's alpha indicates higher internal consistency for a given domain.

Multivariate statistics.

We originally estimated a set of exploratory and confirmatory factor analyses (EFA and CFA) to understand the fit of the original domain structure to the NH data. However, team discussions revealed that these strategies would potentially lead to a homogenous set of items. Consequently, we decided against using EFA or CFA as an overall selection strategy for items.

Regression analysis.

For each of the four resident outcomes described above, we estimated a series of regressions using items from each of the eight domains, separately. Our primary consideration was the fact that there is a trade-off between resident burden and explanatory power for a given number of items in a domain. Although higher number of items may lead to greater explained variance, our main purpose was to reduce the number of items from the original 63 items down to a more reasonable size for this tool. As such, these regression models were used to select the fewest number of items in each domain without losing the explanatory power of the overall domain.

Results: Part 1. Selection of Items

Final Item Selection

As described above, analysis was conducted by domain to ensure that the final measure represented the range of PCC practices. Each item was examined in terms of its overall importance, presence of unmet need (measured by incongruence between very important and experience), its explanatory power within the domain, and for its association with four outcome measures. Except where noted, each item was significantly related to at least three of these factors. Spontaneous comments in response to items were also examined. This process helped to determine how residents thought about the items and the relevance of the item to the measure. Detailed information about each item is presented in Part 1.B., which contains descriptions of quantitative and qualitative findings for every item within each domain.

Analysis revealed that a core set of seven items met criteria for inclusion across all setting types (NH, AL/RC, and AFH). Along with these seven items, other items met criteria for only one or two of the settings. Those working in specific settings can use associated items along with the cross-setting items. This means that the NH Resident VIEW tool may include up to 18 items, the AFH Resident VIEW is a possible 13 items, and the AL/RC Resident VIEW contains up to 14 items. Below are lists of those items and the associated domains. They are phrased in terms of resident experiences rather than the importance of the items.

Cross-setting core items

1. Does this place feel like home? *(Physical environment)*
2. Do you do things you care about? *(Meaningful activity)*
3. Do the people who work here take the time with you that you need?[a] *(Personalized care)*
4. Do the people who work here make you feel comfortable asking for help?[a] *(Personalized care)*
5. Do the people who work here know how you like to spend your time? *(Knowing the person)*
6. Do the people who work here laugh with you? *(Relationship with staff)*
7. Do the people who work here have a good attitude? *(Organizational environment)*

[a]Note: No items met criteria of sufficient evidence for inclusion for personalized care across all settings. However, these Items had sufficient evidence for inclusion across 2 settings, and ambiguous support in one setting for personalized care. No items for the domain *autonomy and choice* met these standards for inclusion in all settings.

Additional items for Nursing home residents

1. Is your room arranged and decorated the way you want it? *(Physical environment)*
2. Is it peaceful here? *(Physical environment)*
3. Do you feel you have a purpose? *(Meaningful activities)*
4. Do the people who work here know who is important to you? *(Knowing the person)*
5. Do you have privacy when you want it? *(Autonomy and choice)*
6. Do you do things for yourself when you want to? *(Autonomy and choice)*
7. Do you feel free to express your opinions about the things you do not like here? *(Autonomy and choice)*
8. Are the people who work here gentle when they are helping you? *(Personalized care)*
9. Do the people who work here show that your needs are important to them? *(Treated like a person)*
10. Do the people who work here answer your questions? *(Treated like a person)*
11. Do the people who work here have time to help you when you need it? *(Organizational environment)*

Additional items for Adult Foster Care Residents

1. Can you easily get around outside of your room? *(Physical environment)*
2. Do you spend your time the way you want it? *(Autonomy and choice)*
3. Do you feel you have a purpose? *(Meaningful activities)*
4. Do the people who work here take into account your health needs? *(Personalized care)*
5. Do the people who work here know the kinds of things you are interested in? *(Knowing the person)*
6. Do the people who work here know what makes a good day for you? *(Knowing the person)*

Additional items for Assisted Living and Residential Care Residents

1. Do you feel welcome in areas outside of your room? *(Physical environment)*
2. Do the people who work here know how you like to have things done? *(Knowing the person)*
3. Do the people who work here know who is important to you? *(Knowing the person)*
4. Do you spend your time the way you want to? *(Autonomy and choice)*
5. Do the people who work here show that your needs are important to them? *(Treated like a person)*
6. Can you talk to the administrator when you have a problem? *(Organizational environment)*
7. Do the people who work here have time to help you when you need it? *(Organizational environment)*

Results: Part 1.B. Selection of Items by Domain

Results from both quantitative and qualitative analyses were used in combination to select each item for the cross-setting short form of the Resident VIEW as well as for setting-specific measures. Quantitative analysis included examination of the inter-item agreement of the questions within each domain using Cronbach's alpha. This provides information about the extent to which items within each domain are measuring the same concept. We also examined the ratings of importance and experience for each item by setting. Finally, we examined the association of experience with the four outcomes of interest, whether the resident would recommend the place to someone else, general satisfaction with the setting, quality of life, and presence of depressive symptoms.

Comments residents made in response to items were captured by interviewers. In the NH study, these comments were noted in margins and then summarized by interviewers in their notes at the end of the interview. Because these comments were a rich source of information about how residents understood and interpreted the items, a more systematic approach to recording comments was used in the CBC study. Space was provided below each set of questions within a domain so that it was easier for interviewers to write down resident comments in full. Content analysis was done for responses to each item for both importance and experience questions to identify the predominant sentiment expressed by the resident. Similar comments were grouped together and considered in determining whether an item was relevant, its meaning clear, represented a range of responses that could be used to distinguish PCC practices in different communities, and to identify factors that either facilitated or served as barriers to PCC practices. In this section of the report, we are not able to connect responses to specific settings. The comments described in this part of the report are specific to the CBC study only.

Results: 1.B.(1) Physical Environment

Introduction. The physical environment has long been recognized as a means for improving the quality of life for people who reside in long-term care settings. In 1973, M. Powell Lawton and Lucille Nehemow emphasized the importance of the environment in either supporting or serving as a barrier to independent functioning and well-being (Lawton & Nahemow, 1973). This was especially true for those who experienced increasing cognitive and/or physical disabilities. As described by Margaret Calkins, the physical environment can be designed to create community; enhance comfort and

dignity; support courtesy, concern, and safety; provide opportunities for choice throughout the day; and provide opportunities for meaningful engagement (Calkins, 2018). Not surprisingly, therefore, the physical environment has been a major area of focus for initiatives to promote person-centered care (PCC). The PCC philosophy emphasizes creating home or homelike environments, consistent with the emergence of assisted living as alternatives for nursing home care (Wilson, 2007) and small household settings such as the Green House model for nursing homes (Zimmerman et al, 2016).

Anjali Joseph and colleagues (2016) and Chaudhury and colleagues (2018) conducted systematic reviews of the literature that focused on elements of PCC and the physical environment. Even with different areas of emphasis, both research teams found evidence that aspects of the physical environment, such as those described by Calkins, have positive associations with multiple measures of quality of life as well as benefits for self-reported health, cognition, improved sleep, physical activity and social interaction. Joseph and his colleagues explored research literature on the physical environments of assisted living, residential care, and nursing homes. They found seven design strategies reported in the literature, including at the facility level; unit configuration and layout; room configuration; lighting, furniture fixtures, and equipment; interior materials; and overall condition. Overall, the best outcomes were associated with AL settings. Exposure to outdoor environments, to bright light throughout the day, and facility and unit size were especially important with respect to quality of life.

Chaudhury and colleagues' (2018) review examined the influence of the physical environment on residents living with dementia, examining both unit and facility-level characteristics as well as key spaces within a setting. Small unit sizes (5-15 residents), spatial layout (I-shaped corridors) and orientation cues (e.g., signage with names and personal photos), homelike décor, and appropriate levels of sensory stimulation were all associated with enhanced resident well-being. Attention to dining and bathing areas along with caregiver behaviors were found important for reducing behavioral expressions of distress as well as with improvements in well-being. Outdoor areas were especially important for improved functioning and reduced distress.

The Resident VIEW included seven items to reflect resident ratings of importance and experiences with aspects of their physical environment that addressed personal space, accessibility to communal space, overall ambiance, and whether the setting felt like home. Please see Results, Part 2, section 1 of this report for an analysis of qualitative data pertaining to residents' descriptions of what makes the setting either feel like or not feel like home.

Overall findings. Cronbach's alpha for the seven items in the original domain was .60 for the pooled sample, ranging from .52 among long-stay NH residents up to .62 among AFH residents. Overall, this indicates a low-to-moderate inter-item agreement for the original domain. For the pooled sample, the strongest association was between items e. ("you go outdoors when you want") and d. ("you easily get around outside of your room/apartment") (see Figure PE1 below).

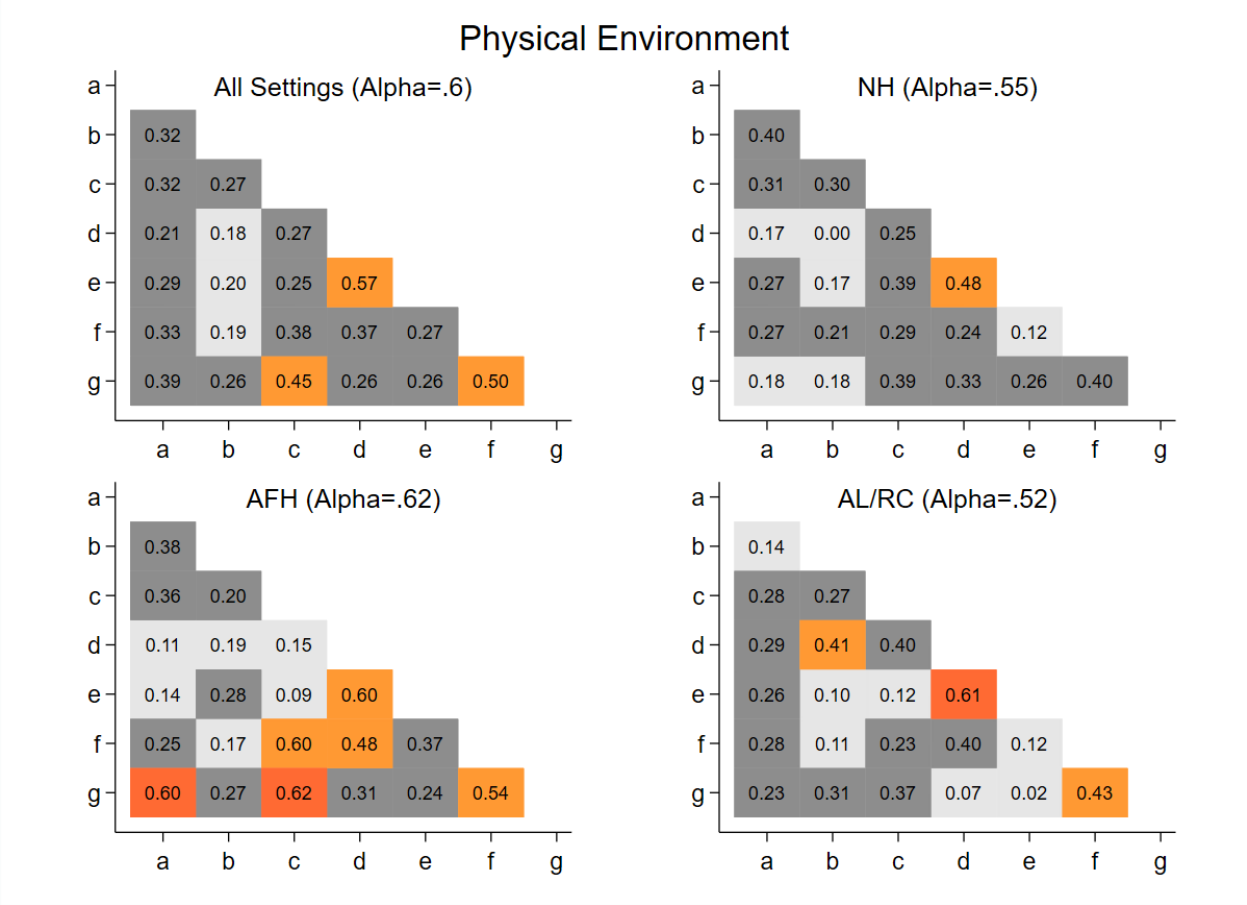


Figure PE1. Strength of association among items in the Physical Environment domain

Table PE1 presents information about unmet need reflected in these items. Unmet need is defined as the incongruence between rating an item as very important and reporting no experience or experience it only some of the time for that item. For those who identified feeling at home in the setting as very important, unmet need averaged 35 percent across all settings and was highest for NH residents (43%) and lowest for AFH residents (24%). Across all settings, having a peaceful environment was rated as very important by more than 75 percent of residents. However, only NH residents indicated they had substantial unmet need in this area. NH residents also indicated unmet need with respect to getting outdoors when they wanted. Eighty percent of AL/RC residents reported getting around easily outside of their apartments was very important, although little unmet need was identified.

Table PE1. Importance and unmet need for the Physical Environment domain by setting type

	NH			AFH			AL/RC			TOTAL		
	VI %	Y %	UN %	VI %	Y %	UN %	VI %	Y %	UN %	VI %	Y %	UN %
a. Room/apartment arranged and decorated the way you want it	50	56	23	54	77	11	61	74	16	55	68	18
b. Enjoy the view from your window	50	58	21	42	63	12	51	64	13	48	61	16
c. Feel welcome in areas outside your room/apartment	63	83	10	67	86	9	66	88	7	65	85	9
d. Easily get around outside room/apartment	70	72	21	74	76	17	85	84	14	76	77	18
e. Go outdoors when you want to	52	54	27	68	73	14	70	81	15	63	68	20
f. Peaceful here	77	66	27	77	83	13	80	88	8	78	78	17
g. Feels like home here	47	26	43	70	63	24	66	49	36	60	44	35

Notes: VI=Very important, UM= Unmet need, Y= Yes.

Table PE2. Association of experiencing each item with positive resident outcomes by setting type

	NH				AFH				AL/RC			
	R	S	Q	P	R	S	Q	P	R	S	Q	P
a. Room/apartment arranged and decorated the way you want it	✓	✓	✓	✓	X	✓	✓	X	✓	✓	✓	✓
b. Enjoy the view from your window	X	✓	✓	✓	✓	✓	✓	✓	X	✓	✓	X
c. Feel welcome outside your room/apartment	X	✓	✓	✓	✓	✓	✓	X	X	✓	✓	✓
d. Easily get around outside room/apartment	X	✓	✓	✓	✓	✓	✓	✓	X	✓	✓	✓
e. Go outdoors when you want to	X	✓	✓	X	X	✓	X	X	X	X	✓	✓
f. Peaceful here	✓	✓	✓	✓	✓	✓	✓	X	✓	✓	✓	X
g. Feels like home here	✓	✓	✓	X	✓	✓	✓	✓	✓	✓	✓	X

Notes: Experiencing is defined as a response of Yes compared to No or Some. R= would recommend this place to someone else, S=general satisfaction, Q=quality of life, P= PHQ9 score (depressive symptoms). No control variables included. Significance was determined at $p < .05$.

The association between each item in this domain with each outcome by setting is presented in Table PE2. Outcomes are resident recommendations of the place to someone else, satisfaction with the setting, quality of life, and depressive symptoms. With the exception of going outdoors when the resident wanted to in AL/RC settings, all of the items in this domain across settings were associated with resident satisfaction. All items, except going outdoors when you want to, were also associated with quality of life. More detailed information about each item is presented below.

a. **Room arranged and decorated the way you want.**

Quantitative findings. The first question in this domain asked residents if they considered it not important, somewhat important, or very important that their room or apartment is arranged and decorated the way they want it. Overall, about half of all residents (55%) across all settings said that this was very important to them. AL/RC residents were significantly more likely to rate this item more importantly compared to NH residents (NH=50%; AFH=54%; AL/RC=61%).

When asked about whether their room was actually arranged and decorated the way they wanted it, 68 percent of all residents across three settings responded positively. However, AL/RC and AFH residents were significantly more likely to have their room arranged and decorated the way they wanted compared to NH residents (NH=56%; AFH=77%; AL/RC=74%).

In this domain, this item was considered the 5th, 6th, and 6th most important item for NH, AFH, and AL/RC residents, respectively. However, there was notable unmet need among NH residents (23%) compared to AFH and AL/RC residents (11% and 16%, respectively) (see Table PE1 above).

Having their room arranged and decorated the way they want was significantly and positively associated with higher reported satisfaction and quality of life across all setting types (see Table PE2 above). It was also significantly associated with higher likelihood of recommending this place to someone else and lower depressive symptoms among NH and AL/RC residents, but not AFH residents.

Qualitative findings. This item asked about personal space and generated about 60 comments from CBC residents. Almost half illustrated why residents felt this was important to their well-being as well as their own examples of arranging their rooms the way they wanted. For some, having familiar items was related to personal autonomy and personhood, *“I want to be my own individual.” “Because I made the choices of what I have here.” “It plays to your own well-being and comfort.”* The importance of familiar

objects was also clear in several responses, *"I wanted my family pictures with me." "the China cabinet and photos are the most important to me. Everything I have out has importance to me."* Elements in function and safety were apparent in some of the comments as well. *"It's very important. It's very minimal because I've got to be able to get around with my walker."*

Another group of responses could be categorized as equivocal. Some indicated family members had done the arranging and decorating. A few indicated their rooms were acceptable, such as comments they were "comfortable" or "alright for the present." Clutter was an issue for some residents. For some, it appeared that they had more things than could comfortably fit in their rooms and others reported lack of assistance with or uncertainty with how to deal with their things. A few residents indicated that their own physical limitations, such as loss of sight or disability, kept them from addressing issues of clutter or arranging their space. Finally, a couple of residents reported that they did not care about their personal space. One because of the expectation the living situation was temporary, and the other because the TV met his needs.

b. **Enjoying the view from window**

Quantitative findings. The second question in this domain asked residents whether they considered it not important, somewhat important, or very important that they enjoy the view from their window. Overall, almost half of all residents (48%) across all settings said that this was very important to them. AFH residents were significantly less likely to rate this item as very important compared to NH and AL/RC residents (NH=50%; AFH=42%; AL/RC=51%).

When asked whether they enjoyed the view from their window, 61 percent of all residents across three settings responded positively and there were no statistically significant differences by setting type (NH=58%; AFH=63%; AL/RC=64%).

In this domain, this item was considered the 5th, 7th, and 7th most important item for NH, AFH, and AL/RC residents, respectively (see Table PE1 above). However, there was notably higher unmet need among NH residents (21%) compared to AFH and AL/RC residents (12% and 13%, respectively).

Enjoying the view from their window was significantly and positively associated with higher reported satisfaction and quality of life across all setting types (see Table PE2 above). It was also significantly associated with higher likelihood of recommending this place to someone else among AFH residents, but not NH and AL/RC residents. Finally,

it was positively and significantly associated with lower depressive symptoms among NH and AFH residents, but not AL/RC residents.

Qualitative findings. Nearly 70 residents made comments about the view from their window. About half the comments referred to the importance of their view and/or their pleasure with it, *"It's not expected, but I was delighted when I saw it." "It's all I have."* Many described seeing nature, *"I watch the birds." "I get to see the deer,"*, and most of the others liked seeing activity outside, *"I like to watch the little kids playing outside." "I open the curtains every day to see what's going on. I get tired of watching TV all day."*

Another group of responses indicated residents liked the view somewhat or that they had adjusted to the view, such as *"It's not outstanding but it is pleasant," ". . . I would have preferred a river view, but this is okay." "If I had a window that had a view, it would be wonderful, but I don't, so I'm okay with it."* Some in this group pointed to other places in the building where they could enjoy a view, such as *"the back porch is where I enjoy the view." "I don't have a view out my bedroom window, but the view out there [common living room] is good."*

A small group of people reported physical disabilities as a reason a view was not important. This was especially true for people with visual impairments, *"I have lost most of my sight, so it's not important anymore." "It's important that I'm down low because I am sensitive to light. . . the light coming in would be a problem."*

About one in five residents indicated that they did not like their view. As examples of what they did not like, views included a highway, a wall, a parking lot, and a dumpster. Some windows were small or obscured by bushes. About one in 10 residents said that a view did not matter to them; they either did not look out of their windows or covered them up.

c. Feeling welcome in areas outside of room or apartment

Quantitative findings. The third question in this domain asked if the focal resident considered it not important, somewhat important, or very important that they feel welcome in areas outside of their room or apartment. Overall, 65 percent of all residents across all settings said that this was very important to them. Residents across different settings did not differ significantly in finding this issue very important (NH=63%; AFH=67%; AL/RC=66%).

When asked about whether they felt welcome in areas outside of their room or apartment, 85 percent of all residents across three settings responded positively and

there were no statistically significant differences by setting type (NH=83%; AFH=86%; AL/RC=88%).

In this domain, this item was considered the 3rd, 5th, and 4th most important item for NH, AFH, and AL/RC residents, respectively (see Table PE1 above). Overall, a small share of residents reported unmet need for this item (NH=10%; AFH=9%; AL/RC=7%).

Across all setting types, feeling welcome in areas outside of one's room or apartment was significantly and positively associated with higher reported satisfaction and quality of life (see Table PE2 above). It was also significantly associated with higher likelihood of recommending this place to someone else among AFH residents, but not NH and AL/RC residents. Finally, it was positively and significantly associated with lower depressive symptoms among NH and AL/RC residents, but not AFH residents.

Qualitative findings. About 40 comments were recorded in response to this item. Nearly half of the comments indicated residents either did not feel welcome (*"Some residents are not very friendly and I don't enjoy encounters with them"),* chose not to be outside of their rooms *(Well, I don't have a desire [to be] outside my room."),* or experienced physical barriers to leaving their rooms *("You have to be able to get around").* Nearly one in seven suggested feeling welcome varied or depended upon the situation or how they felt, *"Some days it's important and sometimes it's not." "You get along and if you don't, you don't associate with them."*

About one-quarter quarter of the comments related to feeling welcome as important or somewhat important (*"we're becoming a part of a different community" "It's important, but not very"*) or something they experienced (*"I can go anywhere." "I make it so." "People are really friendly.")*.

d. **Getting around easily outside of room**

Quantitative findings. This question asked residents if they considered it not important, somewhat important, or very important that they easily get around outside of their room or apartment. Although three-quarters of residents (76%) across all settings said that this was very important to them, AL/RC residents were significantly more likely to rate this item as very important compared to NH and AFH residents (NH=70%; AFH=74%; AL/RC=85%).

When asked if they easily got around outside of their room or apartment, 77 percent of all residents across three settings responded positively. AL/RC residents were

significantly more likely to report that they got around easily outside of their room or apartment compared to NH and AFH residents (NH=72%; AFH=76%; AL/RC=84%).

In this domain, this item was considered the 2nd, 2nd, and the most important item for NH, AFH, and AL/RC residents, respectively (see Table PE1 above). In terms of unmet need, this item was average (NH=21%; AFH=17%; AL/RC=14%).

Getting around easily outside of one's room or apartment was significantly and positively associated with higher reported satisfaction, quality of life, and lower depressive symptoms across all setting types (see Table PE2 above). Among AFH residents, it was significantly associated with higher likelihood of recommending this place to someone else too – but this was not true for NH and AL/RC residents.

Qualitative findings. Sixty comments were made in response to these items, half related to importance and half to experience. Only a few comments indicated that these residents chose not to leave their rooms while over half related difficulties getting around. Reasons for difficulties included their physical disabilities (*"I have bad knees and I can barely walk." "If I walk too fast, I get short of breath. That's why I have my oxygen. That's a hindrance for me."*). For some, difficulties meant reliance on or assistance from others *(I can't go without a keeper." ". . . Usually I wait for my son to come drive me around in my wheelchair." "They decided I was too old to drive. I now have to wait for someone to get me. It's a sad thing when you lose your mobility."* A few comments were specific to limitations of their environment, such as gravel making use of a walker difficult, the lack of sidewalks, or hills that were dangerous to navigate.

About a third of the comments referenced reliance on assistive devices such as canes and wheelchairs to get around. Most of these comments suggest that these devices did enable their access to space outside of their rooms (*"I think anyone in a wheelchair will answer that this is very important." "I have a walker and I could get around my place with that."*).

Few residents made comments indicating that they could get around easily; those include *"[I'm] not having problems that way." "It's not a jail here." "Not having problems that way."*

e. **Going outdoors when you want**

Quantitative findings. This question asked residents if they considered it not important, somewhat important, or very important that they go outdoors when they want to. Sixty-three percent of all residents said that this was very important to them.

However, NH residents were significantly less likely to rate this item as very important compared to AFH and AL/RC residents (NH=52%; AFH=68%; AL/RC=70%).

When asked if they go outdoors when they want to, 68 percent of all residents across three settings responded positively. However, compared to their NH counterparts, AFH and AL/RC residents were significantly more likely to report that they went outdoors when they wanted to (NH=54%; AFH=73%; AL/RC=81%).

In this domain, this item was considered the 4th, 4th, and 3rd most important item for NH, AFH, and AL/RC residents, respectively (see Table PE1 above). NH residents reported higher unmet need compared to AFH and AL/RC residents. (NH=27%; AFH=14%; AL/RC=15%).

Going outdoors when desired was the item in this domain with the fewest number of significant associations with positive resident outcomes. It was significantly and positively associated with higher reported satisfaction among NH and AFH residents only (see Table PE2 above). Similarly, it was associated with higher quality of life only among NH and AL/RC residents (and not AFH residents). Finally, it was associated with lower depressive symptoms only among AL/RC residents. Importantly, this item was not significantly associated with higher likelihood of recommending this place to someone else across any of the care settings.

Qualitative findings. Just over a quarter of the 80 responses to this item described the importance that these residents attributed to being able to get outdoors or else were descriptions of how they did get outdoors. *"That's extremely important to me." "If I want to go, I go. I wouldn't want to depend on anyone else." "Yes, and I smoke when I want to." "I'm not really good around people. I like to go out when it is dark out."*

Nearly half of the comments, however, suggest that residents encounter significant barriers with getting outdoors. Most of the barriers have to do with limitations imposed by the physical layout of the setting, organizational rules, or the need for assistance (*"I can go in the back anytime, but beyond that, no. That's one of the things I miss the most here." "No, they don't let me." "I would, but there isn't much to do. No place to walk and a lot of people smoke." "I have to ask permission." "That's rare because you have to have somebody with you." I don't go outside very often because I can't get into my wheelchair by myself."* Other barriers described focused on their physical limitations, such as being bedbound, their lack of mobility, allergies, or having to stay out of the sun.

About a quarter of the comments indicated that these residents had no interest in going out or did not find getting outdoors to be important. *"I could, I just don't." "I'm not an outside person." "It's becoming less important to me."*

f. **Peaceful here**

Quantitative findings. The sixth question in this domain asked focal residents if they considered it not important, somewhat important, or very important that it is peaceful at the setting. Overall, over three-quarters of residents (78%) across all settings said that this was very important to them. Residents across different settings found this item equally important (NH=77%; AFH=77%; AL/RC=78%).

When asked about whether they found it peaceful at the setting, 78 percent of all residents across three settings responded positively. NH residents were less likely to find the setting peaceful compared to AFH and AL/RC residents (NH=66%; AFH=83%; AL/RC=88%).

In this domain, this item was considered the most important item for NH and AFH residents, and 2nd most important item for AL/RC residents (see Table PE1 above). However, NH residents reported high unmet need (27%), followed by AFH (13%) and AL/RC (8%) residents.

Reporting a peaceful environment was significantly and positively associated with higher likelihood of recommending this place to someone else, higher reported satisfaction, and higher quality of life across all setting types (see Table PE2 above). It was also significantly associated with lower depressive symptoms among NH residents, but not AFH and AL/RC residents.

Qualitative findings. Just over 60 residents commented on the peacefulness of their living situation. About a third of the comments indicated that this was very important to them or that they experienced peacefulness as something positive. *"I'm a quiet person." "It is and it's important." "I have PTSD so it's very important." "Strange things can happen, and you don't even know because it's so soundproof."*

A few comments suggest it is too peaceful for some. *"Too perfect." "It's too painful, sometimes in the dining room it's a morgue."* Similarly, comments suggest that some people like the hustle and bustle of congregate living. *"I like the excitement – who's snuck out? Who's going to the hospital?" ". . . I like outside noises and staff." "I don't want to hear a lot of argument. The owner and her husband laugh all the time and that's great. I love that."*

About one in five indicated that peacefulness varied by time of day and who was present, including other residents. A similar proportion reported that it was not peaceful, a situation which caused distress or discomfort. *"At night you can hear helpers yelling down the hall to each other. Also, they don't close the laundry room door and run laundry around the clock. It's just bang bang all the time. "There's a woman here who constantly yells."* A few individuals indicated that they just accepted or could manage these types of noisy situations *("The person who lives upstairs walks around at night, so I deal with it." "On the days there's confusion, I come to my room and close the door.").*

g. **Feel like home**

Quantitative findings. The last question in this domain asked residents if they considered it not important, somewhat important, or very important that it feels like home at the care setting. Although 60 percent of all residents said that this was very important to them, NH residents were significantly less likely to rate this item as very important compared to AFH and AL/RC residents (NH=47%; AFH=70%; AL/RC=66%).

When asked if the care setting feels like home to them, 44 percent of all residents across three settings responded positively. However, AFH and AL/RC residents were significantly more likely to report that it felt like home compared to NH residents (NH=26%; AFH=63%; AL/RC=49%).

In this domain, this item was considered the 7th, 3rd, and 4th most important item for NH, AFH, and AL/RC residents, respectively (see Table PE1 above). More importantly, it was the item with the highest unmet need across all settings (NH=43%; AFH=24%; AL/RC=36%).

The care setting feeling like home to the resident was significantly and positively associated with higher likelihood of recommending this place to someone else, higher reported satisfaction, and higher quality of life across all setting types (see Table PE2 above). It was also significantly associated with lower depressive symptoms among AFH residents, but not NH and AL/RC residents.

Qualitative findings. With over 100 comments, this item generated the most responses of any item in this domain. Please see Results 2.A. for a complete analysis of how residents describe what made their living situation feel or not feel like home, questions that were asked in follow-up to this question. Here, we present the specific responses to this item asking whether it was important that the setting feel like home and whether it did feel like home. About a quarter of the residents making comments indicated that feeling like home was important to them or that it did feel like home. These comments

included things like, *"If you had seen where I was before this place, you would know how important this is." "I don't want to feel like a guest here – this is my home." "Everybody knows everybody. I feel quite comfortable." "Home is where I am at the moment, if the food is good."*

Nearly one-third of the comments indicated that residents were adjusting or had adjusted to the setting and were comfortable and generally viewed the place positively, if not as home. *"It's not home, but it's getting there." "It's not exactly home, but halfway between." "It ain't home, it's a good place to live." "It's my home now." "Really don't feel like home. It's comfortable, it's peaceful. All this furniture is nice. All the pictures on the wall are nice. That makes me feel like home."*

Another third of the residents emphasized their living situation could never feel like home, with most of these residents saying just that. A few elaborated. *"I miss our house." "I don't expect it to feel like home." "I used to have my own house. No way it can feel like that." "It's important, but it could never. It's not going to if you have workers who don't like their job and want to boss you around."* The few remaining comments described various attributes of home such as the social or physical aspects of home, or ability to do things you want or having family rather than corporate ownership of the building where you live.

Summary

The physical environment can serve as a facilitator or barrier for autonomy and quality of life. Residents, especially those in NH, may have relatively low expectations for the physical environment as indicated as their ratings of "very important," as well as comments provided in response to the items. Examining overall percentages, more residents reported experiencing aspects of the environment represented by the items than residents indicated those items were very important. The exception across settings was the item, "does this place feel like home?" and for NH, "Is it peaceful here?" where residents were less likely to experience a facet of the environment that they had rated as very important.

Only one item in this domain, *does it feel like home?* met criteria for inclusion in the final cross-setting Resident VIEW measure (see Table PE3). It had the highest area of unmet need in all settings within this domain and generated the most comments from residents, and was associated with at least three of the desired outcomes in each setting.

Table PE3. Selection of items from the Physical Environment domain for the final tool based on various sources

	NH	AFH	AR
a. [Room/apartment] arranged the way you want it	✔	×	×
b. Enjoy the view from your window?	×	⇔	×
c. Feel welcome in areas outside your [room/apartment]?	⇔	⇔	✔
d. Easily get around outside your [room/apartment]?	⇔	✔	⇔
e. Go outdoors when you want to?	×	⇔	⇔
f. Peaceful here?	✔	⇔	⇔
g. Feel like home to you here?	✔	✔	✔

Two other items from this domain are recommended for use with NH residents, having rooms arranged and decorated the way the resident wants and the environment being peaceful. These are characteristics of the environment that are particularly difficult to achieve in a NH setting and may be especially salient to those residents.

For those living in AL/RC, the item “do you feel welcome in areas outside of your room?” is recommended. This is likely most salient for these residents who are most likely to desire community with other residents. Residents in AFH settings are those mostly likely to identify their living situation as feeling like home. Most salient for their well-being may be the ability to navigate the home where they live, as reflected in the quantitative analysis.

Results: 1.B.(2) Meaningful Activities

Introduction. Social engagement and access to activity programming have long been recognized as part of quality care in LTC settings as reflected by requirements for NH and CBC settings to have designated activities or life enrichment staff. Activities have been included in studies related to quality of life in LTC settings and are particularly salient to the goals of person-centered care. In 2003, Rosalie and Robert Kane and their colleagues identified meaningful activities as one of eleven domains of quality of life in NH. Included in their measure were items related to getting outdoors, having enjoyable things to do on weekends, pleasurable activities organized by the NH, and giving help to others.

Activity preferences for NH residents were also incorporated into version 3.0 of the Minimum Data Set for NH beginning in the fourth quarter of 2011. Section F3 consists of resident ratings of importance for specific activities: of having preferred reading materials, listening to preferred music, being around animals, keeping up with the news, doing things with groups of people, doing favorite activities, and getting outside in good weather.

Groenendall and her colleagues (2019) define meaningful activity more broadly as "all activities or occupations that are significant or meaningful for the person and reflect someone's current and past interests, routines, habits, and roles and are adjusted to someone's abilities (p.7)." Similarly, William Mansbach and his colleagues (2017) identified three basic features of meaningful activities: active participation, activity content related to interests and past roles of participants, and activities that meet basic psychological needs of identity and belonging.

Finding purpose is related to meaning in life according to Jorunn Drageset and colleagues (2017). They emphasize that more attention needs paid to the meaning and purpose in life experienced by NH residents. Citing Victor Frankl (1963), they describe meaning and purpose as representing a set of attitudes and views that make the world intelligible. Those who fail to find purpose may experience total meaninglessness. In a qualitative study, Drageset found that for NH residents to experience meaning and purpose, they must experience 1) physical and mental well-being (including through "gentle assistance"), 2) belonging and recognition through communion with family and friends and confirming fellowship with staff, 3) personally treasured activities – whether with others or alone, and 4) spiritual connectedness and closeness.

The Resident VIEW has elements in common with all of these approaches. Included are items related to doing things the resident cares about generally and items about importance of and access to specific activities: physical activities, taking care of plants,

listening to or making music, and spending time with animals. Other activities conceptualized as part of a meaningful and purposeful life include sharing wisdom, helping others, having a purpose, and feeling useful.

Overall quantitative findings. Cronbach's alpha for the ten items in the original domain was .72 for the pooled sample and did not differ by setting type (.71 to .73). Overall, this indicated a moderate-to-high inter-item agreement for the original domain. For the pooled sample, the strongest association was between items b. ("do things with other people who live here") and c. ("do things just for fun") (see Figure MA1 below). After examining comments of residents from the NH study, an eleventh item was added to the CBC study, "do you feel useful?". Quantitative analysis of that item is not included in this report.

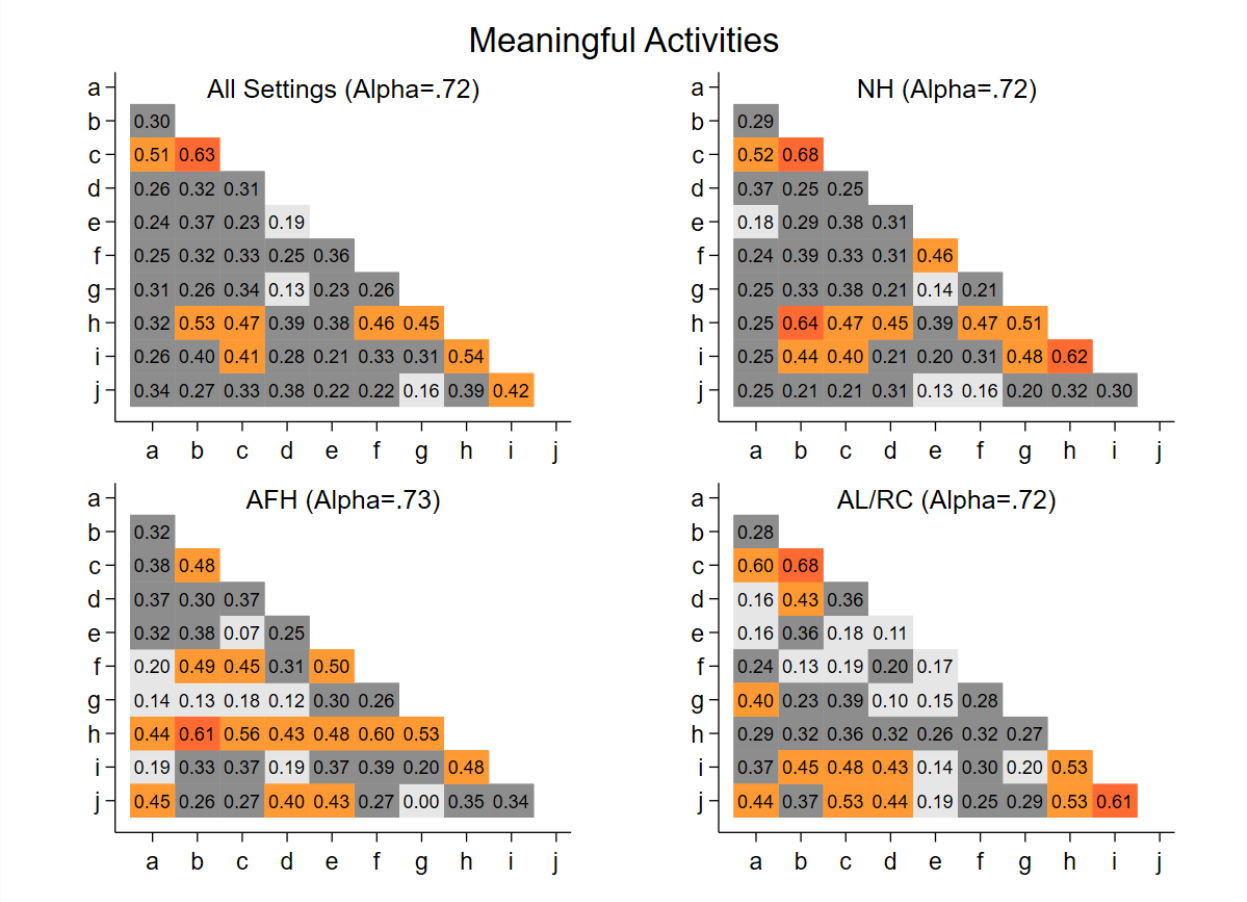


Figure MA1. Strength of association among items in the Meaningful Activities domain

Table MA1 presents information about unmet need reflected in these items. Unmet need is defined as the incongruence between rating an item as very important and reporting no experience or experience it only some of the time for that item. Items where 25% or more of residents expressed unmet need are highlighted.

Residents in each setting reported five areas of unmet need, although these varied somewhat by setting. NH had the largest percentages of unmet need overall, with the greatest for spending time with animals (41%) and doing things residents cared about (39%). Other areas of unmet need for NH residents were taking care of plants, listening to or making music liked, and doing things to help others. AFH and AL/RC residents also reported unmet need with respect to spending time with animals and helping others. These residents also reported unmet need with respect to doing physical activities and having a purpose. AFH residents reported unmet need regarding doing things with other residents and AL/RC residents reported unmet need with respect to sharing their wisdom. Overall, unmet need was identified with respect to doing things residents cared about, spending time with animals, helping others, and having a purpose.

Table MA1. Importance and unmet need for the Meaningful Activity domain by setting type

	NH			AFH			AL/RC			TOTAL		
	VI %	Y %	UN %	VI %	Y %	UN %	VI %	Y %	UN %	VI %	Y %	UN %
h. Do the things you care about	65	46	39	75	70	21	77	66	24	72	60	29
i. Do things with other people who live here	26	33	19	35	33	29	34	47	18	31	38	21
j. Do things just for fun	50	57	23	56	62	21	53	67	15	53	61	20
k. Do physical activities	52	48	22	43	38	27	45	43	25	47	43	24
l. Take care of plants	26	16	27	29	22	23	32	36	16	29	25	22
m. Spend time with animals	46	21	41	48	35	30	41	25	30	45	26	34
n. Listen to or make music that you like	46	44	29	53	59	21	53	64	17	50	55	23
h. Do things to help others who live or work here	42	40	26	50	46	27	49	52	28	47	46	27
i. Share your wisdom with the people who work here	38	40	19	45	43	22	39	38	26	40	40	22
j. Have a purpose	76	64	23	67	60	26	66	59	27	70	61	25
k. Feel useful	X	X	X							X	X	X

Notes: VI=Very important, UM= Unmet need, Y= Yes. Item k was not part of the NH survey and is not analyzed for CBC residents in this report.

The association of each item in this domain with various outcomes reported by residents is presented in Table MA2 by setting. Outcomes include resident recommendations of the place to someone else, satisfaction with the setting, quality of life, and depressive symptoms. Across all settings, doing things residents cared about was associated with most of the desired outcomes. Listening to or making music that

Table MA2. Association of experiencing each item with positive resident outcomes by setting type

	NH				AFH				AL/RC			
	R	S	Q	P	R	S	Q	P	R	S	Q	P
a. Do the things you care about	✓	✓	✓	✓	✓	✓	✓	✓	✗	✓	✓	✓
b. Do things with other people who live here	✗	✓	✓	✗	✗	✓	✓	✗	✗	✓	✓	✓
c. Do things just for fun	✗	✓	✓	✗	✗	✓	✓	✓	✗	✓	✓	✓
d. Do physical activities	✗	✓	✓	✗	✗	✓	✓	✓	✗	✓	✓	✓
e. Take care of plants	✗	✗	✗	✗	✗	✓	✓	✗	✗	✗	✗	✗
f. Spend time with animals	✗	✗	✗	✗	✗	✓	✓	✗	✗	✗	✗	✗
g. Listen to or make music that you like	✓	✓	✓	✗	✗	✓	✗	✗	✗	✓	✓	✗
h. Do things to help others who live or work here	✗	✗	✓	✗	✓	✓	✓	✓	✗	✗	✓	✗
i. Share your wisdom with the people who work here	✓	✓	✓	✗	✓	✓	✓	✗	✗	✗	✓	✗
j. Have a purpose	✗	✗	✓	✓	✗	✓	✓	✓	✓	✓	✓	✓
k. Feel useful	X	X	X	X								

Notes: Experiencing is defined as a response of Yes compared to No or Some. R= would recommend this place to someone else, S=general satisfaction, Q=quality of life, P= PHQ9 score (depressive symptoms). No control variables included. Significance was determined at $p < .05$. Item k was not part of the NH survey and is not analyzed for CBC residents in this report.

residents liked was associated with most of the outcomes for NH residents. Sharing wisdom was associated with most outcomes for NH and AFH residents, while doing things with other residents was associated with most outcomes for AL/RC. AL/RC and AFH residents' alike who experienced doing things for fun and doing physical activities had more positive outcomes.

a. Do the things you care about

Quantitative findings. The first question in this domain asked residents if they considered it not important, somewhat important, or very important that they can do things that they care about. Overall, almost three-quarters of all residents (72%) across all settings said that this was very important to them. AFH and AL/RC residents were significantly more likely to rate this item more importantly compared to NH residents (NH=65%; AFH=75%; AL/RC=77%).

When asked about whether they can do things that they care about, 60 percent of all residents across three settings responded positively. However, AL/RC and AFH residents were more likely to report that they can do things that they care about compared to NH residents (NH=46%; AFH=70%; AL/RC=66%).

Overall, 29 percent of all residents reported unmet need for being able to do things that they care about. There was significantly higher unmet need among NH residents (39%) compared to AFH and AL/RC residents (21% and 24%, respectively).

Being able to do things that residents cared about was significantly and positively associated with higher likelihood of recommending the community to someone else, higher reported satisfaction, and greater quality of life across all setting types (see Table MA2 above). It was also significantly associated with lower depressive symptoms among NH and AFH residents, but not AL/RC residents.

Qualitative findings. This item generated over 130 comments, most in response to the "importance" question. A small number (8) indicated that they did not understand the question when asked about importance, or they were not sure how to answer. It may be that this idea was not relevant to their situation. For example, one person amplified their response by saying, *"I'm old. I'm 71. I'm dying of old age. I can hardly do anything. I don't know how to answer that."* Such comments may also suggest a resignation or lack of expectation. This sentiment was more clearly expressed by a few residents who indicated that this item was not important or not very important to them. *"At my age, there just isn't a lot you think about doing, unless one of the kids takes me out." "Life is like that; you can't always get what you want."*

In contrast, the same number of people emphasized their ratings of "very important." Two people said that it was extremely important, and *"you need to go to 10 [on the 3-point scale]."* Others described why it was important, emphasizing their well-being: *"I'm an artist and that is important to me." "I am limited because of my current conditions [including loss of sight], so the things that I can do, they are very important." "I would be lost without doing some of those things."*

Just over one quarter of comments overall suggest that residents were doing at least some of the things they cared about and that they did these things on their own initiative. Activities described included reading, watching TV, walking, and attending exercise groups or other types of activities provided through the setting. Most of these activities were self- generated. *"I like to read. I work in church administration which I can do from here." "[smart] phone is important. I can get it all day and watch it." "I'm a faithful attender [of chair aerobics] and walking my dog. . . I was watching a good program [on C-span]."*

Others explicitly relied upon staff to facilitate opportunities to do things they cared about. *"I like to fish. We have fishing trips." "They do a good job trying to keep people involved." "I enjoy the weekends, especially because of the Activities Director who's here on weekends."*

About one in twenty of the comments, evenly split between responses to the "importance" and "experience" questions, indicated that these residents were not able to do what they wanted because of their physical limitations. For the most part, these individuals identified their own limitations rather than those imposed on them by staff or others. *"I have constant pain, so it doesn't matter what I want to do. My body dictates it." "I used to volunteer but I can't do that anymore." "Been blind for almost seven years, so I don't really know the things I like to do because I don't get to try them. . ." "I'm limited. I can't do the things I want to do anymore because my energy doesn't last. I can't make it through a Broadway show."*

Nearly one-third of the comments specific to experience suggest that issues of availability and accessibility limited their opportunities to do things they cared about. Several comments had to do with loss of a car or access to transportation. Some mentioned specific activities they wanted to pursue or wanted more of, such as exercise classes or painting. Comments show the variety of interests and hobbies residents were not able to pursue because of lack of availability or accessibility, such as caring for plants or animals, opportunities to do woodworking, or to cook. Some mentioned their small space which limited access to preferred activities. Examples included as wanting but not having space for bookshelves, a desk, or their electronic equipment.

b. Do things with other people who live here

Qualitative findings. The second question in this domain asked if the resident considered it not important, somewhat important, or very important that they do things with other people who lived there. Only 31 percent of all residents across all settings said that this was very important to them. Residents across different settings did not differ significantly in finding this issue very important (NH=26%; AFH=35%; AL/RC=34%).

When asked about whether they did things with other people who lived there, only 38 percent of all residents across three settings responded positively. However, AL/RC residents were significantly more likely to respond positively compared to NH and AFH residents (NH=33%; AFH=33%; AL/RC=47%).

Overall, 21 percent of all residents reported unmet need for this item. However, AFH residents reported a significantly higher unmet need compared to NH and AL/RC residents (NH=19%; AFH=29%; AL/RC=18%).

Across all setting types, doing things with other people who lived there was significantly and positively associated with higher reported satisfaction and quality of life. It was not significantly associated with higher likelihood of recommending this place to someone else. Finally, it was positively and significantly associated with lower depressive symptoms among AL/RC residents, but not NH and AFH residents.

Qualitative findings. Over 100 comments were recorded for this item, with slightly more people commenting in response to the "importance" question. Close to one-third of the comments with respect to importance indicated that residents felt engagement with others in the setting was very important, although their experience doing things with other people varied. At one end of a continuum were those who were very engaged, *"Very important. We are like family. [owner] is a great caregiver." "We like to sit around the table and swap stories."* Others indicated that they were less engaged, sometimes to the detriment of their mental health. *"[I should do things with other people] much more than I do. I find myself marginally depressed." "I don't do it enough. I know it's important for my quality of life. Sometimes I would rather just read a book. But, there are some very nice people here."*

With respect to experience, most residents described what they did with other residents. Some indicated they had close relationships. *"One lady who sits at our table has become a good friend." "Yeah, I smoke with another resident. We are like brother and sister." "Everybody seems to accept everyone else."* Others focused more on specific activities. *"On the weekends I play bingo. It gives me something to do. I also play scrabble with some ladies and I enjoy that. We also did tie-dye shirts recently." "Sometimes they take us to the beach and tulip festival."* Still others described interactions as more like casual encounters. *"Only during dinner. Just eat with them."*

Not all found that doing things with other people were very important and did not seek out other residents. Similar themes were also reflected in comments about their experience. Reasons given included the preference to be by themselves. *"I really don't care what they do. I was an only child and I don't need companionship." "I don't do one-on-one." "I'm not a very social person, so I don't know if I've even gotten to know anyone here."* Others chose not to do things with others because they did not find commonality with other residents. *"Most of their minds don't work." "I don't think any of*

us speak the same language." "They don't smoke, they don't like rap, I can't hear what they say half the time. I do my activism online, I study online."

A very small number of residents indicated they did not do things with other people. Two attributed this to their own physical limitations or two said it was because of the organization, citing frequent staff turnover and the other reporting, *"they [staff] say, 'sit there.'"*

c. Do things just for fun

Quantitative findings. This question asked residents if they considered it not important, somewhat important, or very important that they do things just for fun. Half of all residents (53%) reported that this was very important to them. Residents across different settings did not differ significantly in finding this issue very important (NH=50%; AFH=56%; AL/RC=53%).

When asked about whether they did things just for fun, 61 percent of all residents across three settings responded positively. AL/RC residents were slightly more likely to say "yes" compared to NH residents, but there was no significant difference between AL/RC and AFH residents (NH=57%; AFH=62%; AL/RC=67%).

Overall, one-fifth (20%) of all residents reported unmet need for this item. However, NH residents reported a significantly higher unmet need compared to AL/RC residents (NH=23%; AFH=21%; AL/RC=15%).

Doing things just for fun was significantly and positively associated with higher reported satisfaction and quality of life across all settings. It was not significantly associated with higher likelihood of recommending this place to someone else in any setting. Finally, it was positively and significantly associated with lower depressive symptoms among AL/RC and AFH residents, but not NH residents.

Qualitative findings. Fewer residents (about 75) made comments about this item than others in this domain. Several residents appeared put off by the word "fun." One responded, *"who wrote that question?"* For some residents, this item had no relevance to their current situation. For the most part, this response appeared related to the way they were experiencing this stage of their lives. *"Fun is something that's not much in vocabulary for people my age." "I've kind of lost my drive for fun. I miss my wife." "Since I don't do anything, I don't know how to answer that." "It was [important] when I was growing old, but now it doesn't matter. I've settled that this is the ending of life." "I can, I'm just done." "Fun is a strange word for me at this age. I guess I do things I enjoy." "What do you do at age 80? No, you don't [have fun]. You live."*

Similarly, some residents compared their current situation and abilities related to fun with what had been fun or meaningful activities in the past. Their current living situation

was too different, and most physically could not do these things anymore. For example, one person who said he did not do things for fun said this:

> *"Well, since I was a farmer, it's hard to move into a place where I can't even go outside to spit. But how else could they run this place? I don't really play all the games here. My version of fun would be saddling up a couple of horses and going for a ride. That would be my picnic day!" [laughs]*

At the same time, more than half indicated they did experience fun and/or found it important. *"That's a hard question for me, because everything I do is fun. That's just my attitude." "What is fun is an interesting thing to do." "To do personal things just for fun, that's very important to have freedom to do that." "My daughter picks me up and we do things together."* Other examples of fun offered by residents included those that were self-generated, *"I love to read," "I do what I want, that's the main thing."* Others relied on activities or opportunities that were facilitated by staff. *"We have a lot of fun here. Water balloon fights, badminton. Everything is on Facebook." "They give you choices of things to do. There is always something. When I get bored in here, I hit the halls in my chair and I like that."*

About a quarter of the comments suggest that these residents were limited in experiencing fun. Most were due to physical limitations. *"My ideas of fun are limited because of my current condition." "Well, there's not much I can do. I don't know how I can answer that. I wish I had a car. I suppose I could play monopoly. I can't do things the way I want to. I would like to ride horses and go deep sea fishing, but I can't."*

d. Do physical activities

Quantitative findings. This question asked residents if they considered it not important, somewhat important, or very important that they did physical activities such as exercise classes. Overall, 47 percent of all residents said that this was very important to them. Residents across different settings did not differ significantly in finding this issue very important (NH=52%; AFH=43%; AL/RC=45%).

When asked if they did physical activities, 43 percent of all residents across three settings responded positively. However, NH residents were slightly more likely to report that they did physical activities compared to AFH residents (NH=48%; AFH=38%; AL/RC=43%).

Overall, 24 percent of all residents reported unmet need for this item and there were no significant differences across residents of different settings in terms of unmet need for this item (NH=22%; AFH=27%; AL/RC=25%).

Doing physical activities was significantly and positively associated with higher reported satisfaction and quality of life across all settings. However, it was not significantly associated with higher likelihood of recommending this place to someone else in any setting. Finally, it was positively and significantly associated with lower depressive symptoms among AL/RC and AFH residents, but not NH residents.

Qualitative findings. About 125 residents made comments in response to questions about physical activities. Several stressed its importance. *"It softens how I feel about being cooped up." "It is a must. If I don't, my heart and lungs shut down." "Walking is very important to me."* Even more described their own routines. *"I do exercises every day, my legs especially." "I walk 17 minutes to Target." "Prior to my cancer treatment I did my two-mile walk out and two mile walk back. Now I do my legs, my stretches, my arm movement, and my bends – anything to keep myself active." "I walk, but I don't go to the class."*

Although most people who did physical activities described activities they did on their own, others participated in activities offered through the setting, such as exercise classes or physical therapy. *"I do the sit and be fit. Three times a week and that is very beneficial." "We have a lot of fun here. Water balloon fights, badminton." "I only do exercise when PT is here." "The only exercise classes I go to are the ones at the center and I walk back and forth."*

A large number of residents indicated that they could not do physical activities because of their own disability or poor health. *"It's important, but I haven't felt well enough to do the things I enjoy doing." It's too painful." "It's not important. I have COPD. I walk 20 feet and have a sit down."*

A small number of residents indicated that they did not exercise by choice. *"I never liked exercise." "It should be [important], but it's not." "[I exercise] as little as possible.*

e. Take care of plants

Quantitative findings. This question asked residents if they considered it not important, somewhat important, or very important that they took care of plants. Less than one-third of all residents (29%) said that this was very important to them. Residents across different settings were equally likely to find this issue very important (NH=26%; AFH=29%; AL/RC=32%).

When asked if they took care of plants, one-quarter of all residents (25%) across three settings responded positively. However, AL/RC residents were more likely to report that they took care of plants compared to NH and AFH residents (NH=16%; AFH=22%; AL/RC=36%).

Overall, about one-fifth (22%) of all residents reported unmet need for this item. However, NH residents reported a significantly higher unmet need compared to AL/RC residents (NH=27%; AFH=23%; AL/RC=16%).

Taking care of plants was not associated with any of the four resident outcomes among NH and AL/RC residents. It was associated significantly and positively only with higher reported satisfaction and quality of life among AFH residents.

Qualitative findings. Relatively few residents (about 60) made comments about this item. Some residents talked generally about the importance of plants. *"We have those grape trees. It helps sustain us physically and mentally."* Many of the comments involved descriptions of taking care of plants in the past, often reflecting on the past and contrasting it with the present: *"I used to love it, but it's not important anymore." "I used to be in charge of the garden, but I just passed that on, thank God, because it's a lot of work." "I used to do more gardening, but I think that's part of getting old and dying; you lose interest in things."*

About one-fourth of the comments included descriptions of how these residents were currently caring for plants. *"I take care of all the plants inside the facility." "That's Charlie [pointing to the dresser]. I've been taking care of him for five years." "Working out in the garden with roses has been therapeutic." "I've done that. I have a plant I'm trying to kill." "They have a session every week where they arrange flowers for common areas. I like to go to that with my wife."*

Some residents indicated that they did not take care of plants, mostly because they did not have the opportunity. *"If I had plants, I would." "If I had the room to grow them, it would be very important. I had a plant in my other room." "I would like to take care of the ones outside."* Physical limitations were the reasons given by others for not caring for plants. *"I can't, my leg. They have nice plants here." "It's very important, but I can't because of my MS."*

Only a very few indicated that they did not care for plants and did not want to. *"Throw them away." "They get along well without my help."*

f. Spend time with animals

Quantitative findings. This question asked if the resident considered it not important, somewhat important, or very important that they spend time with animals. Overall, 45 percent of all residents across all settings said that this was very important to them. Residents across different settings did not differ significantly in finding this issue very important (NH=46%; AFH=48%; AL/RC=41%).

When asked if they spent time with animals, 26 percent of all residents across three settings responded positively. However, AFH residents were significantly more likely to

report that they spent time with animals compared to NH and AL/RC residents (NH=21%; AFH=35%; AL/RC=25%).

Overall, about one-third (34%) of all residents reported unmet need for this item. However, NH residents reported a significantly higher unmet need compared to both AFH and AL/RC residents (NH=41%; AFH=30%; AL/RC=30%).

Spending time with animals was not significantly associated with any of the four resident outcomes among NH and AL/RC residents. It was associated significantly and positively only with higher reported satisfaction and quality of life among AFH residents.

Qualitative findings. In contrast to taking care of plants, over 100 comments were made about this item. Nearly one-third of the comments described how animals were loved or were in the residents' lives. A few enjoyed wildlife. *"Just listening to them [birds] in the trees."* Some residents had animals. *"I have a dog." "I'm getting a kitty."* Mostly, the residents we interviewed enjoyed other people's animals or animals belonging to the setting. *"We are not allowed animals, but I spend time with Gizmo [the dog]." "I like to watch them on TV. A lot of people here have dogs. I get a kick out of it." "Pet visit – lady comes here with animals." "I do go visit the cat for cat therapy." "All the cats come in my room and eat."* Some residents described interacting with animals through their families. *"My daughter has a little dog that has stolen my heart." "If I can, if my wife brings our dog, I'll play with it." "I have a cat at my son's house."*

About one in five comments indicated that the resident would like to have an animal, but they could not, either because of the expense or the policies of the place where they live. *"I love animals, but we can't have them here. I wish I could." "It's important, but I don't have animals anymore. I couldn't pay to have an animal." "The worst thing they do Is not allow elderly to have animals. I had to get rid of my dog when I moved here."*

Many of those who did not spend time with animals, indicated that, although they loved them and had pets in the past, they didn't think they could adequately care for animals. *"I've had animals my whole life, but I feel like it would be cruel to have an animal without room to run." "I used to be a dog trainer, but it's important to me that I don't get an animal, because I know I can't take care of it at age 90."* Others simply described animals they had had earlier in life.

Only a few of the residents made comments about not finding it important, or not wanting to spend time with animals. *"I've never really spent time with animals." "That's mostly in the past. I gave up my horseback work 4 or 5 years ago." "They make my allergies worse."*

g. Listen to or make music that you like

Quantitative findings. This question asked if the resident considered it not important, somewhat important, or very important that they listen to or make music that they liked. Overall, half of all residents (50%) across all settings said that this was very important to them. Residents across different settings did not differ significantly in finding this issue very important (NH=46%; AFH=53%; AL/RC=53%).

When asked if they spent time with animals, 55 percent of all residents across three settings responded positively. However, NH residents were significantly less likely to report that they listened to or made music that they liked compared to AFH and AL/RC residents (NH=44%; AFH=59%; AL/RC=64%).

Overall, about one-fifth (23%) of all residents reported unmet need for this item. However, NH residents reported a significantly higher unmet need compared to AL/RC residents (NH=29%; AFH=21%; AL/RC=17%).

Listening to or making music that they liked was significantly and positively associated with higher reported satisfaction across all settings. It was associated with higher quality of life, but only among NH and AL/RC residents (and not AFH residents). Importantly, this item was not significantly associated with depressive symptoms across any of the care settings. Finally, it was associated with a higher likelihood of recommending the setting to someone else only among NH residents.

Qualitative findings. About 65 residents made comments about music, and about two-thirds of those comments were about their experiences. When discussing importance, about half of those responding described their preferences for music or the kinds of music they listened to. *"Oh yeah, especially from the 20's and 30's." "I'm not very musical myself, but I do like certain types of music and they've brought in some good musicians I've liked." "I just got new [earphones] that are noise cancelling, so I can listen anytime." "Very [important]; I have 10 guitars in my room."* Some residents reminisced about their music making in the past. *"[The owner] bought me a guitar. I used to play with my band all the time. Now, I mostly listen to music."*

Those commenting on their experience also described their preferences, what they listened to and, with much less frequently, about making music. Most of these comments suggest that residents were listening to music in their rooms on radios or TV. Others described music offered through the organization or at day centers they attended.

Some residents described limitations on their ability to listen to music. For some, it was part of congregate living. *"I love to listen to music, but I don't because there are all sorts of personalities here. I like to listen to rock 'n roll, but that's not for everyone and I don't want to disturb anyone.* Others were limited by physical disabilities. *There are*

harmonics I can't hear." A few indicated that music was not very important anymore. *"I just like the Hallmark channel. If I can have that, I'm happy." "Not important anymore. It used to be, but not anymore. I'd rather sleep."*

h. Do things to help others who live or work here?

Quantitative findings. This question asked if the resident considered it not important, somewhat important, or very important that they do things to help others who live or work there. Overall, about half of all residents (47%) across all settings said that this was very important to them. Residents across different settings did not differ significantly in finding this issue very important (NH=42%; AFH=50%; AL/RC=49%).

When asked if they did things to help others who lived or worked there, 46 percent of all residents across three settings responded positively. However, NH residents were significantly less likely to report that they did so compared to AL/RC residents (NH=40%; AFH=46%; AL/RC=52%).

Overall, 27 percent of all residents reported unmet need for this item and there were no significant differences across residents of different settings (NH=26%; AFH=27%; AL/RC=28%).

Doing things to help others who live or work at the setting was significantly associated with all four resident outcomes among AFH residents. However, it was associated only with a higher reported quality of life among NH and AL/RC residents (and none of the other three resident outcomes).

Qualitative findings. Over 130 residents made comments in response to this item, with slightly more comments in response to the "experience" question. For some residents, being helpful was part of their identity. *"That's my middle name." "That was number one in my life. I volunteered at a hospital visiting with people who didn't have anyone."* About one in five responded very generally that they helped when it was needed or if they could. *"If they needed my help, I could." "To the degree I can."*

About one-third of the comments provided specific examples of how residents helped others. Some described helping staff. *"For the workers, I try not to complain too much." "I like to make it as easy for them as I can." "I help with the garbage and fold laundry."* Most of the descriptions about helping, however, were about helping other residents. *"If someone needs a push in their wheelchair, I'll go out of my way." "I've been moved around in the dining room a lot because staff want me to talk to people and bring them out of their shells. I used to be a bank manager, so I'm used to people." "I used to just unofficially greet new residents and tell about living here. They, the administrator, gave me a name badge and now I do it officially." "Even if it's simply passing them in the hall and remembering their names and asking how they are."*

Not helping was sometimes attributed to the rules of the place (*"You can't go against the rules")* or because of their own physical limitations *("I can't really help anybody. I don't think about helping people because I can't really help myself.").* Some residents described changes in the way they help since living in residential care, adaptations necessary because of their own physical limitations as well as local policy.

> *They frown on you doing anything to help. I'm a nurse and I want to help people. We can't be helping people up from the table, then we'd have double injury. I help now with more emotional support.*
>
> *They kind of frown on that if I try. How I help people has changed. Different people have different things to help. Have to be cognizant. I help by getting help, like Lassie.*
>
> *I have often wondered why I am here, why I am still here. It seems important to be at the right place at the right time and I can help. It doesn't have to be a big thing, little things are good, too.*

Only a few residents indicated that they did not help and had no interest in doing so. *"I don't see a need to." "I'm not a mingler."*

i. Share your wisdom with the people who work here.

Quantitative findings. This question asked if the resident considered it not important, somewhat important, or very important that they share their wisdom with the people who work at this setting. Overall, 40 percent of all residents across all settings said that this was very important to them. Residents across different settings did not differ significantly in finding this issue very important (NH=38%; AFH=45%; AL/RC=39%).

When asked if they shared their wisdom with the people who worked there, 40 percent of all residents across three settings responded positively and there were no significant differences in responding positively to this item across three settings (NH=40%; AFH=43%; AL/RC=38%).

Overall, 22 percent of all residents reported unmet need for this item and there were no significant differences across residents of different settings (NH=19%; AFH=22%; AL/RC=26%).

Sharing their wisdom with the people who worked at the setting was significantly associated with all four resident outcomes among AFH residents. It was associated with all three resident outcomes except lower depressive symptoms among NH residents. Finally, among AL/RC residents, it was associated with higher reported quality of life only (and none of the other three resident outcomes).

Qualitative findings. This item also generated 150 comments. Laughter in response to the item was common *("what wisdom?").* Other residents criticized the item. *"That's an odd question. I find that presumptions that I should have wisdom to share." "Elderly people may or may not be mature or have wisdom. Some don't give a damn, I like that. It's a relaxation to talk about, wisdom almost seems pandering."* Others suggested alternative wording or provided concepts they thought more important. *"Less about wisdom, but more about affirmation, related to showing appreciation, being kind." "I give advice, but I don't tell people what to do." "I just talk to people. We have regular conversations."*

At the same time, about one-third of the resident comments described how they did share wisdom. Some of these comments suggest that residents were sharing information with staff about their care. *"It's very important to do it right." "If they don't know how or what I am, mistakes could be made."* A few described sharing wisdom with their family members, *"my four great-grandchildren." "With the kids I do sometimes."* A few acknowledged that sharing their wisdom might not be welcome, saying they provided it anyway, *". . . much to their consternation." "Whether they want it or not."*

A few indicated that they did not share wisdom, *"Not my place." "I was going to joke, 'what wisdom?' but I don't try to tell them how to run their business."*

j. Have a purpose

Quantitative findings. This question asked residents if they considered it not important, somewhat important, or very important that living at this setting, they have a purpose. Although 70 percent of all residents said that this was very important to them, NH residents were slightly more likely to rate this item as very important compared to AFH and AL/RC residents (NH=76%; AFH=67%; AL/RC=66%).

When asked if they had a purpose, 61 percent of all residents across three settings responded positively and there were no significant differences in responding positively to this item across three settings (NH=64%; AFH=60%; AL/RC=59%).

Overall, 25 percent of all residents reported unmet need for this item and there were no significant differences across residents of different settings (NH=23%; AFH=26%; AL/RC=27%).

Reporting having a purpose living at this setting was significantly associated with all four resident outcomes among AL/RC residents. It was associated with all three resident outcomes except higher likelihood of recommending the setting to someone else among AFH residents. Finally, among NH residents, it was associated with higher reported quality of life and lower depressive symptoms only.

Qualitative findings. Well over 150 comments were made in response to this item. For many having a purpose was part of living, part of their identity, a way of being. *"It's not worth living if you have no purpose; otherwise you're an animal in a cage." "I've always felt I had a purpose." "Well, I don't know exactly what the purpose is, but I know there is one because God still has me here." "I've chosen to, not really the facility creating it for me. I've created it for myself."*

Having a purpose was related to family for several residents. *"For my children, my grandchildren. We have depression in my family. That is hard and I know my grandson struggles with that. I have to be here for him." "My purpose is to be here with [my husband]. We've been married for 71 years. I'm here for him."* Taking care of themselves was a purpose for some residents. *"It's important to take care of myself to the best of my ability."* Several residents did not know if they had a purpose or what it was. *"I don't think I've figured out what it is and that' why I'm here." "You're getting philosophical. Experience is draining out of me. I think I'm a useless human being. Maybe not." "Sometimes I wonder if I do have a purpose or not."*

Although most residents indicated they had a purpose, even if it was unknown to them, about one in four responded with comments that they had no purpose or that their purpose was limited by the setting or their own physical limitations. For most of these residents, the lack of purpose was a new experience. *"I wish I had more purpose. This is the first time in my life." "It used to be real important, but it's not important anymore [resident cried]." "That's the hardest thing, not feeling worthwhile."* A few indicated their living situation limited their sense of purpose. *"I have so many skills and so much knowledge, but they treat me like I'm demented here." "Hard to find [purpose] around here."*

k. Feel useful

Quantitative findings. Quantitative analysis is not reported for this item because it was not included in the NH study. This item was added to the CBC Resident VIEW survey after noting responses to the item about having a purpose in the NH sample (similar to that reported here). As described above, having a purpose was related to personal identity and a way of being that did not seem directly related to the setting. We posed the question about feeling useful thinking that feeling useful might more directly be influenced by the setting and staff.

Qualitative comments. The themes related to feeling useful were similar to those related to having a purpose. About half of the comments were related to the importance of feeling useful and describing ways of being useful. These responses were typical of those who found being useful to being important. *"That's what keeps you going." "We lose a lot as we get older, so it's important to hang onto that."* Examples of being useful

included being useful to family members. *"I like it when my kids ask for advice." "My grandson, he's 30, says I'm the glue that holds the family together."* Others described being useful to staff or other residents. *"I like to decorate the dining room." "I try to make her job less." "Other people tell me [I am]." One woman told me I am the reason, that it wouldn't be the same without me here."* Feeling useful also varied with some residents saying that some days they felt useful, but other days did not.

As was often the case with other items in this domain, several residents commented that they did not feel useful, whether due to lack of opportunity or their own disabilities. Lack of opportunity was often attributed to living in residential care. *"Last year I lived at home and had a purpose and was useful. Now I'm here and I have none of those things. I'm trying to figure it out." "The management does all the work, I do miss my home." "Not here, I feel like an unplanted potato."* Physical disabilities hindered the ability to be useful for some people. *"At one time it was very important, but my medical condition destroyed that." "I can't do the things I used to do to help people." "Can't offer anything I could have offered 10 years ago. It has nothing to do with this place, just me."*

Summary

Meaningful activity for residents includes, but extends well beyond, a formal program. It is comprised of those activities that support autonomy, help residents stay engaged and connected to others (to the extend desired), and do things that are personally fulfilling and part of one's own identity.

After reviewing the evidence for inclusion of items in the final measure, we found one item that met our criteria across settings: doing things residents cared about (see Table MA3). In NH and AFH, having a purpose was also important for site-specific measures.

Resident comments provide important insights into ways that a care setting can support residents in doing the things they care about. First, this item covers a wide range of activity – fishing for some, watching TV for others. Many residents were able to pursue those activities on their own, but many were not, often due to issues of physical disability, transportation, or supplies. Staff in these settings can learn more about the range of activities that are meaningful to individual residents and do more to reduce barriers to those activities as well as facilitate opportunities.

Although having a purpose in life was often viewed as separate from their living situation, staff can also consider additional ways to support residents in fulfilling their purpose or enhance opportunities to be useful. Residents, particularly those in NH and AFH, are often quite dependent upon staff for their daily living and are therefore in the position of receiving support rather than giving to others. Staff working in partnership

with residents to facilitate residents' ability to give is particularly important in supporting meaning, a most important adjective with discussing activities or life enrichment.

Several items in this domain were not viewed as very important by a large segment of the sample. This may explain, in part, the low Cronbach's alpha coefficient for the domain. However, it is important to note that, although not important to many residents, several of these items reflected areas of unmet need for those who did find them to be very important. As a result, if residents indicate that they do not do the things that they care about, it would likely be useful to ask about some of these specific activities, particularly with respect to music, plants, and animals.

Table MA3. Selection of items from the Meaningful Activity domain for the final tool based on various sources

	NH	AFH	AR
a. Do the things you care about?	✔	✔	✔
b. Do things with other people who live here?	✘	✘	⇔
c. Do things just for fun?	✘	✘	✘
d. Do physical activities (e.g., exercise classes, go on walks, work on strength)?	✘	✘	✘
e. Take care of plants	✘	✘	✘
f. Spend time with animals	✘	✘	⇔
g. Listen to or make music that you like	✘	✘	✘
h. Do things to help others who live or work here	⇔	✘	✘
i. Share your wisdom with the people who work here	✘	⇔	✘
j. Have a purpose	✔	✔	⇔

Results: 1.B.(3) Personalized Care

Introduction. Most people who come to live in long-term care settings (e.g., nursing homes, assisted living, adult foster care) do so because they are experiencing physical and/or cognitive declines or disabilities that make supported living either necessary or beneficial. Those in NH, AFH, and increasingly those living in AL/RC settings, typically require intimate, hands-on care for basic activities of daily living (ADLs), such as bathing, toileting, nutrition, and mobility. Care received to address physical and cognitive care needs has been the focus of efforts to improve quality of care for decades, especially in nursing homes (Castle & Ferguson, 2010; Burke & Werner, 2019). As Castle and Ferguson suggest, however, many of the structure, process, and outcome measures used have been provider or policy defined. Similarly, Burke and Werner argue that what can be measured does not always matter in terms of quality care. Many efforts to improve quality, therefore, have resulted in reinforcing institutional and depersonalized care where safety and staff routine are valued over individual needs, physical condition, experiences, abilities, and preferences. For more than two decades, long-term care culture change advocates have emphasized the importance of individualizing care and making sure that a community consciously resists falling into the habit of "one size fits all" for health and personal care. Examples include Joanne Rader's book, *Individualized dementia care: Creative, compassionate approaches,* published in 1995 and Bev Hoeffer's study, *Bathing without a battle* (see Hoeffer et al., 2006). Advocates for more person-centered care practices have emphasized personalizing other types of hands-on care, including bathing, oral care, pain management, skin care, nutrition, and mobility.

The eight items designed to capture personalized care in the Resident VIEW focus on intimate and supportive care from the perspective of residents. It includes items about staff awareness of their unique health care needs and how responsive staff are to resident requests. Items related to communication are also included such as informing residents of wait times for help and making sure that residents can hear what is said. The remaining items address how care is provided, emphasizing support for the dignity of residents during intimate care. These items address gentleness, taking the time needed, and helping residents feeling at ease and comfortable in asking for help.

Overall findings. Cronbach's alpha for the eight items in the original domain was .82 for the pooled sample. Short-stay NH residents showed lower inter-item consistency compared to all other residents. Overall, these findings indicate a high inter-item agreement for the original domain. For the pooled sample, the strongest association was between items c. ("make you feel at ease when they are helping you") and f. ("make you feel comfortable asking for help") (see Figure PC1 below).

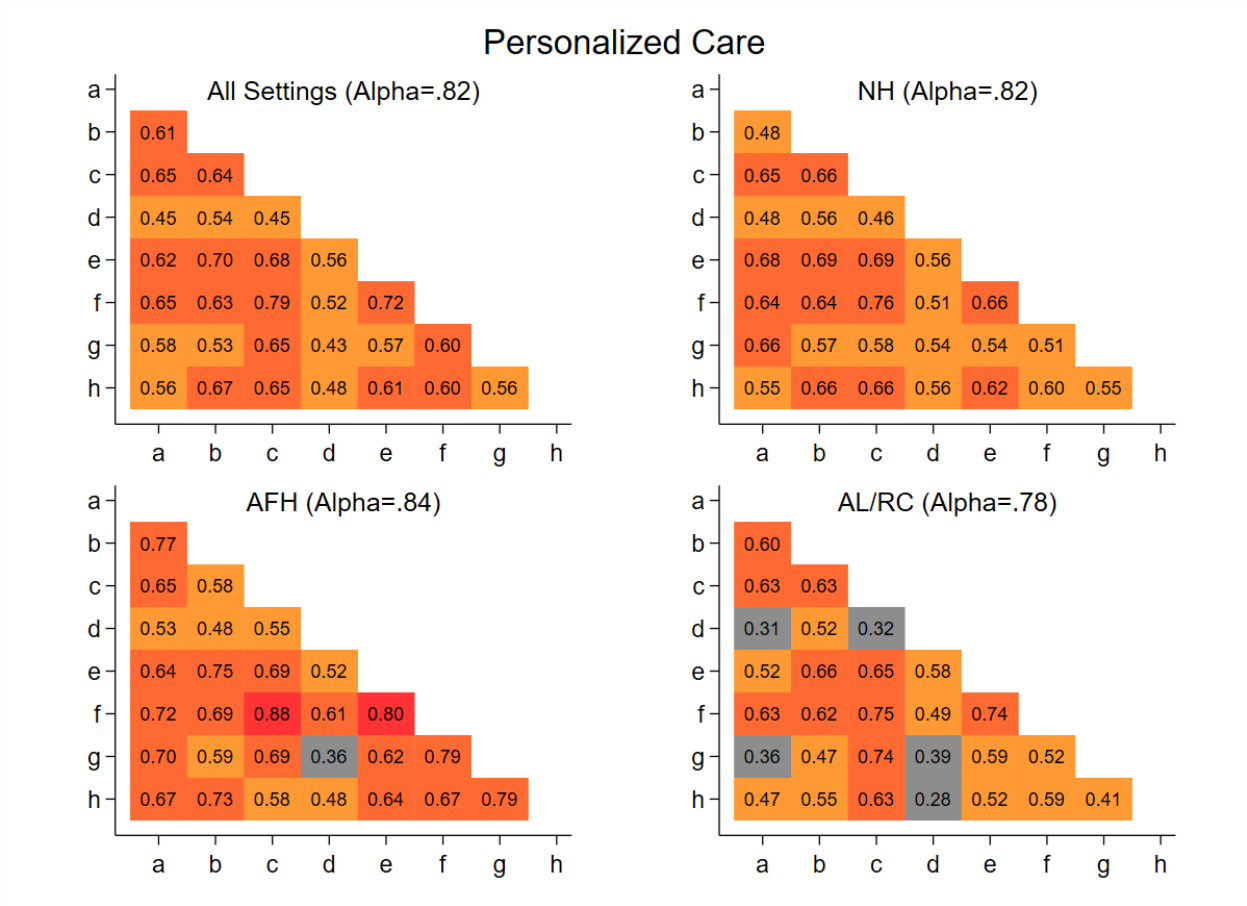


Figure PC1. Strength of association among items in the Personalized Care domain

Table PC1 presents information about unmet need reflected in these items. Unmet need is defined as the incongruence between rating an item as very important and reporting no experience or experiencing it only some of the time for that item. Most of the items within this domain were rated as very important by more than 75 percent of residents across all settings. The exception was for item d. “tell you how long you have to wait if they can’t help you right away,” although two-thirds of NH residents found this item to be very important. Of the NH and AL/RC residents who found this item to be very important, 42 percent and 39 percent respectively had unmet need related to this practice. In addition, among those rating staff quickly responding to requests as very important, both NH (40%) and AL/RC (25%) residents experienced unmet need. Unmet needs also were identified by NH residents for staff taking the time with them that they needed. AFH residents reported the lowest levels of unmet need.

Table PC1. Importance and unmet need for the personalized care domain by setting type

Items	NH			AFH			AL/RC			TOTAL		
	VI %	Y %	UN %	VI %	Y %	UN %	VI %	Y %	UN %	VI %	Y %	UN %
a. Take into account your health care needs	92	81	17	88	88	10	91	85	13	90	84	14
b. Respond quickly to your requests	78	53	40	67	76	13	78	70	25	75	65	27
c. Make you feel at ease when helping you	86	78	17	79	85	10	78	87	10	82	83	13
d. Tell you how long you have to wait if they can't help you right away	65	48	42	47	67	17	55	51	39	56	54	34
e. Take the time with you that you need	80	68	29	75	77	15	79	76	20	78	73	22
f. Make you feel comfortable asking for help	81	78	17	79	79	16	85	79	17	82	79	16
g. Make sure that you can hear what they say	86	82	16	79	83	13	84	82	13	83	82	14
h. Gentle when they are helping you	87	76	21	77	89	8	86	88	11	84	84	14

Notes: VI=Very important, UM= Unmet need, Y= Yes.

The association of each item in this domain with various outcomes reported by residents is presented in Table PC2 by setting. Outcomes include resident recommendations of the place to someone else, satisfaction with the setting, quality of life, and depressive symptoms. All of these items were associated with at least three of the four outcomes across settings. Three items were associated with all outcomes in all settings, including, "take into account your health care needs," "take the time with you that you need," "and "make you feel comfortable asking for help." Detailed information for each item is described below.

Table PC2. Association of experiencing each item with positive resident outcomes by setting type

Items	NH				AFH				AL/RC			
	R	S	Q	P	R	S	Q	P	R	S	Q	P
a. Take into account health care needs	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
b. Respond quickly to your requests	✓	✓	✓	✓	✓	✓	X	✓	✓	✓	✓	✓
c. Make you feel at ease when helping you	✓	✓	✓	✓	✓	✓	✓	X	✓	✓	✓	✓
d. Tell you how long you have to wait if they can't help you right away	X	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
e. Take the time with you that you need	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
f. Make you feel comfortable asking for help	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
g. Make sure that you can hear what they say	✓	✓	✓	✓	✓	✓	✓	X	✓	✓	✓	✓
h. Gentle when they are helping you	✓	✓	✓	X	✓	✓	✓	✓	✓	✓	✓	X

Notes: Experiencing is defined as a response of Yes compared to No or Some. R= would recommend this place to someone else, S=general satisfaction, Q=quality of life, P= PHQ9 score (depressive symptoms). No control variables included. Significance was determined at $p < .05$.

a. Take into account your health needs

Quantitative analysis. The first question in this domain asked if the resident considered it not important, somewhat important, or very important that people who worked there took into account their health needs. Ninety percent of all residents across all settings said that this was very important to them. Residents across different settings did not differ significantly in finding this item very important (NH=92%; AFH=88%; AL/RC=91%).

When asked whether people who worked at the setting took their health needs into account, 84 percent of all residents across three settings responded positively. AFH residents were slightly more likely to report that they did compared to NH residents, but not AL/RC residents (NH=81%; AFH=88%; AL/RC=85%).

Overall, only 14 percent of all residents reported unmet need for this item. However, there was slightly higher unmet need among NH residents compared to AFH residents (NH=17%; AFH=10%; AL/RC=13%).

All four resident outcomes were significantly associated with this item regardless of setting type.

Qualitative analysis. The nearly 80 comments from CBC residents showed a range of resident experiences with staff taking into account their health care needs. These comments suggest that this item could be useful for those who require ADL and IADL assistance. In contrast, some residents, mostly living in AL/RC settings, reported that they did not have health care needs and therefore did not require help; this item was not relevant to their experience. *"They don't help me with anything. I don't need help."*

Several residents who required support indicated it was very important that their needs were recognized because, as one resident said, *"That's why I'm here, they have to."* Others described specific instances where they felt care was personalized (e.g., risk of falling, a brain injury, staff recognizing when they did not feel well). *"It's important they know my disabilities." "I have throat problems that makes me have to spit up food a lot if I can't swallow it. I get to take my meals in my room because of that." "They're very good, remember I'm diabetic."*

In contrast, however, a substantial number of residents indicated that staff do not take their specific needs into account, citing situations where they were ignored, did not have the right diet, experienced poor communication, or where staff had a lack of understanding about their health. *"Don't see a sign of it in this facility." "They ignore me. I could sit here all morning." "You're on your own pretty much. Most people here go to your family. I broke my arm [and] right away they called my son. That's good, but they expect too much of you rather than helping you."*

b. Respond quickly to your requests

Quantitative analysis. The second question in this domain asked if the resident considered it not important, somewhat important, or very important that people who worked in this setting responded quickly to their requests. Three-quarter of all residents (75%) across all settings reported that this was very important to them. NH and AL/RC residents were significantly more likely to rate this item as very important compared to AFH residents (NH=78%; AFH=67%; AL/RC=78%).

When asked about whether people who worked at the setting responded quickly to their requests, 65 percent of all residents across three settings responded positively. AFH and AL/RC residents were more likely to say that they did compared to NH residents (NH=53%; AFH=76%; AL/RC=70%).

Overall, 27 percent of all residents reported unmet need for this item. However, NH residents were most likely to report an unmet need for this issue, followed by AL/RC and AFH residents (NH=40%; AFH=13%; AL/RC=25%).

All four resident outcomes were significantly associated with this item regardless of setting type – except for quality of life among AFH residents.

Qualitative analysis. The more than 100 comments on this item showed differences in experiences, with a fairly even division between "yes" and "no" responses. Examples, respectively, are "*Overall I would say yes,"* and *". . . I have to wait. And you end up apologizing to them because it's inconvenient for them to help you."* Residents also distinguished between staff, saying that some staff were responsive to requests and others were not.

The most common sentiment expressed, however, was acknowledgement from residents that staff are very busy and are often doing the best they can. It appeared that residents were adapting their ratings of importance to this reality: "*They got a lot of other people. At night there's only two on duty for 25 people. You gotta give 'em a break." "I'm so old it wouldn't bother me if they made me wait for somebody younger." "They do the best they can, I don't expect them to get here immediately."* At the same time, residents talked about their own needs, *"I'm not saying I need immediate attention – I need to not be blown off,"* and *". . . I know we only have one caregiver and one med aide up here . . . I need to take two pills before bed, and for a while I'd go looking for the med aide and she'd never be there."*

c. Make you feel at ease when helping you

Quantitative analysis. The third question in this domain asked if the resident considered it not important, somewhat important, or very important that people who worked in this setting made the resident feel at ease when they were helping the resident. Eighty-two percent of all residents across all settings reported that this was very important to them. NH residents were slightly more likely to rate this item as very important compared to AL/RC residents (NH=86%; AFH=79%; AL/RC=78%).

When asked whether people who worked at the setting made the resident feel at ease when they were helping the resident, 83 percent of all residents across three settings responded positively. AL/RC residents were slightly more likely to say that they did compared to NH residents (NH=78%; AFH=85%; AL/RC=87%).

Thirteen percent of all residents across three settings reported unmet need for this item. However, NH residents were most likely to report an unmet need for this issue compared to AFH and AL/RC residents (NH=17%; AFH=10%; AL/RC=10%).

All four resident outcomes were significantly associated with this item regardless of setting type – except for depressive symptoms among AFH residents.

Qualitative analysis. Just over 40 residents made comments about this item, fewer than in response to the two previous items. A few residents commented on the meaning of the item for them. *"I don't feel like I'm being rushed. That's very important." "The staff spoil me." "If you want to get along with people you've got to put them at ease."* As

suggested by the previous quote, some residents seemed to focus more on putting staff at ease. *"I want to know why if they don't feel well. Sometimes I ask if I can pray for them."*

Others commented that it was not especially important to them. *"I'd rather that they just go quickly and get it done." "They do, but it's not that important to me." "I'm not that sensitive. This is a crummy job. It takes a certain personality to get along with old, cranky folks."*

Others reported that staff did not make them feel at ease. *"It's not that they are cruel, but I don't think I am very important [to them]*." For one resident this lack of ease had to do with cultural differences. *"Sometimes I'm a little nervous around them. I still don't know what to think about [ethnic group]. Sometimes I don't understand them, but they are nice.*

d. Tell you how long you have to wait if they can't help you right away

Quantitative analysis. This question asked if the resident considered it not important, somewhat important, or very important that people who worked in this setting told them how long they would have to wait if they can't help the resident right away. Overall, 56 percent of all residents reported that this was very important to them. NH residents were slightly more likely to rate this item as very important compared to AFH and AL/RC residents (NH=65%; AFH=47%; AL/RC=55%).

When asked about whether people who worked at the setting told them how long the they had to wait if they can't help them right away, a little over half of all residents (54%) across three settings responded positively. However, AFH residents were significantly more likely to say that staff did this compared to NH and AL/RC residents (NH=48%; AFH=67%; AL/RC=51%).

Although one-third of all residents (34%) across three settings reported unmet need for this item, AFH residents were much less likely to report an unmet need for this issue compared to NH and AL/RC residents (NH=42%; AFH=17%; AL/RC=39%).

All four resident outcomes were significantly associated with this item regardless of setting type – except for likelihood of recommending the setting to someone else among NH residents.

Qualitative analysis. Well over 100 residents made a comment about this item. In terms of experience, the most frequent comment was that it did not matter whether they were informed or not. This was especially true for individuals who described themselves as independent and not needing help. Other residents did not find this item relevant because they did not experience long wait times. *"They never make me wait." "It would be very important, but I have not come up against that."*

When discussing the importance of this item, busyness and understaffing was once again a common theme, *"I'll understand [that I have to wait] because I know they're busy."* Residents also recognized that other residents needed help, too. *"I never think about it one way or another. You just have to wait your turn." ". . . I'm not the only one who lives here."*

At the same time, some residents commented that it was important to know how long they needed to wait and it would be nice if staff did provide that information. One described this as good manners, another described this experience: *"The day I had to wait 45 minutes for someone to respond was the worst. If no one was available, I would have liked to know."*

e. Take the time with you that you need.

Quantitative analysis. This question asked if the resident considered it not important, somewhat important, or very important that people who worked in this setting took the time with the resident that the resident needed. Overall, over three-quarters of all residents (78%) reported that this was very important to them. There were no significant differences in finding this issue important across three settings (NH=80%; AFH=75%; AL/RC=79%).

When asked about whether people who worked at the setting took the time with them that they needed, 73 percent of all residents across three settings responded positively. However, AFH residents were slightly more likely to say that staff did compared to NH residents (NH=68%; AFH=77%; AL/RC=76%).

Twenty-two percent of all residents reported unmet need for this item. NH residents were much more likely to report an unmet need for this issue compared to AFH and AL/RC residents (NH=29%; AFH=15%; AL/RC=20%).

All four resident outcomes were significantly associated with this item regardless of setting type.

Qualitative analysis. Residents made about 50 comments related to this item, mostly with respect to its importance. A few people found the item was not relevant because they did not have needs that required staff. *"I haven't really needed them to spend a lot of time with me, so I don't know."* About one in four indicated they do not have a problem with getting the time they need, mostly because they have a good relationship with staff and got needed help. *"We get the best care we've ever had." "[The provider] and I always have a laugh about something when I'm going to bed. . ."*

Once again, however, the lack of time and staff constraints, including busyness, being stretched thin, and having multiple people to take care of, was a predominant theme. Most residents recognized staff workload in shaping their own experiences. *"[Time is a]*

double-edged sword, because if they need to take care of someone else, that's very important, too." "They have lots of things to do. I have lots of things wrong with me," "It's very important, but I go with the flow." A few residents simply reported that they did not experience staff taking the needed time. *"They don't. That's not how this place works." "They don't do that kind of thing here."*

f. Make you feel comfortable asking for help

Quantitative analysis. This item asked if the resident considered it not important, somewhat important, or very important that people who worked at the setting made the them feel comfortable asking for help. Overall, 82 percent of all residents across all settings said that this was very important to them and residents across different settings did not differ significantly in finding this item very important (NH=81%; AFH=79%; AL/RC=85%).

When asked about whether people who worked at the setting made the resident feel comfortable asking for help, 79 percent of all residents across three settings said yes. Residents across the three settings were similarly likely to report being comfortable asking for help (NH=78%; AFH=79%; AL/RC=79%).

Only sixteen percent of all residents reported unmet need for this item and residents across three settings had similar responses (NH=17%; AFH=16%; AL/RC=17%).

All four resident outcomes were significantly associated with this item regardless of setting type.

Qualitative analysis. This item generated about 50 comments. Being dependent on others for help with daily personal care activities is a difficult adjustment for most adults. Caregivers can lend dignity to the situation by helping residents to feel comfortable asking for help. However, needing help can itself be an uncomfortable situation for many as illustrated by this resident, *"They make me comfortable, but I'm uncomfortable every time they help me [because] I'm losing my independence*."

A few of those who did get help indicated they were made to feel comfortable asking for it, *"I hate to ask, but I've learned to ask because they are very nice."* Nearly 15% of the comments indicated that these residents either took care of themselves or did not ask for help, *"I've never asked for help," "I've been very independent since I was 12. They have to ask me if I need help."* Some did not ask for help because they felt being comfortable was their responsibility, *"You make your own comfort."*

The following quote is from a person who provided a reason for not asking for help, but it also amplifies the importance of caregivers helping the resident to feel comfortable: *"I'm a private person, I'm shy. Modesty is an obsession. I am a victim of childhood abuse. . . so in those moments when people are taking care of me, that can be hard."*

As with other items in this domain, some comments revolved around staff, including variability among staff, *"I have certain ones I feel real comfortable with." "Most of them are good, but there's one med tech, you could lay bloody on the floor and she would just step over you."* Residents also recognized the busyness of staff and put their own needs behind others. *"I would rather they pay attention to other people here. I keep to myself, and when I need help, I very much appreciate that they are there when I need it."* Only a few residents indicated that staff did not make them feel. *"They shouldn't belittle you for what you ask." "They get mad at you."*

g. Make sure you can hear what they say

Quantitative analysis. This question asked if the resident considered it not important, somewhat important, or very important that people who worked in this setting made sure that the resident could hear what they said. Overall, 83 percent of all residents reported that this was very important to them. However, NH residents were slightly more likely to rate this item as very important compared to AFH residents (NH=86%; AFH=79%; AL/RC=84%).

When asked whether people who worked at the setting made sure the resident could hear what they said, 82 percent of all residents across the three settings responded positively, with similar ratings in each setting (NH=82%; AFH=83%; AL/RC=82%).

Only fourteen percent of all residents reported unmet need for this item, with similar ratings across (NH=16%; AFH=13%; AL/RC=13%).

All four resident outcomes were significantly associated with this item regardless of setting type – except for depressive symptoms among AFH residents.

Qualitative analysis. Residents made over 80 comments in response to this item. Those with hearing loss indicated this was an important item and that they often had difficulties understanding staff, both because of poor hearing and lack of hearing aids. *"I think they do a lot of repeating because my hearing is poor," ". . . I can't afford hearing aids."*

However, many comments revealed the limitation of this item, suggesting a broader term such as "understand" rather than "hear" what you say might be a more useful item. Residents without hearing impairment frequently found this item irrelevant to their needs or experiences, although several commented that staff talked too loudly, *"They shout a lot*." *"What I hear and what they say are two different things. Sometimes I perceive something differently and have to ask for clarification."*

Some residents stressed the importance of understanding and communication generally rather than hearing. For some, the issue was language. *"I can hear just fine, but I can't*

understand when they speak in [language].” “A lot of people who work here don’t speak fluent English, so that makes it harder to hear what they are talking about.” “I’m German, so sometimes it’s hard for me to express myself or understand people.” For others, the rapidity of staff speech was a problem. *“. . . just so I can understand what they are saying, not because I can’t hear but because I don’t understand quick. . .”*

h. Are gentle when helping you or doing things for you

Quantitative analysis. The final question in this domain asked if the resident considered it not important, somewhat important, or very important that people who worked where they lived were gentle when they were helping the resident or doing things for the resident (such as while getting dressed or in the bathroom). Overall, 84 percent of all residents reported that this was very important to them. However, AFH residents were slightly less likely to rate this item as very important compared to NH and AL/RC residents (NH=87%; AFH=77%; AL/RC=86%).

When asked about whether people who worked at the setting were gentle when they were helping or doing things for the resident, 84 percent of all residents across three settings responded positively. NH residents were slightly less likely to respond positively compared to AFH and AL/RC residents (NH=76%; AFH=89%; AL/RC=88%).

Only fourteen percent of all residents reported unmet need for this item. In addition, NH residents were much more likely to report unmet need compared to both AFH and AL/RC residents about this issue (NH=21%; AFH=8%; AL/RC=11%).

All four resident outcomes were significantly associated with this item regardless of setting type – except for depressive symptoms among NH and AL/RC residents.

Qualitative analysis. This item generated almost 60 comments, with about a quarter emphasizing its importance and explaining why, *“because I’m kind of slow and don’t want to be shoved or pushed around;” “I want them to treat me like a human, like an adult . . . I never realized how scary it was to get pushed by someone else in a wheelchair. Some people just start pushing you or they go too fast.”*

As with other items, not all found this relevant, *“I don’t get help with that,”* but several without direct experience indicated they observed gentleness with other residents, *“I’ve have never seen them jerk anyone around or do anything mean, or even look at people mean. If I was the boss here, I would keep all of them. They seem to know what they are doing.”*

Still more reported mixed experiences, *“If they’re not, I yell. They listen right away. Some don’t realize I do have feeling in my leg even though it’s paralyzed.”* Others described a lack of gentleness, *“there is no touching, no gentleness. It’s just do it and*

get it over with, and back to what they were doing." Other residents emphasized that gentleness varies by staff, *"We have a spectrum of caregivers here – some are, some aren't." "The new caregivers, not as much. They don't hurt me, but they aren't gentle."*

Summary

The items in this domain were rated as among the most important in the Resident VIEW measure; only those who required little or no assistance from others found these items less important. Overall, the majority of residents experienced the type of care these items represent: staff who consider their needs, respond quickly, help them feel at ease, take the time needed, and more. At the same time, areas of unmet need were identified, with highest levels reported by NH residents and the lowest levels by AFH residents. Across settings, especially in NH and AL/RC, staff busyness and workload were often given as reasons.

Qualitative comments revealed the importance of the caring aspect of staff support over and above technical skills. Staff play a major role in putting residents at ease as residents experienced new experiences as a dependent adult. Comments also suggest the importance of communication with residents beyond hearing to assuring residents understand staff.

Although majorities of residents across settings identified items in this domain as very important, only two items are included in the final cross-setting Resident VIEW measure (see Table PC3). Neither of these items fully met criteria for inclusion in all settings, though the items fully met criteria for two settings and had ambiguous support for one setting. This likely reflects the difference in personal care needs across these different settings. The two items are, "Take the time with you that you need," and "Make you feel comfortable asking for help." The item "are gentle when they are helping you" met all criteria for the NH-specific tool, and "take into account your health care needs" met all criteria for the AFH-specific tool.

Table PC3. Selection of items from the Personalized Care domain for the final tool based on various sources

People who work here:	NH	AFH	AR
a. Take into account your health care needs?	⇔	✔	⇔
b. Respond quickly to your requests?	⇔	⇔	⇔
c. Make you feel at ease when helping you?	✖	✖	✖
d. Tell you how long you have to wait if they can't help you right away?	⇔	✖	✖
e. Take the time with you that you need?	✔	⇔	✔
f. Make you feel comfortable asking for help?	⇔	✔	✔
g. Make sure that you can hear what they say?	⇔	⇔	⇔
h. Gentle when they are helping you?	✔	✖	⇔

Results: 1.B.(4) Knowing the Person

Introduction. "Knowing the person" is a concept present in most definitions of PCC and is often discussed in conjunction with other PCC domains, including maintaining personhood, individualizing care, facilitating autonomy and choice, and building strong resident-staff relationships. Karen Talerico and her colleagues (2003) described the knowing the person as key to "providing care that is meaningful to the person in ways that respect the individual's values, preferences, and needs (p. 14)." In congregate living situations, the effort to get to know the person often focuses on the individual's pattern of daily living or daily habits. Efforts are made to acknowledge preferences and daily routines by incorporating them into a service or care plan. To this end, Kimberly Van Haitsma and her team (2012) developed the "Preferences in Everyday Living Inventory" (PELI) as a way for care staff to learn about resident preferences. Five domains were included that are consistent with many of the Resident VIEW Domains: social contact, leisure and growth activities, diversionary activities, self-dominion, and enlisting others in care. The PELI asks residents to rate the importance of multiple items and then asks specific questions about care for those items identified as most important.

A person is more than daily habits; every individual has a life story, cultural experiences, and personality. In addition to care preferences and daily routines, therefore, the concept of "knowing the person" also refers to knowing and understanding the qualities that make a person unique. This includes family and work history as well as a person's basic identity as reflected in their name or in the way that they approach problems. Within the LTC culture change movement, knowing each person's history in combination with what the person currently considers important, is essential to enabling staff to enhance quality of life. This is particularly true for understanding behavioral expressions that often accompany dementia.

The "knowing the person" domain in the Resident VIEW examines both daily routines (e.g., "how you like to have things done") as well as information about who the person is (e.g., "the kinds of things you are interested in," "who is important to you").

Overall findings. Cronbach's alpha for the seven items in the original domain was .78 for the pooled sample and did not differ much by setting type (.74 to .79). Overall, this indicated a moderate-to-high inter-item agreement for the original domain. For the pooled sample, the strongest association was between items b. ("the kinds of things you are interested in") and c. ("how you like to spend your time") (see Figure KP1).

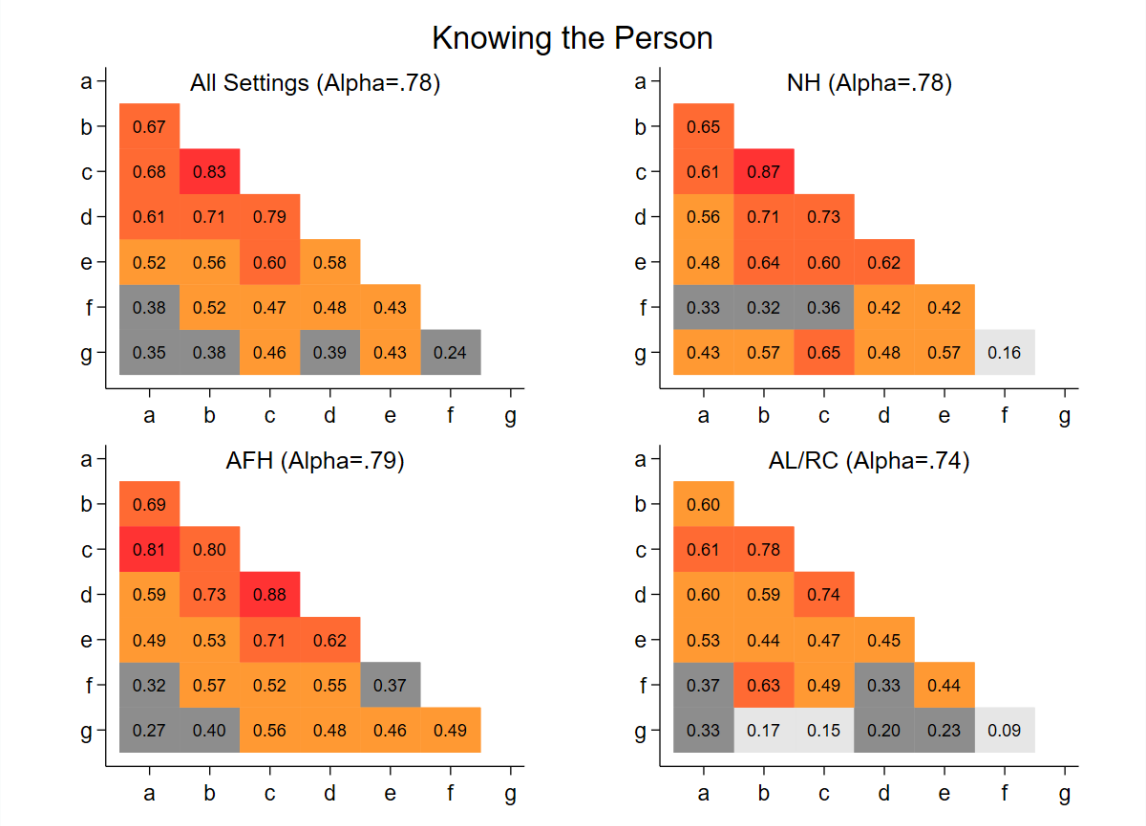


Figure KP1. Strength of association among items in the Knowing the Person domain

Table KP1 presents information about unmet need reflected in these items. Unmet need is defined as the incongruence between rating an item as very important and reporting no experience or experience with it only some of the time for that item. Ratings of unmet need by 25 percent or more of residents are highlighted in yellow and those reporting minimal levels of unmet need are highlighted in red.

Overall, 25 percent or more of residents across settings who reported it was very important that staff know what they worry about, indicated they had unmet need. At the same time, this was not at area of importance for most residents. Residents in NH and AL/RC also reported unmet need in the areas of staff knowing how they like to have things done, the kinds of things they are interested in, and what makes a good day for them. With the exception of knowing what they worry about, residents in AFH had no other areas of unmet need for this domain. Very little unmet need was expressed with respect to staff knowing what residents liked to be called. Indeed, across settings about 90 percent of residents reported that staff knew, while less than 60 percent identified this as very important to them.

Table KP1. Importance and unmet need for the Knowing the Person domain by setting type

	NH			AFH			AL/RC			TOTAL		
	VI %	Y %	UN %	VI %	Y %	UN %	VI %	Y %	UN %	VI %	Y %	UN %
a. Know how you like to have things done	68	61	28	65	73	17	55	51	28	63	61	25
b. Know the kinds of things you are interested in	39	46	26	50	67	16	33	38	28	40	49	24
c. Know how you like to spend your time	45	53	23	55	73	14	35	52	22	45	59	20
d. Know what makes a good day for you	52	49	28	58	68	17	38	41	31	49	52	26
e. Know who is important to you	64	67	17	60	79	10	60	66	22	61	70	17
f. Know, what you worry about	35	30	36	43	42	26	26	18	36	34	29	33
g. Know what you like to be called	59	89	6	58	91	4	55	90	4	57	90	5

Notes: VI=Very important, UM= Unmet need, Y= Yes.

The association of each item in this domain with various outcomes reported by residents is presented in Table KP2 by setting. Statistically significant associations are highlighted in yellow and lack of association are highlighted in red. Outcomes include resident recommendations of the place to someone else, satisfaction with the setting, quality of life, and depressive symptoms. Staff knowing how residents liked to spend their time was associated with all outcomes in all settings and staff knowing what made a good day for residents was associated with at least three of the outcomes in all settings, though specific outcomes varied. Knowing what residents worried about and knowing what they liked to be called was associated with few outcomes. The qualitative comments described below provide insight into residents' ratings for these items. We turn now to a closer look at each item.

Table KP2. Association of experiencing each item with positive resident outcomes by setting type

	NH				AFH				AL/RC			
	R	S	Q	P	R	S	Q	P	R	S	Q	P
a. How you like to have things done	✓	✓	✓	✗	✗	✓	✗	✗	✓	✓	✓	✓
b. The kinds of things you are interested in	✗	✓	✓	✗	✓	✓	✓	✗	✓	✓	✓	✗
c. How you like to spend your time	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
d. What makes a good day for you	✗	✓	✓	✓	✓	✓	✓	✗	✗	✓	✓	✓
e. Who is important to you	✗	✓	✓	✓	✓	✓	✓	✗	✗	✓	✓	✗
f. What you worry about	✗	✗	✗	✗	✓	✓	✗	✗	✗	✗	✗	✓
g. What you like to be called	✗	✓	✗	✗	✗	✓	✗	✗	✗	✗	✗	✗

Notes: Experiencing is defined as a response of Yes compared to No or Some. R= would recommend this place to someone else, S=general satisfaction, Q=quality of life, P= PHQ9 score (depressive symptoms). No control variables included. Significance was determined at $p < .05$.

a. Know how you like to have things done

Quantitative findings. The first question in this domain asked if the resident considered it not important, somewhat important, or very important that people who worked in this setting knew how the resident liked to have things done. Sixty-three percent of all residents reported that this was very important to them. NH and AFH residents were significantly more likely to rate this item more importantly compared to AL/RC residents (NH=68%; AFH=65%; AL/RC=55%).

When asked about whether people who worked at the setting knew how they liked to have things done, 61 percent of all residents across three settings said yes. AFH residents were most likely to say yes to this item, followed by NH residents, and then AL/RC residents (NH=61%; AFH=73%; AL/RC=51%).

Overall, a quarter of all residents (25%) across three settings reported unmet need for this issue. However, there was significantly higher unmet need among NH and AL/RC residents compared to AFH residents (NH=28%; AFH=17%; AL/RC=28%).

Among AL/RC residents, this item was associated significantly with all four resident outcomes. In contrast, it was associated only with reported satisfaction among AFH

residents (but not the other three outcomes). Finally, among NH residents, this item was associated significantly for all resident outcomes except depressive symptoms.

Qualitative findings. Over 100 comments were made in response to this item. A few residents indicated that they were independent and could do things the way they wanted on their own, which made staff knowing less important. *"I do my own chores and I want to do it how I like to do it." "Usually I do stuff on my own." "Other than cleaning, they don't do too much."*

About one in five residents, mostly those who relied on staff for daily support, described ways that staff did things the way they wanted. What is striking is the important role most of these residents play in training staff and the openness of staff to doing things the way residents wanted. *"If they don't do it the way I like it, I tell them. They do listen when I talk." "It helps them out because then they can do it right the first time." "They learned. At first, the owner, I wasn't quite satisfied. But she started picking up my cues." "They seem to learn it; they bring me the things I need." "I know when I was eating breakfast, I got cheese on scrambled eggs because I said I liked it that way. I asked for dark meat when I saw someone else eating it and he had requested it."*

Others indicated that having things done the way they wanted was not or just somewhat important, suggesting their own flexibility and accommodation to the way things were done in the setting where they lived. *"Well, there has to be compromise." "I don't have to have my own way all the time."* Comments regarding their experiences were similar. *"I'm not demanding." "There is a certain way they do things and I'm fine with it." "I'm not sure because when I ask for things a certain way, but they don't always understand why and don't always do it." "I don't know how to answer that. I just take things as they come."* Only two people said they kept to themselves and did not express preferences. *"I'm not that picky. I don't tell them." "I'm a recluse and it drives them crazy that they don't know about me."*

The overall theme that emerged from this question, however, was that staff did not do things the way residents wanted. Most often, residents cited staff turnover and staff busyness as reasons.

> *"They have a big turnover. Serving us in the morning, I like to have coffee in the morning and color in my phone app. There's been such a big turnover that a lot of them don't know that. The ones that have been here a long time know, but not the new ones.*
>
> *The turnover and the training is such that they don't know. They do things when you are not here, so you can't tell them and they can't know. They have so many people to take care of, they need more time and training with each person. They definitely try, but they don't have time to do it the way you want.*

They change caregivers so often, I don't know how they would be able to know.

They can't—too many people [residents] here, to keep all the details straight for all of us.

I don't need [them] to [know]. I can tell them. Most workers get paid minimum wage. If you want to know everyone's history, you need to pay them more.

Sometimes, but less frequently, residents attributed lack of knowing how they liked things done to lack of caring and interest from staff who were more focused on their own routines. *"To me it's very important, to them. . . [gesture]" "I tell them how I like things, but they do it their way." "This assisted living home is very structured, so they don't individualize care." "I'm on their schedule."*

b. Know the kinds of things you are interested in

Quantitative findings. The second question in this domain asked if the resident considered it not important, somewhat important, or very important that people who worked in this setting knew the kinds of things the resident was interested in. Forty percent of all residents reported that this was very important to them. AFH residents were significantly more likely to rate this item as very importantly compared to NH and AL/RC residents (NH=39%; AFH=50%; AL/RC=33%).

When asked about whether people who worked at the setting knew the kinds of things the resident was interested in, about half of all residents (49%) across three settings said yes. AFH residents were more likely to say yes to this item compared to NH and AL/RC residents (NH=46%; AFH=67%; AL/RC=38%).

Overall, a quarter of all residents (24%) across three settings reported unmet need for this issue. However, there was significantly higher unmet need among NH and AL/RC residents compared to AFH residents (NH=26%; AFH=16%; AL/RC=28%).

This item was significantly associated with higher reported satisfaction and quality of life across the three settings. It was not significantly associated with depressive symptoms in any of the settings. Finally, it was significantly associated with higher likelihood of recommending the setting to someone else among AFH and AL/RC residents, but not NH residents.

Qualitative findings. This item generated about 70 comments and about one-third indicated this is important and that residents experienced staff who knew their interests.

Some comments focused on facility-sponsored activities. *"They send out a two-page activity page that asked what you like. They have all kinds of things, more than a person could be involved [in]." "They know some things, like when they have music." "There's some of them know the things I don't like, like bingo."* Residents' interests extend beyond the activities program as reflected in many other comments, including those about their life in general, as well as those about food. *[It is very important] because this would suck if you didn't have people interested in you." "At first I didn't care because I thought it was temporary. Now, it's very important because it's longer term and my career keeps going." "I like it that they know. I want two glasses of milk with my dinner, not juice."*

"It depends" was a response from some, with many of these residents identifying a staff person who did express interest. *"Depends on their duties and how it relates to me. The Activities director is very important." "The white-haired lady at the desk . . . she is the best one. The head nurse here, I think they got a new one, is very nice. The one they used to have, I didn't have much use for."*

Another group of residents did not find this to be an important, or even a useful item. *"I don't care if anyone knows what I'm 'interested' in. I don't think it's a good question. Why should a caregiver be interested in what I'm reading? They should pay attention to my care as a person." "I'm not interested in anything besides a nap."* Others said they did not share information with staff about their interests. *"No [they don't know], but that's okay, that's my choice." "Not an issue, not important."* A few noted it was their own responsibility to share the information. *"That's up to me." "It's supposed to be your home, you should let them know."*

Nearly one-third reported that staff did not know their interests, many because they lacked the type of relationship with staff where that information would be shared. *"[I do not have] a personal relationship with any of them." "Because I don't socialize with them, I have no way of knowing." "I have noticed some caregivers don't say a word to people they're helping, like wheeling people from the dining room." "Yes, technical [they know], but the staff are business, no personal connection."* Some residents attributed lack of knowledge to staff busyness. *"They don't have time for that here." "They don't have time, [so] I haven't shared it really."*

Others indicated that staff did not care or that staff encouraged specific activities regardless of resident interests. *"None of them do." "That's hard to answer because it's important, but I don't get it." "They tried to make me an artist. I ain't no artist." "They want us to be interested in exercise."* A couple of the residents did not have access to things they were interested in. *"We don't have a flower garden tour. That's what I like." "There aren't as many blind people here . . .I try not to get resentful, because I know that I am not the majority."*

c. Know how you like to spend your time

Quantitative findings. The third question in this domain asked if the resident considered it not important, somewhat important, or very important that people who worked in this setting knew how the resident liked to spend their time. Forty-five percent of all residents reported that this was very important to them. AFH residents were most likely to find this issue important, followed by NH residents, and then AL/RC residents (NH=45%; AFH=55%; AL/RC=35%).

When asked whether people who worked at the setting knew how they liked to spend time, 59 percent of residents responded positively. AFH residents were more likely to say yes to this item compared to NH and AL/RC residents (NH=53%; AFH=73%; AL/RC=52%).

Overall, one-fifth of all residents (20%) across three settings reported unmet need for this issue. However, there was significantly higher unmet need among NH and AL/RC residents compared to AFH residents (NH=23%; AFH=14%; AL/RC=22%).

All four resident outcomes were significantly associated with this item regardless of setting type.

Qualitative findings. Relatively few comments, about 50, were made in response to this item. As with several items within this domain, these comments represented a range from very positive to quite negative. About one-third of the comments indicated it was important to them that they spend time the way they wanted and, for the most part, this is what they experienced. *"They sometimes take us to breakfast, to a restaurant, and to a home and to stores. They're real good to us." "They know us, what we want to do and what we like." "Most of the time I watch TV and they know that. I'm pretty adaptable to things." "No one bothers me here, I like to spend my time sleeping." "I would say that they generally know how I like to spend my time. It is mostly writing, but they don't know the details. And that governs how they take care of me."*

Some residents talked about the things that they did not like, including daily routines and interactions (or lack of interactions) with others. *"First thing that comes to mind is mealtime. I don't like how much I'm eating. Four hours apart is too frequent." "It is [important], but they don't leave me alone. I want to watch TV or crochet." "One thing I don't like. There are cliques, people [residents] are in charge. They don't invite new people. Cards and bowling is by invitation only. I fight that. Everything should be open, all welcome. Annoys and upsets me. It's a quality of life issue."*

Staff busyness or lack of caring were also mentioned by some residents. *"They try to be as personal as they can. There is only so far you can go. There are 40 people here. Some require a lot of care, some not at all." "I spend my time in this room. I wouldn't say*

I like it. Sometimes I call it my prison." "I quilt a lot, but I can't do it here. I think they know, sometimes I think they don't care."

A few residents said they did not know if staff knew how they liked to spend their time or that it was not important. *"I would put it at zero [importance]. If they leave me alone, it's greatly appreciated. They take great care at the place and that's more important."*

d. Know what makes a good day for you

Quantitative findings. This question asked if the resident considered it not important, somewhat important, or very important that people who worked in this setting knew what made a good day for the resident. About half of all residents (49%) reported that this was very important to them. AL/RC residents were much less likely to find this issue important compared to NH and AFH residents (NH=52%; AFH=58%; AL/RC=38%).

When asked whether people who worked at the setting knew what made a good day for them, 52 percent of residents responded positively. AFH residents were more likely to say yes to this item compared to NH and AL/RC residents (NH=49%; AFH=68%; AL/RC=41%).

Overall, a quarter of all residents (26%) across three settings reported unmet need for this issue. However, there was significantly higher unmet need among NH and AL/RC residents compared to AFH residents (NH=28%; AFH=17%; AL/RC=31%).

This item was significantly associated with higher reported satisfaction and quality of life across three settings. It was significantly associated with higher likelihood of recommending the setting to someone else among AFH residents only, and not NH or AL/RC residents. It was also significantly associated with lower depressive symptoms among NH and AL/RC residents only, and not AFH residents.

Qualitative findings. This item generated about 100 comments. Many were dismissive or critical of the question in this domain. *"You ask the same question over and over in different ways. I don't care what they think." "I truly don't know the answer to that, there are so many ramifications." "You see, the approach of these questions throws me off. What does it mean if something is 'somewhat important' or 'very important?' Sometimes these things are very important and sometimes they are not." "Hard to answer, answering for someone else."*

Several residents indicated that a good day was their own responsibility and knowing what makes a good day was not a staff responsibility. *"I think it's up to you, not their concern." "I make my own [good] days, my own entertainment." "I can't expect them to know everything." "I think you make your own good day. I'm just as happy sitting in my room reading and doing an activity."* A few people indicated that they kept this

information to themselves. *“no [they don’t know] and I’m not going to tell them.” “I don’t want them to know, I don’t care if they know.”*

Others indicated that staff knowing what made a good day was important and provided examples of how they did this. *“That’s one of the qualities a good caregiver has.” “They remind me to play cards.” “They know if I’m not outside walking up and down the road, something is wrong.” “They do, it’s just part of life here.” “The people here are amazing. If they see you having a bad day, they go out of their way to liven you up. I feel like I hit the lottery being here. I’ve been in other places that weren’t so great.” “Because if you have a good day and they help, it makes it even better.”*

Similarly, others provided examples of what made a good day for them. *“They know what keeps me safe. We have mutual respect.” “I don’t know that they know what I do, but they know I like my alone time.” “Having an extra cookie.” “Going to the beach.” “I try to keep a routine and they help me.”*

In contrast, several residents indicated that staff knowing what made a good day for them was not important, they did not have good days, or that staff did not know what made a good day. *“If they show interest it’s, nice, but not important.” “I’ve been alone more of my life, so it isn’t earth-shattering.” “I haven’t had a good day since my birthday.” “Doesn’t happen, I don’t know if they know anything about me.” “I guess it’s very important, but I settle for less.” “They are here to help and they’re gone. They don’t know everything about me.” “I don’t know if they care.” “Mostly, they leave me alone.”*

Staff busyness was a theme and a barrier to staff knowing. *“They’re busy.” “It’s not part of their job.” “I know that they are busy, so if I can be obliging and keep to myself, I will.” “I think they do a lot of that. They are kind, tired, sort of overworked.” “I don’t think they have the time. The question should be ‘do employees have time to do these things?’ And they don’t!” “They are taking care of 50 other people and have tasks to do.”*

Finally, over 10 percent of residents said that they could not answer the question because they did not know whether the staff know what made a good day for them or not. *“I don’t know what they know.” “We’ll, I don’t know. I suppose.”* Two of these residents indicated that they didn’t know themselves what made a good day. *“I don’t even know that myself.” “I don’t know if they do, I don’t even think I know.”*

e. Know who is important to you

Quantitative findings. This question asked if the resident considered it not important, somewhat important, or very important that people who worked in this setting knew who

was important to the resident, such as family and, friends. About 61 percent of all residents across three settings reported that this was very important to them. Residents did not differ in terms of finding this issue very important significantly across three settings (NH=64%; AFH=60%; AL/RC=60%).

When asked about whether people who worked at the setting knew who was important to them, 70 percent of residents replied yes. AFH residents were more likely to reply yes to this item compared to NH and AL/RC residents (NH=67%; AFH=79%; AL/RC=66%).

Although 17 percent of all residents reported an unmet need for this issue, unmet need was significantly higher among NH and AL/RC residents compared to AFH residents (NH=17%; AFH=10%; AL/RC=22%).

This item was significantly associated with higher reported satisfaction and quality of life across three settings. It was significantly associated with higher likelihood of recommending the setting to someone else among AFH residents only, and not NH or AL/RC residents. It was also significantly associated with lower depressive symptoms among NH residents only, and not AFH or AL/RC residents.

Qualitative findings. Residents made about 60 comments in response to this item. Most of these related to the item's importance or to providing specific examples. These included *"Critically important" "Probably very important so they know where I'm coming from." "If there's an incident, I want them to know who to call." "In general, they know, like my family or daughter who comes to see me. Staff see them quite often." "They know my two daughters. One lives in [town]. They know I can't stand her husband. . ." "My niece, my wife, my friendships that have developed here. Yes, I think they know."*

A few did not find this item to be important, or could not answer the question, because they didn't have any family. *"I don't have no one." "My family's right here [others in the setting]. I don't have family. They [family] are in [state]. Don't even know where they live. I haven't seen them for 50 years. I traveled a lot, going from one ranch to another, farms, dairies." "There isn't anybody in my life, so I don't know how to answer that."*
A few other residents reported that staff did not know. For two, this was because they did not share information about people who were important to them. One cited the importance of autonomy and the other held private information close. A few others indicated that staff did not know, especially if they did not see people important to the resident in the setting. An example was a resident who talked to family members by phone rather than having visits from them in the setting. Others indicated it varied by staff. *"Some do [know]" "They've never asked that. They don't ask personal questions.*

They don't get to an emotional level." "They know my daughter, but not others. There is such high turnover. The ones that have been here a long time know."

f. Know what you worry about

Quantitative findings. This question asked if the resident considered it not important, somewhat important, or very important that people who worked in this setting knew what the resident worried about. Only one-third of all residents (34%) across three settings reported that this was very important to them. AL/RC residents were least likely to find this issue very important compared to NH and AL/RC residents (NH=35%; AFH=43%; AL/RC=26%).

When asked about whether people who worked at the setting knew what they worried about, a small share of residents (29%) replied yes. AFH residents were most likely to reply yes to this item, followed by NH residents, and then AL/RC residents (NH=30%; AFH=42%; AL/RC=18%).

For those who found this item to be very important, unmet need was considerable, with one-third (33%) of all residents across three settings reporting an unmet need. Unmet need was significantly higher among NH and AL/RC residents compared to AFH residents (NH=36%; AFH=26%; AL/RC=36%).

This item was associated with none of the four resident outcomes among NH residents, only two of the resident outcomes among AFH residents (likelihood of recommending the setting to someone else and general satisfaction), and only one among AL/RC residents (depressive symptoms).

Qualitative findings. This item resulted in nearly 150 comments, the most within this domain. Four distinct themes were represented in these comments. Thirty percent of the comments were made by residents who reported that they did not worry. *"My daughter takes care of everything, so I don't worry." "My daughter worries more about things than I do – what to do with my things." "I don't have worries. I have accepted my life here." "I don't worry much. I have very little to worry about living here."* Lack of worry made it difficult to answer the question about their experience with staff knowing their worries. *"I don't worry; I don't know how to answer that."*

The second theme, keeping their worries to themselves, also accounted for about 30 percent of the comments. With respect to importance:

That's a tough one to answer. I don't like anyone to know what I worry about. That's private. It's important to me that they don't know. There is a certain level of privacy one must maintain to stay an individual.

Some things I don't think are anybody's business.

Try to keep that stuff to myself. She has enough going on.

I wouldn't confide in someone I'm not connected to.

Comments in response to the question about experience were similar: *"I don 't tell them. So how could they know?" "I don't tell anybody." "Well, I'm not too open in what I worry about."*

Some residents talked about the importance of having a confidant to share their worries with, but those confidants were not staff. *"I confide in friends."*

Staff supportive of residents with worries was the third theme and accounted for about one in six comments. Health was a common worry. *"My blood pressure; we're all worried about that." "I don't want to gain any more weight. That scares me because of my health."* Worries about family members were also common. *"I worry about my husband." "I worry about my son who's in the foster home, too*." *"I have some concern over the decisions my adult granddaughter makes."* Other worries reported included "everything," money, and transportation.

The fourth major theme involved comments related to limitations of staff knowledge, often due to staff busyness. These comments also represented about one in six responses to this item. *"They have their own worries and their own homes and families to take care of." "Nothing they can do about it usually" "I don't have direct relationships with the staff here." "That's not their concern. That would pertain more to people who have dementia and they don't know what they are worried about." "They don't care. If you share something with them and they don't respond, then you don't share anything else." "They don't go out of their way to find out, but they are helpful when they do."*

The rest of the comments included those from residents who reported they did not know whether staff knew about their worries or indicated that their ratings of this item depended on their specific situation, worries, or the specific staff involved: *"If you are sick, some of these things are important, but if you can do things yourself, then they may not be important." "[know worries] only if it has to do with here." "It depends on*

what it is. Is my heart aching or do my toenails need clipping?" Finally, some residents did not know whether staff knew their worries or not.

g. Know what you like to be called

Quantitative findings. This question asked if the resident considered it not important, somewhat important, or very important that people who worked in this setting knew what the resident liked to be called. Fifty-seven percent of all residents reported that this was very important to them and there were no significant differences across settings in terms of finding this issue very important (NH=59%; AFH=58%; AL/RC=55%).

When asked about whether people who worked at the setting knew what they would like to be called, most residents (90%) indicated that they did. Residents reported similar levels of positive response across three settings (NH=89%; AFH=91%; AL/RC=90%).

There was little unmet need about this issue among residents, with only five percent of all residents reporting an unmet need and residents reported similarly little unmet need across settings (NH=6%; AFH=4%; AL/RC=4%). This item was significantly associated with higher reported satisfaction among NH and AFH residents, but none of the other resident outcomes across any of the settings.

Qualitative findings. About 60 comments were generated about this item. About one-third indicated it was important and that staff did call them by their preferred names. For many, being called their preferred name represented a relationship with staff or a maintenance of their identity. *"It means they are taking the time to get to know me." "Everyone knew my name from the first day. That was a very important gesture." "It builds you up. Makes you feel important." "I go by my middle name, so it's very important. . . most of them do." "The provider and her kids call me 'grandma' and I like that."*

Some residents rated this item important but did not experience staff who called them by their chosen name. *"I don't want to be called [name], but everyone wants to call me that. I can't stand it." "At one point they called me [nickname] and I hated that. I used to be called that as a kid when I was teased, so it brings up bad memories." "And not make up names for me because I'm shorter than everyone else." "They know what I don't want to be called, but they do it anyway."*

Several reported that the name they were called did not matter to them. *"Doesn't come up. I just got the one name." "I don't care what they call me. Half say, 'hey you,' other times they call me [name], but my name is [name]. I really don't care. Just as long as*

they talk to me." "Not important, especially since I only know of a few of the staff's names. I call everyone 'honey,' so I can't expect them to know my name." "You can call me anything you want." Some of these comments also suggest some accommodation over time. *"At first I was annoyed that they called me by my full name, but now it doesn't matter as much to me." "It was shocking when I moved here and people started calling me by my first name. I'm used to being called Mrs. [name]. But it's okay. Remember, I can take care of myself."*

Summary

A wide range of responses were made to the items within the domain with respect to both importance and experience. Some found it important that staff know the things about them represented in the items, and others did not. Similarly, some residents experienced staff with who knew them in the ways described by items and others reported that staff did not know. The role of residents teaching staff about their needs and how to provide support was apparent in several responses. Responses also revealed residents who have adapted to their situation, often by lowering expectations related to staff knowledge and actions. Within this domain, staff busyness or staff turnover were identified as major barriers to staff knowing residents in these ways. Asking residents what staff knew about them was difficult for some residents because they did not know what staff knew.

Although this domain is focused on what staff know about residents, their lives, and their routines, these items are also indicative of a type of relationship that the resident has with those who work most directly with them. It is striking that AHF residents were most likely to report that they experienced staffing knowing about them. In NH and AL/RC, residents are more anonymous and caregivers may be more focused on tasks rather than getting to know the residents.

As presented in Table KP3, one item met criteria for inclusion in the final Resident VIEW measure across all settings, staff knowing how residents liked to spend their time. AFH residents also valued staff knowing the kinds of things they are interested in and what makes a good day for them. These areas of knowing seem especially important for those living in small households and need support with daily living. An additional item to include for both NH and AL/RC residents is staff knowing who is important to them. In both settings, staff busyness and the number of residents may make people feel invisible. Staff knowing this information about them may be especially important and an indicator that they are seen as individuals. Staff knowing how residents like things done, is an item to include in the AL/RC tool.

Table KP3. Selection of items from the Knowing the Person domain for the final tool based on various sources

People who work here know:	NH	AFH	AR
a. How you like to have things done?	⇔	×	⇔ ✔
b. The kinds of things you are interested in?	×	⇔ ✔	×
c. How you like to spend your time?	✔	✔	✔
d. What makes a good day for you?	⇔	⇔ ✔	⇔
e. Who is important to you?	✔	⇔	⇔ ✔
f. What you worry about?	⇔	⇔	⇔ ✔
g. What you like to be called?	×	×	×

Results: 1.B.(5) Autonomy and Choice

Introduction. As people age and/or become increasingly dependent upon others for help and support, they often lose the ability to direct their daily lives. This is especially true for those living in congregate care settings. The ability to control the rhythms one's life is one of the central tenants of the culture change movement (Lustbader, 2014). Daily routines (e.g., when to get up and go to bed, when and what to eat), how and with whom to spend time, and the amount of risk one is willing to accept in pursuit of preferred activities are examples.

Policies governing LTC settings have been instituted to promote autonomy and choice by emphasizing the importance of identifying and supporting resident preferences. For nursing homes, the Minimum Data Set assessment, Section F contains instructions for identifying and supporting resident preferences with respect to choosing clothes, taking care of personal belongings, bathing choice, availability of snacks, choosing one's own bedtime, having family or close friends involved in decisions about care, ability to use a phone in privacy, and a place to lock one's things (Centers for Medicare and Medicaid, https://www.in.gov/isdh/files/Section_F_MDS_3.0.pdf).

AL and AFH were developed to enhance autonomy and choice (Wilson, 2007; Kane, Kane, Illston, Nyman, & Finch (1991). The National Core Indicators aging and disability adult consumer survey includes four items that emphasize resident decision making: where they live, what they do during the day, the staff that supports them, and with whom they spend time. Other items ask residents about feeling in control of their lives (NASUAD and HSRI, 2017).

Although autonomy and choice are included in most definitions of PCC, it appears to be a difficult concept to operationalize, beginning with the process of person-centered care planning (National Quality Forum, 2020). Studies using the Person-Directed Care (PDC) Staff Assessment have consistently rated autonomy the lowest among the PDC domains (Hunter et al., 2016; Martínez, Suárez-Álvarez. Yanguas, Muñiz 2016; Sullivan, Meterko, Baker, et al., 2012). Scales, Lepore, Anderson, and their colleagues (2017) identified PDC planning as central to empowering residents and their chosen family members by co-creating care plans. Barriers to care planning they identified included the conflict between priorities of safety and autonomy as well as limited resources, especially as related to staff.

The Resident VIEW Autonomy and Choice domain contains 9 items for all settings, with one item added for the CBC sample. Most address decisions about daily routines (e.g., when to get up, when to eat, how to get clean, and spending one's time as one chooses). Other items have to do with privacy, involvement in decisions about the setting (e.g., expressing opinions) or one's care (ability to make decisions even if others do not approve).

Overall findings. Cronbach's alpha for the nine items in the original domain was .69 for the pooled sample and did not differ much by setting type (.66 to .68). Overall, this indicated a moderate inter-item agreement for the original domain. For the pooled sample, the strongest association was between items f. ("spend your time the way you want to") and g. ("have privacy when you want it") (See Figure AC1 below).

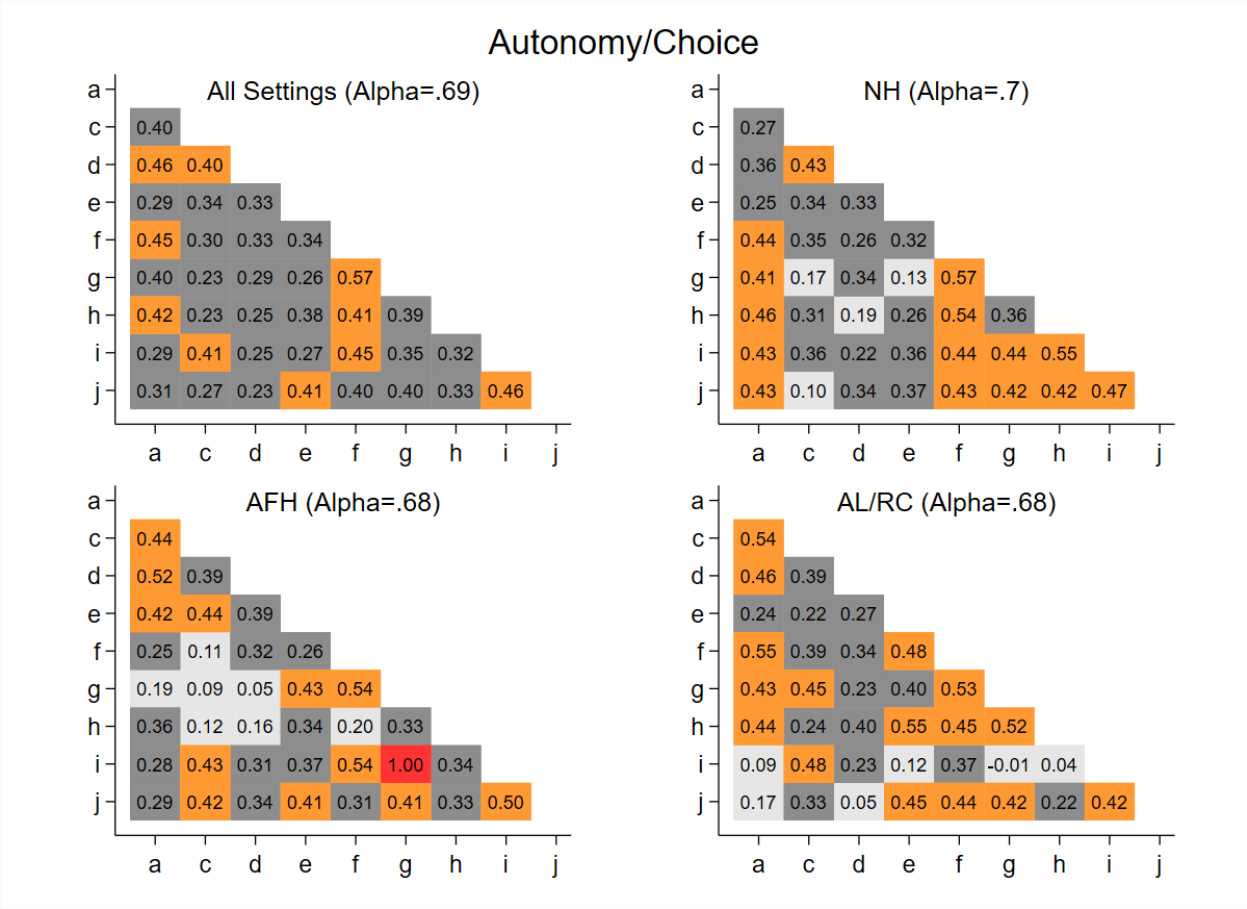


Figure AC1. Strength of association among items in the Autonomy and Choice domain

Table AC1 presents information about unmet need reflected in these items. Unmet need is defined as the incongruence between rating an item as very important and reporting no experience or experience only some of the time for that item. Items where 25 percent or more of residents reported that they did not experience something they had rated as very important are highlighted in the table as are items rated very important by 75 percent or more of residents.

Within this domain, 75 percent or more residents across settings identified one item they felt was very important, "you can do things for yourself." The area of greatest unmet need for residents across settings, was taking a shower or bath when the

resident wanted do and having a say in how the place worked. At the same time, "having a say in how this place works," had relatively low importance for the majority of residents in all settings. Being able to eat meals when the resident wanted met criteria in NH and AL/RC and nearly met criteria (24%) for AFH residents. NH residents reported the greatest amount of unmet need, indicating this was so for eight of the 10 items. AL/RC and AFH residents each identified three areas of unmet need.

Table AC1. Importance and unmet need for Autonomy and Choice domain by setting type

	NH			AFH			AL/RC			TOTAL		
	VI %	Y %	UN %	VI %	Y %	UN %	VI %	Y %	UN %	VI %	Y %	UN %
a. Get up when you want to?	78	65	27	61	77	14	75	77	17	72	72	20
b. Choose what you eat	X	X	X							X	X	X
c. Eat meals when you want to	47	47	32	37	48	24	37	52	32	41	49	30
d. Take a shower or bath when you want to	63	43	45	60	62	25	72	66	27	65	56	33
e. Make your own decisions even if others don't approve	76	66	26	60	58	27	74	75	16	71	67	23
f. Spend your time the way you want to	71	67	25	72	79	15	80	77	15	74	74	19
g. Have privacy when you want it	80	72	25	72	88	9	81	86	10	78	81	15
h. Can do things for yourself	83	74	21	79	71	19	87	88	10	83	78	17
i. Have a say in how this place works	39	17	52	37	24	39	45	16	60	41	19	51
j. Feel free to express your opinions about things you do not like.	74	74	17	54	72	15	69	74	16	66	73	16

Notes: VI=Very important, UM= Unmet need, Y= Yes. Item b was not part of the NH survey and is not analyzed for CBC residents in this report.

The association of each item in this domain with various outcomes reported by residents is presented in Table AC2 by setting. Outcomes include resident recommendations of the place to someone else, satisfaction with the setting, quality of life, and depressive symptoms. No items were associated with all outcomes across settings, although the item "feel free to express your opinions for things you do not like" met all outcomes except depressive symptoms in AL/RC.

Table AC2. Association of experiencing each item with positive resident outcomes by setting type.

	NH				AFH				AL/RC			
	R	S	Q	P	R	S	Q	P	R	S	Q	P
a. Get up when you want to?	✓	✓	✓	✓	✗	✗	✓	✗	✓	✓	✓	✓
b. Choose what you eat	X	X	X	X								
c. Eat meals when you want to	✗	✓	✗	✗	✓	✓	✗	✓	✓	✓	✓	✗
d. Take a shower or bath when you want to	✗	✓	✓	✗	✓	✓	✓	✓	✓	✗	✓	✓
e. Make your own decisions even if others don't approve	✗	✓	✓	✗	✓	✓	✓	✓	✓	✗	✗	✗
f. Spend your time the way you want to	✓	✓	✓	✓	✗	✓	✓	✓	✗	✓	✓	✓
g. Have privacy when you want it	✓	✓	✓	✓	✗	✓	✗	✗	✗	✓	✓	✓
h. Can do things for yourself	✗	✓	✓	✓	✓	✗	✓	✓	✗	✗	✗	✓
i. Have a say in how this place works	✗	✓	✓	✗	✗	✓	✓	✓	✗	✗	✓	✗
j. Feel free to express your opinions about things you do not like.	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✗

Notes: Experiencing is defined as a response of Yes compared to No or Some. R= would recommend this place to someone else, S=general satisfaction, Q=quality of life, P= PHQ9 score (depressive symptoms). No control variables included. Significance was determined at $p < .05$. Item b was not part of the NH survey and is not analyzed for CBC residents in this report.

a. Do you get up when you want to?

Quantitative findings. The first question in this domain asked residents if they considered it not important, somewhat important, or very important that they get up when they want to. Overall, almost three-quarters of all residents (72%) across all settings said that this was very important to them. NH and AL/RC residents were significantly more likely to rate this item very important compared to AFH residents (NH=78%; AFH=61%; AL/RC=75%).

When asked if they got up when they wanted to, 72 percent of all residents across three settings said yes. However, NH residents were less likely to report that they did so compared to AFH and AL/RC residents (NH=65%; AFH=77%; AL/RC=77%).

Overall, about one-fifth (20%) of all residents reported unmet need about this issue. However, NH residents reported a significantly higher unmet need compared to both AFH and AL/RC residents (NH=27%; AFH=14%; AL/RC=17%).

Among NH and AL/RC residents, this item was significantly associated with all four resident outcomes. However, it was significantly associated only with higher quality of life among AFH residents.

Qualitative findings. Eighty-five residents commented on this item. Almost 40 percent indicated that they don't necessarily get up when they want to, but that they've accepted the schedule according to getting up ("*That is scheduled but everybody is at breakfast at 9, so if you want to sleep in for half an hour, you just don't. A man here sleeps almost all day, but I don't have the nerve to ask to sleep in," "I get up every morning at 6 o'clock because that works best, not because I want to")*.

Ten residents explained that they're not able to get up when they want to or that it just doesn't happen (*"I could kill some of them [laughter]. Some of them come in and flip the light on and holler at you, and we've been struggling with sleep," "On a good day I'll get three hours of sleep. Sometimes I don't sleep for two days").* Eight residents explained that they have communicated their preference to staff (*"There is a system rotation and I ask to be last because I don't mind lying in bed").* Seven residents stated that they have a choice when they get up (*"Usually that isn't an issue. I'm generally up before everyone anyway")*. Lastly, six comments were made by residents emphasizing the importance of the question.

b. Do you choose what you eat?

Quantitative findings. NOT REPORTED. This item was added to the CBC data, so no comparisons can be made across all settings.

Qualitative findings. Residents made about 160 comments to this item. About a quarter of the comments were related to residents mentioning a set or predetermined menu (*We have a menu. You can't always have what we want," "There are options, but there aren't really choices").* About 15% of residents made comments indicating that they had some or limited choice in what they wanted to eat ("*Well you can, there is a scant alternative menu. I keep stuff in my fridge," "There's one caretaker that works on Mondays, Tuesdays, and Wednesdays and he always takes what I say seriously. I used to cut the burritos in half, but finally, I said I hate it, and they make me a sandwich, which is fine").* An additional 15% of comments were general comments regarding the resident's preference *("Sometimes the food is too bland," "As long as I get to go out with my wife every once in a while").*

Just under 10 percent of comments were made related to each of the following categories: allergies or food restrictions, having a choice in what to eat, not having a choice in what to eat, staff knowing food preferences, and miscellaneous. For example, one resident explained their sensitivities to various foods and staffing knowing their preferences by saying, "[*Choosing what I eat is] very important because I'm trying to figure out what is wrong with my gut…[the owner] is wonderful. She helped me be gluten-free for a month and now we're going sugar-free."* One resident described having a choice in what they ate by stating, "*Well, I choose it from the menu, but if I don't like it, then I get my own stuff."* Lastly, as it relates to residents not having choices in what they eat, one resident stated, "*No, [name] fixes the meal and sets it in front of you and you're supposed to eat it."*

c. Do you eat meals when you want to?

Quantitative findings. This question asked if the resident considered it not important, somewhat important, or very important that they eat meals when they want to. Forty-one percent of all residents across all settings said that this was very important to them. NH residents were significantly more likely to rate this item more importantly compared to AFH and AL/RC residents (NH=47%; AFH=37%; AL/RC=37%).

When asked if they ate meals when they wanted to, about half (49%) of all residents across three settings replied yes. There were no significant differences in responding positively to this item across three settings (NH=47%; AFH=48%; AL/RC=52%).

Thirty percent of all residents reported unmet need about this item and there were no significant differences across residents of different settings (NH=32%; AFH=24%; AL/RC=32%).

This item was associated with general satisfaction among residents of all three settings. It was also associated with higher likelihood of recommending the setting to someone else among AFH and AL/RC residents. Only among AFH residents was it significantly associated with lower depressive symptoms. Finally, it was associated with higher quality of life among AL/RC residents only, and not NH or AFH residents.

Qualitative findings. Residents made over 130 comments regarding eating when they want to. Over half (57%) of these comments indicated that residents adjusted to a meal schedule set by the staff (*"Eat when the meals are served. Same time each day. I guess that's when I want to," "There's a schedule here. The important food group I get every day is chocolate")*. An additional 15 percent of the comments were related to having some or limited choice of eating meals when the resident wanted to (*"Unless I buy something and keep it in my room", "Yes and no, because we have designated food times")*. About 7 percent of the comments addressed not being able to eat when they

wanted to (*"That would be nice if they allowed that," "It's rigid. They get cross if you're not on time")*.

d. Do you take a shower or a bath when you want to?

Quantitative findings. This question asked if the resident considered it not important, somewhat important, or very important that they take a shower or a bath when they want to. Two-third of all residents (65%) replied that this was very important to them. AL/RC residents were significantly more likely to rate this item vert important compared to NH and AFH residents (NH=63%; AFH=60%; AL/RC=72%).

When asked if they took a shower or a bath when they wanted to, a little over half of all residents (56%) replied yes. However, NH residents were less likely to report that they did so compared to AFH and AL/RC residents (NH=43%; AFH=62%; AL/RC=66%).

One-third (33%) of all residents reported unmet need about this issue. However, NH residents reported a significantly higher unmet need compared to both AFH and AL/RC residents (NH=45%; AFH=25%; AL/RC=27%).

Among AFH residents, this item was associated with all four resident outcomes. Among NH residents, it was associated with general satisfaction and higher quality of life, but not higher likelihood of recommending the setting to someone else or depressive symptoms. Finally, among AL/RC residents, it was significantly associated with all three outcomes except general satisfaction.

Qualitative findings. Over 100 comments related to the item taking a shower or bath when you want to. About half of the comments referenced residents adjusting to the staffs' schedule (*"I shower when she wants me to. I used to come home and shower. She and I butt heads on that sometimes, she wants to be sure I'm showering enough," "That's something I'm adjusting to- can you imagine me letting another man's wife bathe me in all my male glory").* Twelve percent of comments related to taking a shower or a bath when you want to were related to a general statement of preference, even if it was something they did not experience. (*"That would be wonderful," "I take a shower Monday, Wednesday, Friday, and Saturday")*. Lastly, about 10 percent of the comments were related to residents expressing their inability to take a shower or bath when they want to (*"They don't show up", "Sometimes it's more difficult to obtain than others. There are 19 people [here] with one person helping"*).

e. Do you make your own decisions even if others don't approve (e.g., eating foods not on your diet, taking or not taking some medications)?

Quantitative findings. This question asked residents if they considered it not important, somewhat important, or very important that they make their own decisions

even if others don't approve, such as eating foods not on their diet or taking or not taking some medications. Overall, almost three-quarters of all residents (71%) across all settings said that this was very important to them. NH and AL/RC residents were significantly more likely to rate this item more importantly compared to AFH residents (NH=76%; AFH=60%; AL/RC=74%).

Two-third of all residents (67%) said that they made their own decisions even if others did not approve. However, AL/RC residents were significantly more likely to report that they did so compared to NH and AFH residents (NH=66%; AFH=58%; AL/RC=75%).

Overall, 23 percent of all residents across three settings reported unmet need about this issue. However, NH and AFH residents reported a significantly higher unmet need compared to both AL/RC residents (NH=26%; AFH=27%; AL/RC=16%).

Among AFH residents, this item was associated with all four resident outcomes. Among NH residents, it was associated with general satisfaction and higher quality of life, but not higher likelihood of recommending the setting to someone else or depressive symptoms. Finally, among AL/RC residents, it was significantly associated only with higher likelihood of recommending the setting to someone else (and not the other three resident outcomes).

Qualitative findings. Residents at assisted living, residential care communities, and adult foster homes made about 100 comments related to the item making your own decisions even if others don't approve. About one out of five comments were related to having a choice or control (*"If the only person you have control over is yourself, then I better have control over my life," "They can disagree with me, but they can't overrule me"*). About 14 percent of residents explained that they didn't understand the question or that it didn't apply to them (*"That's a hard one to answer because I don't know of any choice I've had to make," "That doesn't apply to me whatsoever"*). Just over 13 percent of comments indicated that they had some choice (*"The older I get, the more I wonder about that. I have to depend on people"*). About 10% of comments made explained that this particular situation hasn't come up (*"Doesn't come up," "They're not pushy, not a problem"*).

f. Do you spend your time the way you want to?

Quantitative findings. This question asked if the resident considered it not important, somewhat important, or very important that they spend their time the way they want to. Three-quarters of all residents (74%) responded that this was very important to them. AL/RC residents were significantly more likely to rate this item very important compared to NH and AFH residents (NH=71%; AFH=72%; AL/RC=80%).

When asked if they spent their time the way they wanted to, three-quarter of all residents (74%) responded positively. However, NH residents were less likely to report that they did so compared to AFH and AL/RC residents (NH=67%; AFH=79%; AL/RC=77%).

Nineteen percent of all residents reported unmet need about this issue. However, NH residents reported significantly higher unmet need compared to both AFH and AL/RC residents (NH=25%; AFH=15%; AL/RC=15%).

This item was associated with all four resident outcomes among NH residents, and all three resident outcomes except higher likelihood of recommending the setting to someone else among AFH and AL/RC residents.

Qualitative findings. About 50 comments were made related to the item about spending time the way you want. About 45% of the comments suggested the residents did not spend their time or only partially spent their time the way they want to. For example, one resident stated, "*Right now, even though it's very important to me, I can't go out when I want. [Owner] has a sweet face, but her words cut like iron. I felt like I was cooperating with them, but I got grounded instead."* Out of the 24 comments about probably or mostly being able to do what they want, six residents indicated that their health impacts how and if they spend their time the way they want to. For example, one comment read, "*I can't get up and walk. Some of the stuff, I do. If I get this [procedure], maybe I can walk with a cane.*" About a quarter of comments suggested that these residents had full control or choice in how they spend their time (*"I keep track of programs I want to watch, hair appointments, my toenails. I know how each of my days are going [to go]. I run my own life," "I don't like being bossed around"*).

g. Do you have privacy when you want it?

Quantitative findings. This question asked residents if they considered it not important, somewhat important, or very important that they had privacy when they wanted it. Over three-quarters of all residents (78%) across all settings said that this was very important to them. NH and AL/RC residents were significantly more likely to rate this item very important compared to AFH residents (NH=80%; AFH=72%; AL/RC=81%).

Eighty-one percent of residents reported that they had privacy when they wanted it. However, AL/RC and AFH residents were significantly more likely to report that they did so compared to NH residents (NH=72%; AFH=88%; AL/RC=86%).

Only fifteen percent of all residents reported unmet need about this issue. However, NH residents reported a significantly higher unmet need compared to both AFH and AL/RC residents (NH=25%; AFH=9%; AL/RC=10%).

Among NH residents, having privacy when desired was associated significantly with all four resident outcomes. In contrast, it was associated with general satisfaction only among AFH residents (and not the other three resident outcomes). Finally, among AL/RC residents, this item was associated with all three resident outcomes except higher likelihood of recommending the setting to someone else.

Qualitative findings. Out of all of the items in the autonomy/choice domain, the item about having privacy when you want it had the fewest comments (n= 45). About a quarter of these comments were related to residents stating that they don't have a choice or that they don't have privacy when they want it (*"[Privacy] is important, but you don't get it. This is a revolving door", "We don't have any privacy here, that's why we are here- it's called assisted living. That's probably the one thing that disturbs us the most. That's just how it is and we accept it")*. An additional eight comments suggested that residents do not have privacy largely because their boundaries are crossed by staff (*"There's no privacy here! They are already halfway across my room before I even say, 'Come in' when they knock," "A locked door means nothing here"*). About one in five residents explained that they have privacy when they want it or that they've have adapted to how things are (*"Privacy went out the window a long time ago. You can't worry about that, and it would smell a lot in here," "People do not drop-in unexpectedly, and that's wonderful")*. Fifteen percent of the comments were general comments or statements related to privacy (*"This has to do with feeling at home," "Sometimes I get shy, so I like to be away on my own"*). Lastly, 9% of the comments emphasized the importance of the question (*"Do you have a '10' on there? Everyone needs a break from time to time. Otherwise, it's stifling," "Very much so [important]")*.

h. Do you do things for yourself?

Quantitative findings. This question asked if the resident considered it not important, somewhat important, or very important that they did things for themselves. Overall, 83 percent of all residents across all settings said that this was very important to them; this item had the highest rating of importance in this domain. AL/RC residents were significantly more likely to rate this item very important compared to AFH residents, but not NH residents (NH=83%; AFH=79%; AL/RC=87%).

Overall, three-quarter of all residents (78%) across three settings said that they did things for themselves. However, AL/RC residents were significantly more likely to report that they did so compared to NH and AFH residents (NH=74%; AFH=71%; AL/RC=88%).

Overall, 17 percent of all residents across three settings reported unmet need about this issue. However, NH and AFH residents reported a significantly higher unmet need compared to both AL/RC residents (NH=21%; AFH=19%; AL/RC=10%).

Doing things for oneself was associated with lower depressive symptoms across residents of three settings. It was also significantly associated with higher quality of life among NH and AFH residents. Only among NH residents was it associated with general satisfaction and only among AFH residents was it associated with higher likelihood of recommending the setting to someone else.

Qualitative findings. Nearly 60 comments related to residents being able to do things for themselves. About 44 percent of the comments generally described doing things for themselves as much as they can (*"Well, I'm very helpless so why say important? I need everything at arm's length. I have lost a lot of independence, so I don't know how to answer that. I could say it's very important, but I have accepted the fact that I am dependent," "I try to, yes. I think I've aged a lot since I moved here. I've lost a lot of mobility. You can't get in the car and go shopping when you want")*. About 10 percent of the comments emphasized the importance of the item (*"There's another one that should be a '10'", "Very, very important. I'm kind of a neat freak, and I can't stand jumbled up things around me")*. An additional five comments were related to residents explaining that they can do everything for themselves (*"I do everything myself," "Oh yeah, no problem there. The owner used to take me out for a cup of coffee once a month and talk about how things are going"*). Five more comments were related to residents not being able to do things for themselves (*"God, I wish I could," "I'm unable to do much for myself")*. Lastly, there were five comments where residents mentioned doing too much for themselves (*"I get scolded quite a bit because I don't ask for more help," "I need a retreat"*).

i. Do you have a say in how this place works (e.g., meal schedules, decorating communal areas, planning social events, hiring and evaluating staff)?

Quantitative findings. This question asked residents if they considered it not important, somewhat important, or very important that they had a say in how the setting worked, such as, in arranging meal schedules, decorating communal areas, planning social events, etc. Two-fifth of all residents (41%) reported that this was very important to them. Residents across different settings did not differ significantly in finding this issue very important (NH=39%; AFH=37%; AL/RC=45%).

Only 19 percent of all residents said that they had a say in how the place worked. AFH residents were slightly more likely to respond positively compared to AL/RC residents, but not NH residents (NH=17%; AFH=24%; AL/RC=16%).

Half of all residents (51%) across three settings who found this item to be very important reported unmet need. Compared to NH and AL/RC residents, AFH residents reported a significantly lower unmet need, although still the highest in this domain (NH=52%; AFH=39%; AL/RC=60%).

Having a say in how the setting works was associated with higher quality of life among residents of NH, AFH, and AL/RC. Among NH and AFH residents, it was also associated higher general satisfaction. In none of the settings was this item associated with higher likelihood of recommending the setting to someone else. Finally, among AFH residents only, it was associated significantly with lower depressive symptoms.

Qualitative comments. The item related to residents having a say in how a given care setting works received 142 comments from residents. About 17 percent of the comments were related to residents generally feeling fine or okay with their setting as it was. These same residents expressed not having any particular complaints (*"I don't have to worry too much about," "It's basically the same as anywhere"*). An additional 13 percent of comments mentioned or described a residents' council (*"It's not that convenient for me to attend resident council, but it's important to have a say", "I used to go to residents' council but I don't go anymore because there were problems. We would like to have a say, but we don't. I would love to go to the administrator and say things, but I couldn't")*. Twelve percent of comments expressed feelings of satisfaction with the way the setting works, and some of these residents explained that leadership would listen to them if they weren't satisfied (*"[Admin] calls on us, has a meeting, listens to us, gives us a chance to relate to her. She listens. She's a sweetheart. I nearly fell in love with her when I moved in here," "Adaptability- you have to adapt your pattern to how things are here. Staff are well-trained, know what their roles are and do those roles. I think that shows good leadership").* Additionally, 12 percent of the comments were related to residents saying that it's not their business to provide a say how in the place works (*"It's their business," "In a way, I don't have the right to- don't know how to easily explain it. I'm happy"*). An additional 12 percent of comments indicated they don't have a say in how the setting works (*"I would like to have, that but I don't. Here you have 300 howling extroverts- they change things. It's in flux. For an introvert, that's hard," "I let them decide. Sometimes I disapprove, but I can't say anything"*).

Nine percent of the comments made were related to residents stating that they do, in fact, have a say in how this place works (*"I feel like the rules and regulations at this place don't affect me because I abide by them. If I don't like some things, I go tell them," "If I make myself loud enough, yes")*. Over eight percent of comments were related to residents expressing that their comments about how the place works haven't been listened to by the staff (*"I've talked with the owner many times, and when he visited, he walked away from me and slammed the door on me," "They don't give a crap about what we think. They just care about their paycheck")*.

j. Do you feel free to express your opinions about things you do not like here?

Quantitative findings. The last question in this domain asked residents if they considered it not important, somewhat important, or very important that they feel free to express their opinions about things that they do not like there. Two-third of all residents (66%) across all settings responded that this was very important to them. NH and AL/RC residents were significantly more likely to rate this item very important compared to AFH residents (NH=74%; AFH=54%; AL/RC=69%).

When asked if they felt free to express their opinions about things that they did not like there, 73 percent of all residents across three settings replied yes. There were no significant differences in responding positively to this item across three settings (NH=74%; AFH=72%; AL/RC=74%).

Only 16 percent of all residents reported unmet need about this issue. Additionally, residents living in different settings had similar levels of unmet need (NH=17%; AFH=15%; AL/RC=16%).

Among NH and AFH residents, this item was associated significantly with all four resident outcomes. Among AL/RC residents, it was associated with all three resident outcomes except lower depressive symptoms.

Qualitative findings. The item regarding feeling free to express opinions about things residents don't like yielded 114 comments. Nearly one in five of the comments were related to residents communicating things they don't like, but not having their opinions listened to by staff (*"I was kind of disgusted the other day. I said, if I don't get some help, I'm going to call 911," "As long as I get my way. I like the way they run things most of the time, but there are times I don't think they listen enough to what your qualms are. Other than that, things are pretty good"*). An additional 18 percent said that the option to express their opinions about things they don't like hasn't come up, many because they have not experienced things that they do not like (*"So far, I haven't found anything I don't like," "I would feel okay saying something. I'm easily pleased"*). Around 12 percent of comments indicated that residents do not feel free to express their opinions about things they don't like in their setting (*"I don't want to bother them because they're so overworked," "No, because I don't know who to [express my opinions] to. I don't know who's in charge, not even in the kitchen"*). About ten percent of the comments were explaining that residents feel like they are able to express certain or specific opinions about things they don't like (*"I'm 74. To express opinions, you have to be careful because the days continue, and it affects your relationships. Uncertainty becomes the norm," "Not necessarily-I know who I can talk to"*). Lastly, an additional 10% of comments were related to residents saying that they do feel free to express their opinions about things they don't like (*"They encourage that. The big thing here is honesty," "Very outspoken, sometimes I like to ruffle the feathers").*

Summary

This domain reflects a wide range of resident perspectives about autonomy and choice, which are likely influenced by a combination of different levels of dependency, the setting, and amount of resident adaptation to the situation. Limited staff availability, resulting from staff busyness and high levels of turnover, appeared to be barriers for residents who were dependent in personal care to follow their desired routines and to make choices about their daily lives.

Table AC3. Selection of items from the Autonomy domain for the final tool based on various sources

	NH	AFH	AR
a. Get up when you want to?	✖	✖	⇔
b. Eat meals when you want to?	✖	✖	✖
c. Shower or bath when you want to?	⇔	✖	✖
d. Make your own decisions even if others don't approve	✖	✖	✖
e. Spend your time the way you want to?	✖	✔	✔
f. Have privacy when you want it?	✔	✖	✖
g. Do things for yourself?	✔	⇔	✖
h. Have a say in how this place works?	⇔	✖	✖
i. Feel free to express opinions about things you do not like here?	✔	⇔	⇔

NH residents were least likely to experience autonomy and choice; in seven of nine items residents reported significant unmet need. Dependency levels in AFH can also be quite high, but the smaller setting with fewer residents for providers to care for may have made it easier for them to accommodate preferred routines and resident decisions. An alternative explanation is that the characteristics of the setting, such as a close relationship with the provider, may have resulted in resident adaptation and acceptance of less autonomy.

Perhaps it was because of these differences that no item within this domain met criteria for inclusion across all settings, even when considering ambiguous levels of support for an item. At the same time, at least one item in the domain met criteria for each setting-specific tool.

Results: 1.B.(6) Treated Like a Person (Personhood)

Introduction. “Personhood” is a key concept of person-centered care, although the concept was better understood as being “treated like a person” by residents in our pilot project (White, Elliott, & Hasworth, 2016). The importance of being treated as a person was highlighted by Thomas Kitwood (1997), who stressed the inherent value of each individual, including those living with dementia. Being treated as a person requires staff to consider the strengths, abilities, possibilities, and the social contributions of a person in the present – regardless of physical, emotional, or cognitive abilities. Treating someone like a person also demands empathy and sensitivity to individual perspectives about their lives and the meanings each person has constructed about their current situation.

The centrality of personhood is further illustrated in the literature, where like the Resident VIEW, other components of PCC must be based first on the idea of the resident as person. Building on Kitwood (1997) and others, Brenden McCormack and his colleagues (2012) emphasized that PCC practices and other frameworks of care will be meaningless without the primacy of the person. They explore frameworks of culture change, PCC, and resident-centered care and identified some contradictions and differences in emphasis. Resident-centered care is particularly compelling to these authors who feel that relationships between direct care staff and residents are necessary to enable the realization of PCC. Although they see overlap and complementarity in these frameworks and argue for an integration of the models, McCormack and colleagues also note the lack of emphasis on personhood in regulation and policy—including a lack of focus on the personhood of staff who require a supportive work environment to develop relationships with residents and people significant to them to truly understand and implement PCC for individuals.

Similarly, Milte and colleagues (2016) examined quality care from the perspective of residents living with dementia and their family members. The overarching themes were that good quality care supports personhood and maintains the person’s connection to family. Similar to the Resident VIEW, subthemes in support of personhood included autonomy and choice, meaningful activities, feeling useful and valued, and respect of possessions and personal space.

Eight items composed the Resident VIEW “treated like a person” domain, with each designed to reflect a specific aspect of personhood. This included items to reflect dignity and respect afforded the resident, such as being listened to and being treated with kindness. Items also reflected empathy shown to residents such as staff understanding their individual health care needs and residents’ feelings about living in the setting.

Overall findings. Cronbach's alpha for the eight items in the original domain was .83 for the pooled sample. It ranged from .80 among short-stay NH and AL/RC residents up to .87 among AFH residents. Overall, this indicated a high inter-item agreement for the original domain. For the pooled sample, the strongest association was between items g. ("treat you with respect") and h. ("treat you with kindness") (see Figure TP1 below).

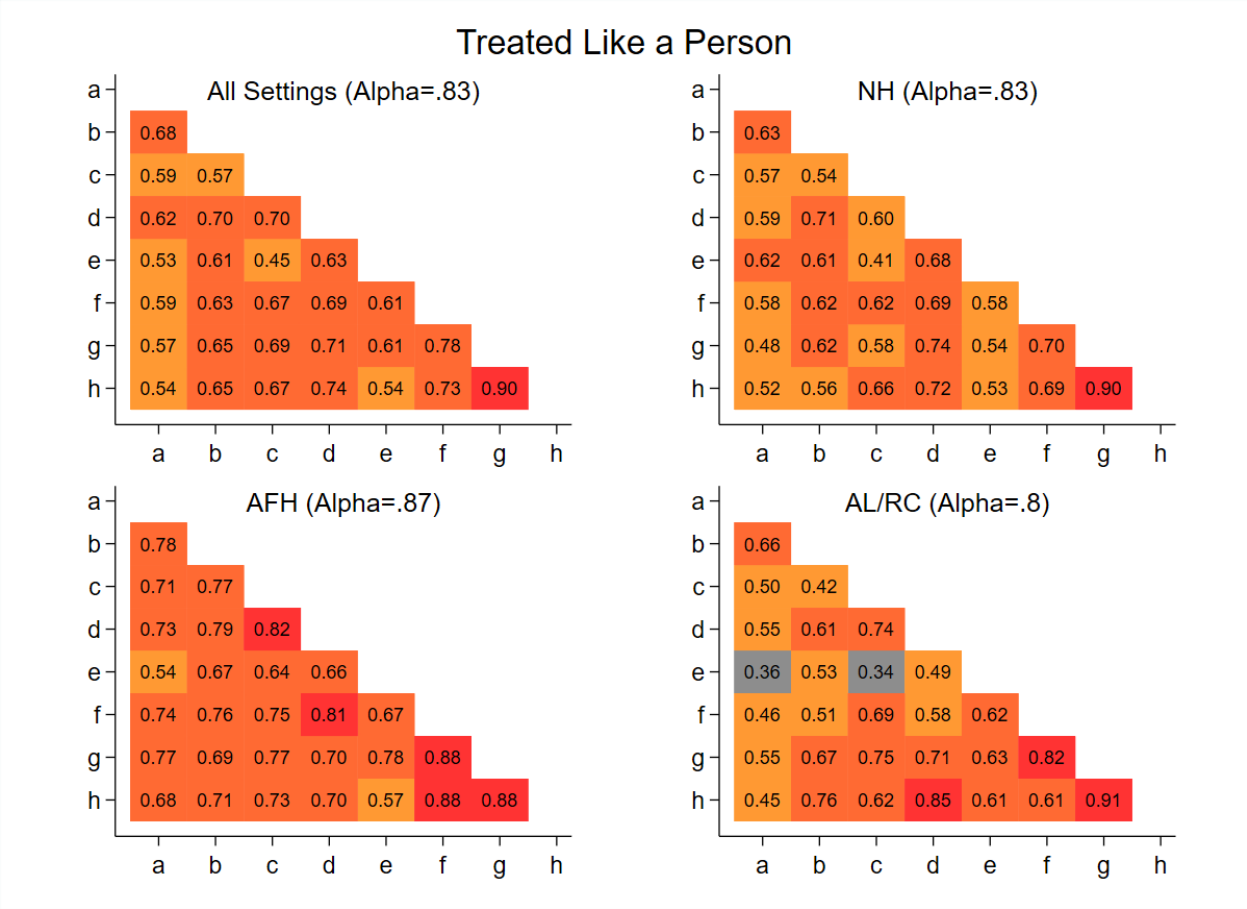


Figure TP1. Strength of association among items in the Treated Like a Person domain

Table TP1 presents information about unmet need reflected in these items. Unmet need is defined as the incongruence between rating an item as very important and reporting no experience or experience only some of the time for that item. Items where 25 percent or more of residents reported that they did not experience something they had rated as very important are highlighted in the table as are items rated very important by 75 percent or more of residents.

Within this domain, 75 percent or more residents across settings identified four items they felt were very important. They wanted the people who worked with them to show that resident needs were important to them, answer their questions, treat them with respect, and treat them with kindness. The area of greatest unmet need for residents

across settings, was for staff understanding what it was like for the residents to live there. Unmet need was highest in AL/RC and lowest for AFH. About 30 percent of NH and AL/RC residents who felt it was very important for staff to pay attention to their opinions indicated this was not something they experienced or only experienced it somewhat. NH residents also reported unmet need related to staff showing resident needs were important to them.

The association of each item in this domain with various outcomes reported by residents is presented in Table TP2 by setting. Outcomes include resident recommendations of the place to someone else, satisfaction with the setting, quality of life, and depressive symptoms. Six of eight items in this domain were associated with all outcomes and those two items were associated with nearly all outcomes across the settings. The exceptions were that “pay attention to your opinions” was not associated with depressive symptoms for NH residents, and “show that your needs are important to them” was not associated with depressive symptoms for AFH residents.

Table TP1. Importance and unmet need for the Treated like a Person domain by setting type

	NH			AFH			AL/RC			TOTAL		
	VI %	Y %	UN %	VI %	Y %	UN %	VI %	Y %	UN %	VI %	Y %	UN %
a. Pay attention to your opinions	71	57	31	59	68	17	64	54	30	65	59	27
b. Show that they are interested in you as a person	69	62	24	65	75	13	64	65	22	66	67	20
c. Listen to you without interrupting	67	69	21	62	72	18	66	76	15	65	72	18
d. Show that your needs are important to them	78	67	26	74	78	16	75	69	22	76	71	22
e. Understand what it is like for you to live here	69	45	40	70	59	32	69	38	48	70	47	40
f. Answer your questions	81	73	22	76	84	11	87	78	18	82	78	17
g. Treat you with respect	92	82	15	86	86	11	94	89	10	91	86	12
h. Treat you with kindness	90	84	13	86	89	9	89	90	8	88	88	10

Notes: VI=Very important, UM= Unmet need, Y= Yes.

Table TP2. Association of experiencing each item with positive resident outcomes by setting type

	NH				AFH				AL/RC			
	R	S	Q	P	R	S	Q	P	R	S	Q	P
a. Pay attention to your opinions	✓	✓	✓	X	✓	✓	✓	✓	✓	✓	✓	✓
b. Show that they are interested in you as a person	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
c. Listen to you without interrupting	✓	✓	✓	✓	✓	✓	✓	X	✓	✓	✓	✓
d. Show that your needs are important to them	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
e. Understand what it is like for you to live here	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
f. Answer your questions	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
g. Treat you with respect	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
h. Treat you with kindness	✓	✓	✓	X	✓	✓	✓	✓	✓	✓	✓	✓

Notes: Experiencing is defined as a response of Yes compared to No or Some. R= would recommend this place to someone else, S=general satisfaction, Q=quality of life, P= PHQ9 score (depressive symptoms). No control variables included. Significance was determined at $p < .05$.

a. Pay attention to your opinions

Quantitative findings. The first question in this domain asked if the resident considered it not important, somewhat important, or very important that people who worked at the setting paid attention to the resident's opinions. Sixty-five percent of all residents across all settings said that this was very important to them. NH residents were significantly more likely to rate this item very important compared to AFH residents (NH=71%; AFH=59%; AL/RC=64%).

When asked whether people who worked at the setting paid attention to their opinions, 59 percent of all residents across three settings responded positively. AFH residents were significantly more likely to report that they did, compared to NH and AL/RC residents (NH=57%; AFH=68%; AL/RC=54%).

Over a quarter of all residents (27%) across three settings reported they were not being paid attention to at the level they wanted. However, unmet was higher among NH and AL/RC residents compared to AFH residents (NH=31%; AFH=17%; AL/RC=30%).

All four resident outcomes were significantly associated with this item regardless of setting type, except depressive symptoms among NH residents.

Qualitative findings. About 100 comments were generated by this item, evenly split between "importance" and "experience" questions. About one-third of those indicating this item is important also provided examples about being listened to. *"I think it's important that they hear it, and they do." "They'll get it anyway sometimes." "It's nice. I'm pretty opinionated. I'm on the residents' council. You can go in there and bitch and moan and maybe something will change."*

A smaller number indicated that staff paying attention to their opinions was not important and did not make much difference. *"Not the end-all for me to have my wishes met. I get all I want." "I don't think it makes a difference if they know how you feel." "They don't do it; it doesn't matter."*

When asked about experience, however, about half the comments indicated that these residents did not typically give their opinions, with some saying simply that they did not offer or rarely offered opinions (*"I've never shared my opinion about anything.").* and others suggesting that if they did offer opinions, they would be listened to *("Probably would, but I don't give it. Very nice group of people. Thoughtful. . ." "Haven't had a reason to believe they wouldn't.").* A few indicated that staff would not listen to their opinions if they did express them.

A sizeable number of responses to both types of questions, suggest that staff do not listen or are limited in the way they can respond when residents do offer opinions. *"They act like they do by listening, but nothing changes." "They listen, but nothing they can do about it." "Probably goes in one ear and out the other."* A few residents suggested that paying attention to resident opinions is part of their job responsibility. *"They don't have to accept them, but they better pay attention." "They must listen to us residents in order to do their jobs."*

"It depends" was another response. The opinions being expressed mattered to some as illustrated by this comment: *"It depends on how important the issue is and my knowledge of the topic."* Others indicated that paying attention, and its importance, varied by staff. *"I think there's a difference between management (who don't care) and caregivers (they care) . . . "Depends on the staff you're talking about. Is it just the third floor? The whole building?"*

b. Show that they are interested in you as a person

Quantitative findings. The second question in this domain asked if the resident considered it not important, somewhat important, or very important that people who worked in that setting showed that they were interested in the resident as a person. Two-third of all residents (66%) responded that this was very important to them. There were no significant differences in finding this issue important across three settings (NH=69%; AFH=65%; AL/RC=64%).

Sixty-seven percent of all residents across three settings responded yes when asked whether the people who worked at the setting showed that they were interested in the them as a person. AFH residents were more likely to say that they did compared to NH and AL/RC residents (NH=62%; AFH=75%; AL/RC=65%).

Twenty percent of all residents reported unmet need about this issue. However, AFH residents were less likely to report an unmet need about this issue compared to NH and AL/RC residents (NH=24%; AFH=13%; AL/RC=22%).

All four resident outcomes were significantly associated with this item regardless of setting type.

Qualitative findings. Fewer than 50 residents made comments about this item. Most indicated that this is important, with some specifying this attribute is a professional responsibility. *"If they are good at their job, they [do]. That's part of their job."* Other reasons were given for the importance of this item which included elements of respect or friendliness. *"I want them to at least treat me as an equal." "When we were looking for a place to be, this was one of the most important factors. The other facilities were lacking in friendliness. Here, they have to learn your first name." "They take time out to talk to me as a person."*

A few residents found that this was not important, *"I'm not that important, even to me." "They don't have to go overboard."* Some indicated that their relationship with staff was distant and that they did not connect on a personal level. *"I just don't know them that well." "They're professional." "They are never rude." "They, and I, could care less."*

"Staff busyness" was a factor for some residents, suggesting that being interested in residents as a person was too much to ask. *"As much as they can. They naturally have a lot of people to look after." "With the number of people they have, how can they?"*

Other residents noted that being interested in residents as people varied by staff. *"Some do and some don't. It seems like some people who work here are just interested in passing time." "I keep thinking of the one person who is our major aide. She is a 'yes' for all of these things, but they aren't all like her.*

c. Listen to you without interrupting

Quantitative findings. The third question in this domain asked if the resident considered it not important, somewhat important, or very important that people who worked in this setting listened to the resident without interrupting. Sixty-five percent of all residents across all settings reported that this was very important to them. There were no significant differences in finding this issue important across three settings (NH=67%; AFH=62%; AL/RC=66%).

When asked about whether people who worked at the setting listened to them without interrupting, 72 percent of all residents across three settings responded positively. Residents across the three settings were similarly likely to report receiving this item (NH=69%; AFH=72%; AL/RC=76%).

Overall, 18 percent of all residents across three settings reported unmet need for this item and there were no significant differences in terms of reporting an unmet need about this issue across different settings (NH=21%; AFH=18%; AL/RC=15%).

All four resident outcomes were significantly associated with this item regardless of setting type – except for depressive symptoms among AFH residents.

Qualitative findings. Just over 50 residents commented on this item. About one-fourth of those questioned the item itself, with half indicating interruptions are part of conversations. *"If they do interrupt, it's not to be rude – it's just because they are excited about what you are saying. It is [not] the kind of interruption that's annoying." "It's normal for people to interrupt people. Listen to any group of people talk. They interrupt all the time." "I want them to interrupt me, it means we are having a conversation."* Others couldn't relate to the item because they hadn't experienced interruptions. *"It has never come up."* Similarly, a group of residents emphasized the reciprocal nature of listening without interruption. *"It's important that they listen and that I listen to them." "I have too much to say to begin with. I need to listen to people more."*

At the same time, many residents suggested that listening without interruption was a sign of respect. *"I mean, that's just appropriate. It's polite." "Who likes to be butted into?"* Some were critical of staff, *"Most people talk too fast. Mostly young people. . . So, they need to allow somebody to take their time." "They always interrupt. It's terrible."* A couple of people noted staff busyness as a factor. *"Their job is more important than them paying attention to me." "They don't have time. They just race around."*

As with other items, a few residents commented that they do not talk with staff, which precludes being interrupted. *"I don't provide them with that opportunity." "I've never talked with them."* A few residents indicated that their experience with being interrupted varied, depending on the caregiver. Another commented, *"It depends. If they're busy,*

got a lot going on. They're a bit self-absorbed. I think it's a cultural thing. Not how I was raised, anyways."

d. Show that your needs are important to them

Quantitative findings. This question asked if the resident considered it not important, somewhat important, or very important that people who worked in this setting showed that the resident's needs were important to them. Overall, three-quarters of all residents (76%) reported that this was very important to them. There were no significant differences in finding this issue important across the three settings (NH=78%; AFH=74%; AL/RC=75%).

When asked about whether people who worked at the setting showed that their needs were important to them, 71 percent of all residents replied yes. However, AFH residents were significantly more likely to say that they did compared to NH and AL/RC residents (NH=67%; AFH=78%; AL/RC=69%).

Although one-fifth of all residents (22%) across three settings reported unmet need for this item, NH residents were slightly more likely to report an unmet need compared to AFH residents (NH=26%; AFH=16%; AL/RC=22%).

All four resident outcomes were significantly associated with this item regardless of setting type.

Qualitative findings. About 60 comments were generated by this item. About one-fourth of the comments indicated this is important to these residents and that it is something they experience. *"Otherwise you don't have empathy, understanding. You would just be part of the routine." "They always do. The owner is a sweet person." "They are always asking how I feel and how I'm doing."* A few of these individuals indicated this was not relevant to their situation, but they seemed to be saying this is something they experience. *"One of these things you take for granted that happen. One thing I have learned here talking with staff. The lead guy, the girls, they do a great job, so I don't think about these things." "I don't even think about it. People do respect me and care what I think."* Some residents described paying attention to their needs as part of the staff role and responsibility. *"They can't be a caregiver if they don't." "It's important that they take care of what I need, but not that it is personally important to them."*

A few residents indicated that this item was not important, largely because they did not have many needs requiring staff support. *"I don't have needs except my doctor's appointment."*

As with other items, some residents responded that that it depends on the situation, including which staff are involved and what their needs are. With respect to variability

among staff were these comments. *"Staff yes, management no." "The RN is most important in caring about my needs, and they don't always. I hear it from lots of people. Other staff caring about my needs is less important."*

Staff busyness was also a factor and was often given as a reason for staff not to show residents their needs were important. *"They're so busy, they don't have time." "Don't spend much time with us. All friendly and kind, but not a lot of interaction with them."* In addition, some residents downplayed their needs with others within the context of busyness. *"It's very important if they can, but I'm not the only person here." "Other people have needs that are more urgent than mine." "They're so busy they don't have time. Once one of the caregivers said to me, 'you know we have other people here.' That really hurt my feelings. . ."*

e. Understand what it is like for you to live here

Quantitative findings. This question asked if the resident considered it not important, somewhat important, or very important that people who worked in this setting understood what it was like for the resident to live there. Overall, 70 percent of all residents reported that this was very important to them and there were no significant differences in finding this issue important across three settings (NH=69%; AFH=70%; AL/RC=69%).

When asked about whether people who worked at the setting understood what it was like for them to live there, less than half (47%) of all residents across three settings responded positively. AFH residents were slightly more likely to say that they did compared to NH and AL/RC residents (NH=45%; AFH=59%; AL/RC=38%).

Forty percent of all residents reported unmet need for this item. AL/RC residents were much more likely to report an unmet need for this issue compared to AFH residents (NH=40%; AFH=32%; AL/RC=48%).

All four resident outcomes were significantly associated with this item regardless of setting type.

Qualitative findings. Nearly 120 comments were made in response to this comment, making it the item within this domain with the most comments. The comments suggest this is not a useful item for most residents. About one-third of the comments indicate that staff cannot understand because the staff do not have the experience living in a residential setting. Many cited the age differences between staff and residents as reasons for lack of understanding.

> *I don't know how to answer that. How can they unless they live here?*

> *That is difficult. It would be "very [important]," but they can't understand unless they've been through it.*
>
> *That's a tough one, because they are all younger people. Like I was at that age, I didn't understand. They haven't gotten there yet, so I would be different.*

In a similar vein, when asked if the staff understood, several residents indicated that they could not know. *"I don't know, that would be a question they would have to answer." "How could I know?"*

In spite of the difficulty for staff to understand, some residents provided reasons why it was important and why staff should seek understanding. *"They treat you different when they understand" "It would make things more congenial that way."*

> *"That's a good question. A lot of these kids don't take the time to figure it out. It's not like you are a checker at Safeway. You have to have compassion. My neighbor has dementia and I don't think they understand what she's going through. I think they avoid her because they don't know how to relate to her or it's difficult."*

About twenty percent of the comments emphasized residents' positive relationships with staff, regardless of their understanding. *"They must or they wouldn't be able to give such good care. You can't walk down the hall without seeing our director lugging boxes around. She's a real hands-on person and I like that." "If I wasn't happy, I'd go someplace else." "I really like the people who work here."*

With a similar percentage of the comments, however, other residents provided negative assessments of staffing indicating that staff were not understanding. *"It doesn't happen. At first it is important, but then it isn't." It's important, but they don't [understand]" "It's their place, not mine." "I believe they have working knowledge of how I feel, but not a personal knowledge."*

> *Sometimes you get the impression it's a job for them and they couldn't put themselves in your shoes. I think they don't understand how much it means to interact with a resident. Some residents are more neglected or isolated. I'm not trying to be derogatory They don't get paid well, and it's hard to get to know some people who have more behavioral problems, dementia.*

Finally, some of the comments suggest other concepts and words that might have more meaning to residents. These include having empathy, understanding *"that this life is new to you,"* having patience, and being compassionate.

f. Answer your questions

Quantitative findings. This item asked if the resident considered it not important, somewhat important, or very important that people who worked at the setting answered the resident's questions. While 82 percent of all residents across all settings said that this was very important to them, AFH residents were significantly less likely to find this issue important compared to AL/RC residents (NH=81%; AFH=76%; AL/RC=87%).

Seventy-eight percent of all residents said that people who worked at the setting they were living in answered their questions. AFH residents were slightly more likely to respond positively compared to NH residents, but not AL/RC residents (NH=73%; AFH=84%; AL/RC=78%).

Although 17 percent of all residents reported unmet need for this item, NH and AL/RC residents were significantly more likely to report unmet need about this issue compared to AFH residents (NH=22%; AFH=11%; AL/RC=18%).

All four resident outcomes were significantly associated with this item regardless of setting type.

Qualitative findings. About 50 comments were made in response to this question. Many found this to be very important, with some residents adding that answering honestly was key. Others suggest that answering questions is a sign of caring and respect. One person noted that answering questions *"makes you feel like they care."* Another emphasized it was the consideration that was important, not necessarily receiving desired answers. Some residents described how staff attempted to answer their questions. *"If they don't know the answer, they'll go find out for me." "Yes, because I treat them with respect."*

Most often, however, residents recognized that not all questions could be answered. Several residents referenced privacy issues. *"There are some things that are forbidden to answer. That is a privacy thing." "Sometimes they can't answer your questions because it's too personal. Like you want to know what's going on with another resident."* Other times, residents acknowledged that staff did not have some information. *"If it's a house question, yes, but if it's about getting a hold of Senior and Disabled, no."*

As with other items, some residents indicated that they did not ask questions, either because they didn't have any or they didn't talk to staff much. Others stated that staff do not answer questions. *"they don't ever come around so that I could ask them." "It doesn't pay to ask questions."*

g. Treat you with respect

Quantitative findings. This question asked if the resident considered it not important, somewhat important, or very important that people who worked in this setting treated the resident with respect. Most residents (91%) reported that this was very important to them. However, NH and AL/RC residents were slightly more likely to rate this item more importantly compared to AFH residents (NH=92%; AFH=86%; AL/RC=94%).

When asked whether people who worked at the setting treated them with respect, most residents (86%) across the three settings replied yes. NH residents were slightly less likely to respond positively compared to AL/RC residents (NH=82%; AFH=86%; AL/RC=89%).

Only twelve percent of all residents reported unmet need for this item. Residents across the three settings did not differ in terms of reporting an unmet need about this issue (NH=15%; AFH=11%; AL/RC=10%).

All four resident outcomes were significantly associated with this item regardless of setting type.

Qualitative findings. About 45 comments were made in response to this item. Similar themes were present as described for other items within this domain. This item was viewed as very important, *"That's the main thing."* Many also felt respected. *"Most definitely." "Yes, they know me very well." "They do it all the time."* Some of the residents emphasized that respect goes both ways. *"If I don't respect, I don't have anything." "I feel a lot of respect for them, too." "Very [important]! I treat them with respect."* Many comments provided examples of being shown respect.

Others describe lack of respect. *"Some of the things I hear staff say to residents are not respectful; that would not fly if I owned this place." "Some talk down to me like I am three years old."* Others were more equivocal, indicating it varies. *"That depends on who." "The owner is wonderful, but there are some caregivers who don't [treat me with respect]." "All but one person, yes."*

Only two residents indicated that it was not important. *"I never have given a damn what people think of me." "As long as they do their job."*

h. Treated with kindness

Quantitative findings. The final question in this domain asked if the resident considered it not important, somewhat important, or very important that people who worked where the resident lived treated the resident with kindness. Most residents (88%) across the three settings reported that this was very important to them and there were no significant differences in finding this issue very important by setting type (NH=90%; AFH=86%; AL/RC=89%).

Most residents (88%) reported that people who worked at the setting treated them with kindness. NH residents were slightly less likely to respond positively compared to AL/RC residents (NH=84%; AFH=89%; AL/RC=90%).

Only ten percent of all residents reported unmet need for this item and residents across three settings reported similarly low levels of unmet need about this issue (NH=13%; AFH=9%; AL/RC=8%).

All four resident outcomes were significantly associated with this item regardless of setting type – except for depressive symptoms among NH residents.

Qualitative findings. Only about 35 comments resulted from this item. The term resonated with several residents. *"Kindness is an interesting word because it encompasses so much and is so important." "Even more important than respect."* One the other hand, there were a few critics. *"These are silly questions. These should be important to anybody, I think."*

As with respect, a large proportion of the comments provided information about why kindness is important or provided specific examples. *"You're not just another person that needs help; they are considerate." "I think that's the biggest thing you can do in life, is to be kind." "That's the way I was raised." "I have bipolar and schizophrenia, but they take me how I am."*

Lack of kindness was also described, often related to specific staff or to staffing issues. *"When you get a gal working a shift who is hard to deal with, it ruins your whole day." "Some do and some don't. They're not mean, but they tend to ignore you." "In general, staff here are great and friendly. But I think they are understaffed. Sometimes I wait an hour for food at mealtime."*

Summary

Findings from analysis of this domain support its centrality to PCC. All items except two were associated with all four outcomes examined. Furthermore, those two items were each associated with all outcomes across all settings except for depressive symptoms in one of the three settings (See Table TP1).

At the same time, no item within this domain met all criteria for inclusion in the cross-setting version of the Resident VIEW. “Show that your needs are important to them” did meet criteria for use with NH and AL/RC residents, and “answer your questions” met criteria for NH residents. No item met criteria for the AFH resident tool, although four items had some support for inclusion: “Pay attention to your opinions,” “show that they are interested in you as a person,” “understand what it is like for you to live here,” and “treat you with kindness.” A large majority of residents found being treated with respect, being treated with kindness, and having their questions answered were very important. Similarly, large majorities also experienced this treatment by staff. Although it is encouraging to know that these areas of great importance are being experienced, this may make these items less useful for a short measure of the Resident VIEW.

Some themes that emerged from the qualitative analysis provide some reasons why many items failed to be included in a cross-setting short measure. Some residents see these items as attributes that are basic to professional role and as well as key to common courtesy. This included items that require interaction, such as staff paying attention to resident opinions, listening to residents, and answering questions. “It depends” was also a common theme across many items indicating the residents do and do not experience these items based on which staff they are interacting with. That is, many residents identified staff who did treat them like a person as well as staff who did not. Busyness was often given as a reason for staff falling short on these items. Most of these residents recognized that it is difficult for some staff to fulfill these aspects of their job when they have so many demands on their time.

Comments in responses to two items suggest why they may be of limited use in the measure, but nevertheless may be interesting areas to explore. First is “listen to you without interrupting.” As several residents pointed out, interruptions are common in conversations and are often indicators of engagement and active exchange of ideas and information. Second is the item that asks if staff understand what it is like for the resident to live in the setting. A significant number of residents felt that it is impossible for staff, especially those who are young or have not experienced dependency, to understand residents’ experiences. As a result, importance ratings were in the mid-range for this item within this domain. At the same time, this item scored highest in unmet need within this domain, emphasizing incongruence between importance and experience for many residents.

Table TP3. Selection of items from the Treated like a Person domain for the final tool based on various sources

People who work here:	**NH**	**AFH**	**AR**
a. Pay attention to your opinions?	⇔	⇔	✘
b. Show that they are interested in you as a person?	✘	⇔	✘
c. Listen to you without interrupting?	✘	✘	✘
d. Show that your needs are important to them?	✔	✘	✔
e. Understand what it is like for you to live here?	⇔	⇔	⇔
f. Answer your questions?	✔	✘	⇔
g. Treat you with respect?	⇔	✘	⇔
h. Treat you with kindness?	✘	⇔	⇔

Results: 1.B.(7) Relationships with staff

Introduction. Proponents of person-centered care have emphasized the importance of relationships between care staff and residents in long-term care settings. In particular, nurse researchers have argued that intentional relationships with residents, especially those with dementia, are necessary to get to know residents and to be able to personalize their care. For example, Kathy McGilton and her colleagues (2012) developed the Relational Behavioral Scale for observing nursing staff care for people with dementia. This measure examines the way that care is provided, staff ability to be tuned in to the needs of residents, and whether emotional comfort and reassurance is offered during care. Barbara Bowers and her colleagues, supported by The Commonwealth Fund (no date), authored *Implementing change in long-term care: A practical guide to transformation.* In discussing staff-resident relationships, ways to foster mutual relationships are emphasized, including allowing staff time to sit with residents for meaningful activity and conversation, and to share some of their own lives with residents. Organizational structure supporting consistent assignment is viewed as necessary to support close relationships.

Several qualitative studies have been conducted in nursing homes to gain the perspective of residents about relationships with staff. These studies have revealed a range of preferences and attitudes. McGilton and Boscart (2007) found that residents and staff define relationships differently. Care staff described feeling connected, knowing the resident, and reciprocity in the relationship (e.g., the resident expressing appreciation). Residents, in contrast, wanted staff who had their interests at heart, took the initiative to do things without being asked, being dependable, and laughing and joking around. Barbara Bowers and her colleagues (2001) asked residents how they defined quality of care. Three types of relationships with staff emerged, with over half of the residents describing “care as relating.” That is, their definitions of good quality of care related to their closeness with and affection for staff. Those with positive relationships described more personalized care and being perceived as an individual beyond their age and disability. Many of these residents also described the busyness of staff and their own efforts to reduce staff burdens. Other types were “care as comfort” and “care as service.” The former was largely described by those with the greatest functional needs and were therefore reliant on staff for timely assistance and physical comfort. The latter represented a more consumer orientation. These residents focused on staff timeliness and efficiency in completing instrumental tasks. Similar to Bowers and her colleagues, Bergland and Kierkevold (2005), conducting research in Norway, also found different residents wanted different kinds of relationships, categorizing them as personal, non-personal (but friendly and kind), and distant. Tanya Roberts (2018) conducted a series of in-depth interviews with a group of residents over time to gain

understanding about their relationships with staff and peers. With respect to staff, Roberts found few instances of residents describing relationships with staff as close, although relationships were often described as friendly. Close relationships depended on staff spending non-care time with residents and doing extras to make residents feel cared about and special. It was especially important to make residents feel comfortable about needing help. Like others, Roberts also found that some residents preferred to maintain a professional boundary with staff, desiring a utilitarian or neutral relationship. Adversarial relationships with staff were also described, where staff delayed or neglected to provide needed assistance.

Overall findings.

Cronbach's alpha for the seven items in the original domain was .77 for the pooled sample. However, it ranged from .63 among short-stay NH residents up to .81 among AFH residents. Overall, this indicated a moderate-to-high inter-item agreement for the original domain. For the pooled sample, the strongest association was between items a ("listen to you share stories about your life") and c ("talk to you about things you are interested in") (see Figure RS1).

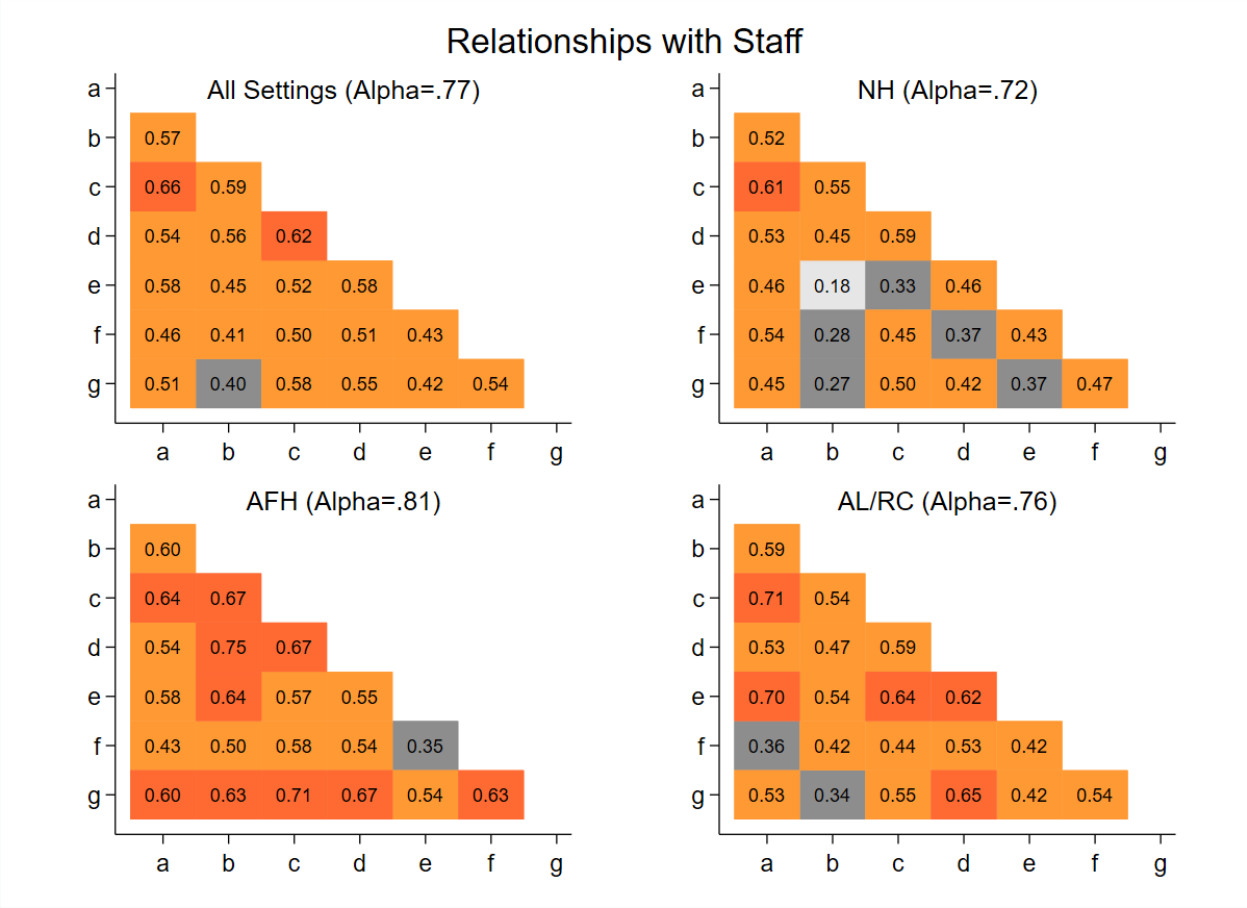


Figure RS1. Strength of association among items in the Relationships with Staff domain

Compared to other domains, residents' ratings of importance for relationships with staff were lower for all items across all settings. Only one item was rated as very important by 50 percent or more of residents and that was having staff who would laugh with them. Ratings of experience with many items in this domain were higher than ratings of importance, which suggests that a large segment of the residents experienced more sharing of stories and conversations about things residents were interested in than they felt were important.

Table RS1 presents information about unmet need reflected in these items. Unmet need is defined as the incongruence between rating an item as very important and reporting no experience or experience only some of the time for that item. Only NH and AL/RC residents indicated they had areas of unmet need, including staff spending time just talking and being with them, and staff having thing in common with them. AL/RC residents also indicated unmet need with respect to hearing stories from staff about their lives, talking about things residents were interested in, and staff knowing what they had done in their lives.

Table RS1. Importance and unmet need for the Relationships with Staff domain by setting type

Items	NH			AFH			AL/RC			TOTAL		
	VI %	Y %	UN %	VI %	Y %	UN %	VI %	Y %	UN %	VI %	Y %	UN %
a. Listen to you share stories about your life	32	50	16	38	57	19	23	42	22	31	49	19
b. Tell you about their personal lives	26	29	20	25	33	20	23	24	25	25	29	22
c. Talk to you about things you are interested in	38	44	21	45	54	20	35	42	26	39	46	22
d. Spend time with you just talking and being with you	38	30	34	42	48	24	34	25	34	38	34	31
e. Know what you have done in your life	23	27	23	31	49	19	19	22	26	24	32	23
f. Have things in common with you	22	21	27	31	36	23	19	22	27	24	26	26
g. Laugh with you	59	71	13	51	72	10	55	74	9	55	73	11

Notes: VI=Very important, UM= Unmet need, Y= Yes.

The association of each item in this domain with various outcome reported by residents is presented in Table RS2. by setting. Outcomes include resident recommendations of the place to someone else, satisfaction with the setting, quality of life, and depressive symptoms. Across settings, the items in this domain were associated most with satisfaction with the setting and least with depressive symptoms. All items were related to positive outcomes of quality of life, satisfaction, and resident recommendations for those living in AFH. With one exception, none of the items were associated with depressive symptoms. The exception was the item “tell you about their personal lives” was associated with depressive symptoms in AL/RC.

Table RS2. Association of experiencing each item with positive resident outcomes by setting type

	NH				AFH				AL/RC			
	R	**S**	**Q**	**P**	**R**	**S**	**Q**	**P**	**R**	**S**	**Q**	**P**
a. Listen to you share stories about your life	✓	✓	✓	✗	✓	✓	✓	✓	✗	✓	✓	✗
b. Tell you about their personal lives	✗	✓	✗	✗	✓	✓	✓	✗	✗	✗	✗	✓
c. Talk to you about things you are interested in	✓	✓	✓	✗	✓	✓	✓	✓	✓	✓	✓	✗
d. Spend time with you just talking and being with you	✓	✓	✓	✗	✓	✓	✓	✓	✗	✓	✗	✗
e. Know what you have done in your life	✗	✓	✗	✗	✓	✓	✓	✗	✓	✓	✗	✗
f. Have things in common with you	✗	✓	✓	✗	✓	✓	✓	✗	✗	✓	✓	✗
g. Laugh with you	✓	✓	✓	✗	✓	✓	✓	✗	✓	✓	✓	✗

Notes: Experiencing is defined as a response of Yes compared to No or Some. R= would recommend this place to someone else, S=general satisfaction, Q=quality of life, P= PHQ9 score (depressive symptoms). No control variables included. Significance was determined at $p < .05$.

a. Listen to you share stories about your life

Quantitative findings. The first question in this domain asked if the resident considered it not important, somewhat important, or very important that people who worked at the setting listened to the resident share stories about the resident's life. Overall, 31 percent of all residents across all settings said that this issue was very important to them. AL/RC residents were significantly less likely to rate this item as very important compared to NH and AFH residents (NH=32%; AFH=38%; AL/RC=23%).

When asked whether people who worked at the setting listened to them share stories about their lives, 49 percent of all residents across three settings responded positively. AFH residents were significantly more likely to report that they did compared to AL/RC residents (NH=50%; AFH=57%; AL/RC=42%).

Nineteen percent of all residents across three settings reported an unmet need about this issue and there were no significant differences across settings (NH=16%; AFH=19%; AL/RC=22%).

Among NH residents, this item was significantly associated with three resident outcomes, but not with depressive symptoms. Among AFH residents, it was associated with all four resident outcomes. Finally, among AL/RC residents, it was associated with reported satisfaction and quality of life, but not with higher likelihood of recommending the setting to someone else or depressive symptoms.

Qualitative findings. Over 130 comments were made in response to this item, divided fairly evenly between responses to the "importance" and "experience" questions. With respect to importance, about one-third of the comments related to staff busyness (*"They don't have much time, they have so many people to take care of;" "It's very important, but I have to realize they don't have time.")* or to a lesser extent, a lack of staff interest *("It matters, but they act like they don't care." "They don't take time to listen. I have tried to share some things, but they don't give me the time.").* Consistent with these comments, some residents indicated that they would share their stories if they were asked, suggesting they had an interest in doing so but may not have either because of busyness or lack of staff interest. About 15 percent of residents indicated that sharing stories was not important to them because they did not want to share ("*I don't talk much about my life, my past. I haven't told anybody here about my past or anything because I didn't think it was important*.").

When asked about their experience with sharing stories about their lives, nearly half of the residents said that they did not share stories, mostly because they chose not to *("I don't share stories much. I don't do it." "I'm not one to share about that.")* Many other residents who did not share added that staff would listen to them if they did share, suggesting that this group of residents made the choice not to share. Similar to

comments related to importance of the item, about 15 percent of residents indicated that they did not share or only shared some because staff were so busy *("Don't do it that much, they don't have enough time to do that")* and a few said they didn't share because staff did not care about them.

Fewer than one in five of the comments in response to either importance or experience questions described instances of staff listening to them share stories ("*Yeah, it's important. My son [indicated picture on the wall] died young, and my partner left me this year. It's important they [caregivers] know that about me. I have a lot of abuse in my past, too, and they are very understanding").* Three of those individuals indicated they had a reciprocal relationship with staff that involved mutual sharing (*"We both talk about our past. She makes me feel at home"*). A few residents indicated they shared stories with other residents, a therapist, or others and not with staff.

b. Tell you about their personal lives

Quantitative findings. The second question in this domain asked if the resident considered it not important, somewhat important, or very important that people who worked in that setting told the resident about their own personal lives. Only a quarter of all residents (25%) responded that this was very important to them and there were no significant differences in this finding across the three settings (NH=26%; AFH=25%; AL/RC=23%).

Less than one-third (29%) of all residents across the three settings responded yes when asked whether the people who worked at the setting told them about their own personal lives. AFH residents were more likely to say that they did compared to AL/RC residents (NH=29%; AFH=33%; AL/RC=24%).

Overall, 22 percent of all residents reported unmet need about this issue and residents living in different settings reported similar levels of unmet need (NH=20%; AFH=20%; AL/RC=25%).

Among NH residents, this item was significantly associated only with general satisfaction. Among AFH residents, it was associated with three resident outcomes, but not depressive symptoms. In contrast, among AL/RC residents, it was associated with depressive symptoms, but not the other three resident outcomes.

Qualitative findings. About 100 residents made comments about this item, with two-thirds in response to questions about importance. Of those, a majority indicated that they did hear stories and most liked knowing about staff regardless of whether they rated this item as important or not important. Many said they invited the staff to share.

(". . . one person here, I'd ask 'how are you today?' and through her responses got to know her over time." "That's none of my business. But they tell me things sometimes and I don't mind it; it's nice." "It's so interesting to me . . . I haven't found a person here who hasn't had a story." "I like to know about people.") Similarly, some residents explained why hearing staff stories was important, mostly because stories were interesting and they gained understanding of the staff. *("I've found the more I learn about other people, the more I understand what they are going through." "It makes them more human.")* As with sharing their own stories, a small group of residents indicated hearing staff stories was part of a reciprocal relationship *("We just have normal conversations." "It would be nice if they did, like a friend.").*

Others listened to staff stories with less enthusiasm. These comments were made in response to both importance and experience questions. For example, *"They do [share stories] and I listen. There's some here that could go to a counselor." "Sometimes they tell me more than they should.")* Mostly, those who did not share reported that staff stories were none of their business *("That's sticking your nose in where it don't belong."*) or that they did not care *("I don't care about that. I just want them to get on with things*.")*)*.

A new theme that emerged, especially in responses to the question about experience, involved professional boundaries, whether determined by the organization *("They have been told on numerous occasions not to share their personal lives."),* individual staff *("some just want to separate their work and life*"), or resident *("They shouldn't because it's a business relationship.")* Many of the responses, however, suggest ambivalence. For example, the resident who described the relationship with staff as a business relationship went on to say, "*Sometimes it just kind of breaks the ice, especially with new people who aren't comfortable with the residents yet."* Although comments about staff busyness or disinterest did not appear as frequently for this item as it did with respect to sharing their own stories, these staff barriers did emerge in resident comments. As with other items, some residents qualified their responses saying it depended on the individual staff.

c. Talk to you about things you are interested in

Quantitative findings. The third question in this domain asked if the resident considered it not important, somewhat important, or very important that people who worked in this setting talked to the resident about things that the resident was interested in. Thirty-nine percent of all residents across all settings reported that this was very important to them. AFH residents were slightly more likely to find this issue very important compared to AL/RC residents (NH=38%; AFH=45%; AL/RC=35%).

When asked about whether people who worked at the setting talked to the resident about things that they were interested in, 46 percent of all residents across three settings responded positively. AFH residents were more likely to say that they did compared to NH and AL/RC residents (NH=44%; AFH=54%; AL/RC=42%).

Twenty-two percent of residents reported an unmet need about this issue and there were no significant differences in reporting an unmet need about this issue across the different settings (NH=21%; AFH=20%; AL/RC=26%).

All four resident outcomes were significantly associated with this item regardless of setting type – except for depressive symptoms among NH and AL/RC residents.

Qualitative findings. About 70 comments were made in response to this item and over half were related to experience. Busyness *("I don't talk to them that much, they're too busy.")*, staff boundaries *("There isn't much chatting here. It isn't professional, so we don't do a lot of chit chat.")*, and reports of lack of conversations *("Nobody has asked me.")* were once again themes that accounted for nearly half of the responses explaining why it was not important or why staff did not talk to them about their interests. Lack of staff knowledge was a related theme *("They don't know what I'm interested in, like my books").*

A few residents indicated that lack of conversation about interests was a result of their own lack of interests *("I don't have any interests that I know of really"),* their perceived lack of commonality *("I wish people here shared my interests, but not many do." "Usually my interests don't align with theirs.")* or their own lack of desire to share *("I don't care or want them to know*." *"I'm very happy inside. I don't need someone to do that - constant encouragement.")*.

Only about one in ten indicated that they talked with staff about interests, though none of the comments suggested a strong relationship based on these interests *("We all visit with each other, but it's not important." "They always ask what I'm building.").* A small number of residents suggested that although they had few, if any, conversations about their interests, they might do so if either they or staff initiated an exchange or if it was something the staff was interested in.

d. Spend time with you talking or just being with you

Quantitative findings. This question asked if the resident considered it not important, somewhat important, or very important that people who worked in this setting spent time with the resident just talking or being with them. Overall, 38 percent of all residents across the three settings reported that this was very important to them. There were no

significant differences in rating this item very important across the three settings (NH=38%; AFH=42%; AL/RC=34%).

When asked about whether people who worked at the setting spent time with them just talking or being with them, one-third of all residents (34%) replied yes. However, AFH residents were significantly more likely to say that they did compared to NH and AL/RC residents (NH=30%; AFH=48%; AL/RC=25%).

Although about one-third of all residents (31%) across the three settings reported unmet need for this item, AFH residents were slightly less likely to report an unmet need compared to NH and AL/RC residents (NH=34%; AFH=24%; AL/RC=34%).

Among AFH and NH residents, all four resident outcomes were significantly associated with this item regardless of setting type – except for depressive symptoms among NH. Among AL/RC residents, it was significantly associated only with general satisfaction and none of the other three resident outcomes of interest.

Qualitative findings. Over 120 residents made comments in response to this item, and most of those were related to importance. Half of all of the comments (importance and experience) described the busyness of the staff which precluded them from spending time with them *(I would love that, but they don't have time." "I don't care because they're busy. Why should they spend time with me if it's not necessary?" "No, they don't have time. They're short-handed all the time. Some of the help make you feel like they have nobody but you, but most are in a hurry.").* Without providing reasons, another 12 percent said that staff did not spend time with them *("It's kind of lacking," "I haven't had anybody do that, so I don't know how to answer.").*

About one in 10 residents indicated that staff spending time with them was important even if it didn't always happen *(That shows they're accepting you as a person, and you are accepting them, not as a servant." "Quality time is so important for human interaction.").* About one in five residents reported that they experienced this *("At my request they will." "I never had that before. Here, the owner does that." "They'll come in and love [the dog] and throw themselves on the couch)*, or occasionally experienced this depending on the staff and their availability *("Every once in a while." "Only on their breaks." "That depends on who it is.")*.

A small number of residents indicated that it was not important to them or that they did not want or need staff to spend time with them *("It would just be about them." "I can entertain myself. I have interests and an incredible DVD collection")*. Two people said that they had friends or family available to spend time with.

e. Know what you have done in your life

Quantitative findings. This question asked if the resident considered it not important, somewhat important, or very important that people who worked in this setting knew what the resident had done in their lives. Only a quarter of all residents (24%) reported that this was very important to them. In addition, AFH residents were significantly more likely to report this issue as very important compared to AL/RC residents (NH=23%; AFH=31%; AL/RC=19%).

When asked about whether people who worked at the setting knew what they had done in their lives, 31 percent of all residents across three settings replied yes. AFH residents were much more likely to say that they did compared to NH and AL/RC residents (NH=27%; AFH=49%; AL/RC=22%).

Twenty-three percent of residents reported an unmet need about this issue and there were no significant differences in terms of reporting an unmet need across the different settings (NH=23%; AFH=19%; AL/RC=26%).

Among NH residents, this item was associated only with general satisfaction. Among AFH residents, it was significantly associated with three resident outcomes, but not depressive symptoms. Finally, among AL/RC residents, this item was significantly associated with higher likelihood of recommending the setting to someone else and general satisfaction, but not quality of life or depressive symptoms.

Qualitative findings. About 65 people made comments about this item. Fifteen percent indicated that it was important or described why it was important *("That helps them take care of me." "I think they have a right to know within limits. It helps them know what kind of person they are dealing with.")*. Just over one in four indicated that staff did know at least something about their lives *("I pretty much say where I've been and what I've done.")*. At the same time, some of this knowledge appeared limited *("They come in and look at my wall, and must have some idea," "They know I was a volunteer firefighter. . ." "They don't all know everything, but they know I'm a teacher.").*

Another 25 percent reported that either it was not important (*"It's what we're doing here now that is important." "No, that's gone. That's the past. Deal with today, that's what you've got.")* or that they chose not to share their past *("No thank you." "I don't want to talk with them about that.").* Some residents had past traumas that they did not want to relive *("They're really good about knowing that if you didn't want to talk about something, you don't gotta. If it's something in the past that's hurt you, or what you've done, they take you as you are. Don't make you explain.")*. Some residents also suggested they were more than one aspect of their past *("They know my criminal history, but not what I'm proud of." "It's embarrassing being introduced as a minister - that puts me in a pinch, on a pedestal.").*

About 12 percent of residents indicated that staff did not know about their past either because they were too busy or did not care to know.

f. Have things in common with you

Quantitative findings. This item asked if the resident considered it not important, somewhat important, or very important that people who worked at the setting had things in common with the resident. Only 24 percent of all residents across all settings said that this was very important to them. AFH residents were significantly more likely to find this issue very important compared to both NH and AL/RC residents (NH=22%; AFH=31%; AL/RC=19%).

Only 26 percent of all residents said that people who worked at the setting they were living in had things in common with them. AFH residents were significantly more likely to say they had things in common compared to NH and AL/RC residents (NH=21%; AFH=36%; AL/RC=22%).

A quarter of all residents (26%) reported unmet need for this item and residents across the three settings reported similar levels of unmet need (NH=27%; AFH=23%; AL/RC=27%).

All four resident outcomes were significantly associated with this item regardless of setting type – except depressive symptoms across the board and likelihood of recommending the setting to someone else among NH and AL/RC residents.

Qualitative findings. About 70 residents commented on this item, with most in response to the question about experience. About half of the residents talking about importance indicated that it was important to have things in common with staff *("It's irrelevant to the job, but it's relevant for the human interaction and relationships." "Well, I think it's very important to me, because that's what makes it work.")*. As with other items in this domain, some indicated it was not important. As one resident said, *"You have to get along with people even without things in common."*

Several residents described areas where they did experience commonality with staff *("On a global level, yes." "Some staff will bring their kids in and I like meeting them because I have kids and we have that in common." "Crocheting.").* About 10 percent responded that they did not know whether staff had things in common with them. A comparable number indicated that staff either did not have things in common with them or that staff couldn't due to age or cultural differences *("I've had such an uncommon life." "They're too young.")*. A few indicated that there were barriers to finding commonality including professional *("Not my business to know.")* or organizational barriers *("If you have something in common you can't go out and do something.").*

h. Laugh with you

Quantitative findings. This question asked if the resident considered it not important, somewhat important, or very important that people who worked in this setting laughed with the resident. A little over half of all residents (55%) rated this issue as very important and this item was the most important issue in this domain as reported by residents. Residents who lived in different settings rated this issue similarly (NH=59%; AFH=51%; AL/RC=55%).

When asked about whether people who worked at the setting laughed with them, three-quarter of residents (73%) replied yes. Residents living in different settings had similar experiences with this issue (NH=71%; AFH=72%; AL/RC=74%).

Only eleven percent of all residents across three settings reported an unmet need with this item. Residents across the three settings did not differ in terms of reporting an unmet need about this issue (NH=13%; AFH=10%; AL/RC=9%).

All four resident outcomes were significantly associated with this item regardless of setting type – except depressive symptoms.

Qualitative findings. Relatively few residents made comments in response to this item, 30 with respect to importance and 15 when asked about their experience. The major theme from both questions identified laughing as a way of relating. Some commented specifically about what humor meant to them, *"[owner] and I joke around all the time. I'm a funny guy . . . I like to stir the pot, get people laughing. It gives me joy."* For others it was the humor emanating from the relationship (*"That tells me I'm getting through to others, that we can relate, that they understand me." "She laughs with everybody." "We laugh all the time here.").*

Several residents indicated that humor is important, *("the best medicine" "It's important for anyone to laugh with me.")*. Some of these residents indicated this was a good question. A few residents indicated that laughing with others was not important and a small number emphasized the importance of "laughing with" instead of "laughing at."

Residents were divided in indicating whether staff did or did not laugh with them *("How could they laugh with me if I don't see them or talk with them?" "They are good at this.")*.

Summary

The quantitative data suggest that items about relationships with staff are less important than those of other domains. In fact, this domain received the lowest ratings for both importance and experience. Only one item in this domain, that staff "laugh with you," was rated as very important by half or more of the residents. The quotes above provide

insight into the importance of this item: Laughter is beneficial, it represents a way of human relating, and denotes a positive and friendly relationship.

What is striking in examining resident comments in response within this domain is one of staff busyness. Residents across multiple items indicated that staff were simply too busy to listen to their stories, share stories with residents, or spend time with them apart from providing care. A second major theme involved the social boundaries that exist between staff and residents. These boundaries frequently were generated by residents themselves who, for multiple reasons, chose not to be in relationship with staff. This may or may not be related to staff busyness or perceived lack of interest. Professional distancing was also described resulting from organizational policies to reinforce boundaries.

AFH stand out because residents in those settings consistently provided higher ratings of importance and experience than residents in other settings. The smaller and more intimate setting of this type of residence likely contribute to strengthening relationships between residents and providers.

As shown in Table RS3, only one item from this domain met criteria for inclusion in the final cross-setting Resident VIEW measure. No other item from this domain met criteria for inclusion in any of the site-specific measures.

Table RS3. Selection of items from the Relationships with Staff domain for the final tool based on various sources

People who work here	NH	AFH	AR
a. Listen to you share stories about your life?	×	⇔	×
b. Tell you about their personal lives?	×	×	×
c. Talk to you about things you are interested in?	⇔	×	×
d. Spend time with you just talking or being with you?	⇔	×	×
e. Know what you have done in your life?	×	×	×
f. Have things in common with you?	⇔	×	×
g. Laugh with you?	✓	✓	✓

Results: 1.B.(8) Organizational Environment

Introduction. The system within which people work and live shape the ability of staff to provide PCC and for residents to experience that practice. The organizational environment includes within organization factors such as leadership, staffing, culture, and climate. These environments, in turn, are influenced by location (e.g., urban/rural), ownership type (for profit, not for profit), and state and national regulations. Definitions of organizational culture vary, particularly within long-term care. Cassie and Cassie (2012) define culture as shared values, beliefs, and expectations for staff with respect to job responsibilities. They define climate as employees' shared perceptions of the work environment on their own well-being. Anderson, Corazzini, and McDaniel (2004) argue that climate is "a set of management practices that are part of organizational processes that interact to create the whole" (p. 379). Miller and her colleagues focus on a set of issues as part of the nursing home culture change movement designed to enhance PCC practices (Miller, Schwartz, Lima, Shield, Tyler, Berridge, Gozalo, Lepore, & Clark, 2018). These issues include workplace practices, the physical environment, care practices, leadership, family and community engagement, as well as the larger regulatory environment.

Prior research indicates that leadership and structural characteristics greatly influences an organization's culture, which in turn is associated with PCC practices. These practices, in turn, are associated with various staff outcomes including staff turnover (Anderson, Corazzini, & McDaniel, 2004; Banaszak-Holl, Castle, Lin, Shrivastwa, & Spreitzer, 2013; Hunter, Hadjistavropoulos, Thorpe, Lix, & Malloy, 2016; Lyons, 2010; Miller et al., 2018),

In the Resident VIEW research, we asked residents about the organizational environment as they experience it. This includes resident interaction with administrators or AFH providers, staffing issues including consistent assignment with direct care staff, staff attitudes, and sufficient time for staff to provide care. Integration of residents in decision making with respect to staff who work in the setting was explored with the question "do you have a say in who works here?" A related question was added later, "do you have a say in who helps you?"

Overall findings. Cronbach's alpha for the seven items in the original domain was .65 for the pooled sample. However, it ranged from .58 among long-stay NH residents up to .67 among AFH residents. Overall, this indicated a moderate inter-item agreement for the original domain. For the pooled sample, the strongest association was between items f. ("the people who work here have time to help you when you need it") and g. ("the people who work here have a good attitude") (See Figure OE1. Below). One item,

“do you have a say in who helps you?” has not yet been analyzed since it was added midway through the NH study and so we do not have complete data for this item.

Table OE1 presents information about unmet need reflected in these items. Unmet need is defined as the incongruence between rating an item as very important and reporting no experience or experience only some of the time for that item. Three items within this domain were rated as very important by more than 75 percent of residents across all settings: “talk to the administrator/provider if you have a problem” “the people who work here have a good attitude,” and “this place is run well.”

Twenty-five percent or more of NH residents who rated items as very important met criteria indicating unmet need (25%) for all items in this scale. An exception was the item about staff having good attitudes, which, at 24% of NH residents, nearly met this threshold for unmet need. AFH residents had unmet need in only one area, “having a say in who works here,” although only a quarter of residents indicated this was very important to them. AL/RC residents had unmet need with respect to talking to the administrator if they had a problem, having the same person help on most days, feeling the place was run well, and having a say who works here. Similar to residents in other settings, relatively few AL/RC residents rated having a say in who worked there as very important.

Table OE2 indicates which items predicted positive resident outcomes. Three items were significantly and positively associated with residents’ recommendations, their satisfaction, quality of life, and lower levels of depressive symptoms: the people who work here have time to help you when you need it,” “the people who work here have a good attitude,” and “this place is run well.” Being able to talk to the administrator when the resident had a problem was associated with all outcomes in all settings except for NH resident recommendations. The item with the least association with outcomes in all settings was, “you have a say in who works here.”

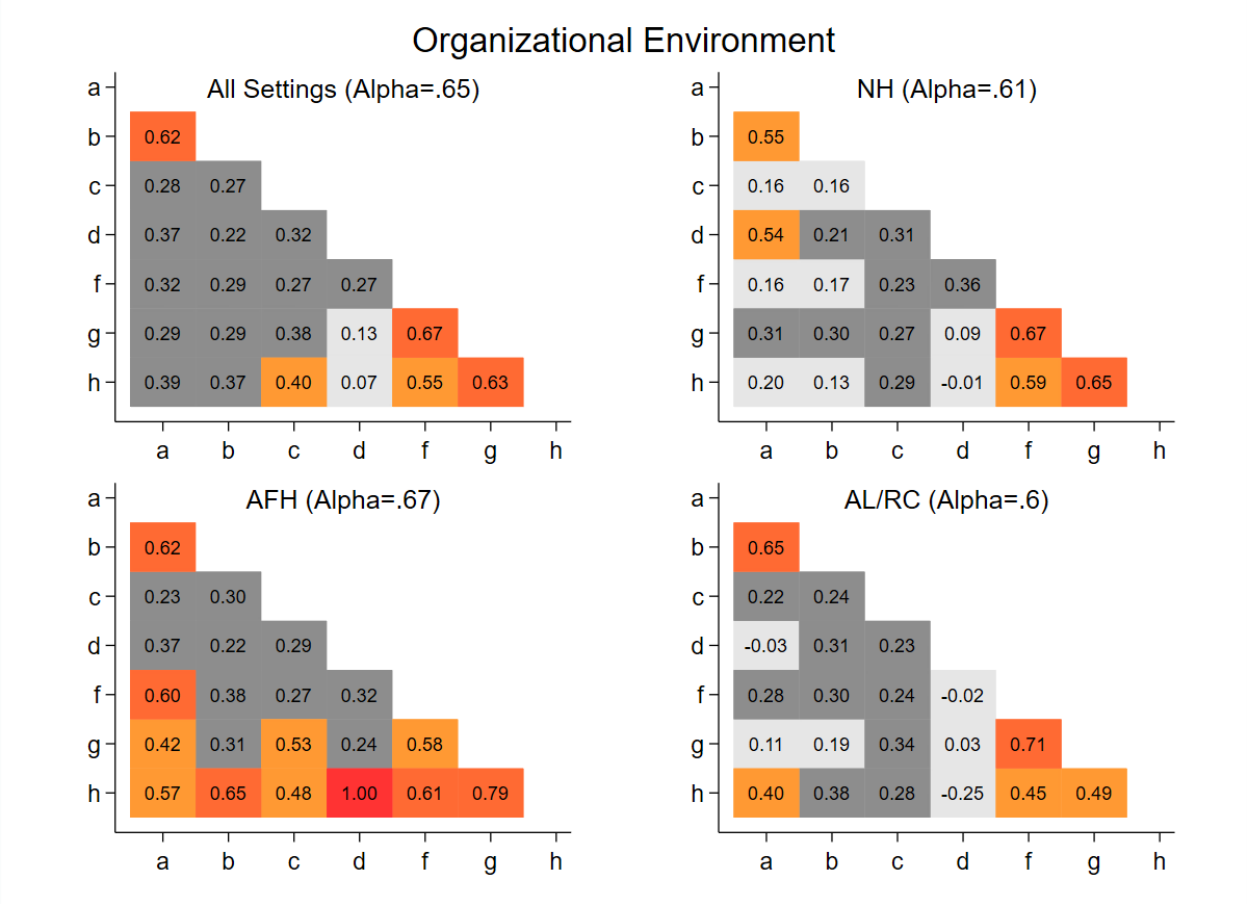


Figure OE1. Strength of association among items in the Organizational Environment domain

Table OE1. Importance and unmet need for Organizational Environment domain

	NH			AFH			AL/RC			TOTAL		
	VI %	Y %	UN %	VI %	Y %	UN %	VI %	Y %	UN %	VI %	Y %	UN %
a. You can talk to the [provider/owner/administrator] if you have a problem	80	64	29	82	86	10	83	69	25	81	72	22
b. You see the [provider/owner/administrator] around the place	50	53	26	71	79	12	69	69	19	62	66	20
c. The same people help you most days	57	50	36	53	82	8	46	47	30	52	58	26
d. You have a say in who works here	28	11	41	24	13	40	23	4	47	25	9	43
e. You have a say in who helps you	X	X	X							X	X	X
f. The people who work here have time to help you when you need it	81	60	35	69	74	17	75	68	24	76	67	26
g. The people who work here have a good attitude	91	74	24	85	84	12	86	76	21	87	77	20
h. This place is run well	92	65	32	84	89	8	93	66	32	90	72	25

Notes: VI=Very important, UM= Unmet need, Y= Yes. . Item e was not included in the NH survey and is not analyzed for CBC residents in this report.

Table OE2. Association of experiencing each item with positive resident outcomes by setting type.

	NH				AFH				AL/RC			
	R	S	Q	P	R	S	Q	P	R	S	Q	P
a. You can talk to the [provider/owner/administrator] if you have a problem	X	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
b. You see the [provider/owner/administrator] around the place	X	✓	✓	X	✓	✓	X	X	X	✓	✓	X
c. The same people help you most days	X	✓	X	X	✓	✓	X	X	X	✓	✓	✓
d. You have a say in who works here	X	X	✓	X	✓	✓	X	X	✓	X	✓	X
e. You have a say in who helps you	X	X	X	X								
f. The people who work here have time to help you when you need it	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
g. The people who work here have a good attitude	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
h. This place is run well	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓

Notes: Experiencing is defined as a response of Yes compared to No or Some. R= would recommend this place to someone else, S=general satisfaction, Q=quality of life, P= PHQ9 score (depressive symptoms). No control variables included. Significance was determined at $p < .05$. Item e was not included in the NH survey and is not analyzed for CBC residents in this report.

a. Do you talk to the [provider/owner/administrator] if you have a problem?

Quantitative findings. The first question in this domain asked residents if they considered it not important, somewhat important, or very important that talk to the provider/owner/administrator (of the setting) if residents had a problem. Overall, over three-quarters of all residents (81%) across all settings said that this was very important to them, and did not differ significantly by setting type (NH=80%; AFH=82%; AL/RC=83%).

When asked if they talked to the provider, owner, or administrator if they had a problem, 72 percent of all residents across three settings replied yes. However, AFH residents were significantly more likely to report that they did so compared to NH and AL/RC residents (NH=64%; AFH=86%; AL/RC=69%).

About one-fifth (22%) of all residents reported unmet need about this issue. However, NH and AL/RC residents reported a significantly higher unmet need compared to both AFH residents (NH=29%; AFH=10%; AL/RC=25%).

This item was significantly associated with all four resident outcomes across three settings – except likelihood of recommending the setting to someone else among NH residents.

Qualitative findings. This item generated nearly 100 comments. Residents described why this was important, *"I think it's very important that you can go directly to your director, not going through the chain of command,"* and "*she needs to know if there is a problem."* Nearly one in five of the comments provided examples of residents talking with their administrators or providers, *"No matter what she's doing, she'll stop and listen," "she has an open-door policy."*

Nearly one-third of residents said that they did not have a problem that required speaking with the administrator or provider, with most of those indicating that they could talk with them if they did. *"If I have a problem, but I never have a problem." "She says, 'you can tell me if you have a problem,' but I haven't had anything to tell." "I haven't done it, but I suppose I could."*

At the same time, about one-third of the residents made comments that indicated they could not talk to the administrator or if they did, it would not be effective. *"[administrator] doesn't seem to care one way or another what you have to say." "It's very important, but she doesn't listen to me. She always has an excuse. She'll tell me something one time and then she'll say something else." "He has tendencies to skip over some peoples' problems. It bothers me sometimes, but I'm not going to die." "He's my son's age, so it's hard to talk to him." "It's very important, but there is no follow-through."* More than half of these residents referred to administrative turnover as they were answering this question. *"We have sometimes administrators that only work for a month. We have a lot of administrators since I've been here. One just took selfies in her office all day." "The one that was here before, yes. The one that's here now, I don't think she would listen if I tried." "Having had four different administrators, it was frustrating when they didn't listen or told me I didn't know what I was talking about. I don't say it if I don't know it." "She's new, but she's a capable individual."*

The remaining comments were made by a small number of residents (five or fewer). Some indicated their family members would talk to administrators on their behalf, others felt it was not relevant to their situation, and a few reported they did not know who the administrator or provider was.

b. Do you see the [provider/owner/administrator] around this place?

Quantitative findings. The second question in this domain asked if the resident considered it not important, somewhat important, or very important that the resident saw the provider/owner/ administrator (of the setting) around the place. Although 62 percent of all residents across all settings said that this was very important to them, NH residents were significantly less likely to rate this item very important compared to AFH and AL/RC residents (NH=50%; AFH=71%; AL/RC=69%).

When asked if they saw the provider, owner, or administrator around the place, two-thirds (66%) of all residents across three settings replied yes. However, NH residents were least likely to say so, followed by AL/RC residents. AFH residents were most likely to say so (NH=53%; AFH=79%; AL/RC=69%).

Twenty percent of all residents reported unmet need about this item. NH and AL/RC residents had higher unmet need compared to AFH counterparts (NH=26%; AFH=12%; AL/RC=19%).

Among NH and AL/RC residents, this item was associated only with general satisfaction and quality of life. Among AFH residents, it was significantly associated only with higher likelihood of recommending the setting to someone else and general satisfaction.

Qualitative findings. About 85 comments were made in response to this question. About half of the comments emphasized the importance of seeing the administrator or provider around the place or indicated that they did see these individuals regularly. Some described why it was important: *"Someone you relate to and have a personal relationship with." "He comes in and parks and goes into the dining room and talks to every person there. That makes me feel good." "I think owners should spend a certain amount of time here. We've gone through four caregivers because of one resident. She would be aware of these issues if she was here."* Some described administrators or providers who were very involved in care. *"This one is everywhere. When everyone had this flu, she was taking care of everyone. When we had a cook who was out, she was in the kitchen." "She and her husband are wonderful. They run a good place." "She actually was serving dinner last night. They are very short staffed." "I am impressed by how she comes in at night. She's very busy."* Some residents felt administrators were too present, *"I hate how much he's here, not in a bad way. He needs some time away, to go fishing, to relax. He should limit his time here for himself." "I think it's important for [the provider] to have time on their own when they are upstairs."*

Nearly one in five comments indicated that the residents did not regularly see administrators or providers around or made comments that suggested poor relationships with these individuals. *"She will briefly say something to somebody, but*

she doesn't sit with us and just be friendly. Too strict. You have to love people, put your arm around them sometimes. She might do that, but it doesn't feel genuine." "I don't think she's around as much as she should be. She's gone a lot." "A lot of times the managers know my dog, but not me."

About 12 percent of comments were from residents who did not know who the administrator was. *"I don't know who that is." "I don't know what she looks like."* A similar percentage of comments reflect administrator turnover, which is common in these settings. With these comments, residents are comparing and contrasting the different leadership attributes they have experienced. *"We just got a new one, thank goodness!" "Since I've been here, we've had two kinds. The guy here now is truly interested in making it a good place." "I used to know who they were, and now I don't. The old administrator used to come up at mealtimes and see everybody. The new administrator called a meeting to introduce herself and that's it."*

A few other residents indicated seeing the administrator depended on day of the week, was not important or relevant to them, or described their respect for the administrator or provider.

c. Does the same person help you on most days?

Quantitative findings. This question asked if the resident considered it not important, somewhat important, or very important that the same person help the resident on most days. Half of all residents (52%) replied that this was very important to them. AL/RC residents were significantly less likely to rate this item more importantly compared to NH residents, but not AFH residents (NH=57%; AFH=53%; AL/RC=46%).

Over half of all residents (58%) reported that the same person helped them on most days. However, AFH residents were significantly more likely to report that they did so compared to NH and AL/RC residents (NH=50%; AFH=82%; AL/RC=47%).

A quarter (26%) of all residents across three settings reported unmet need about this issue. However, AFH residents reported a significantly lower unmet need compared to both NH and AL/RC residents (NH=36%; AFH=8%; AL/RC=30%).

Among NH residents, this item was associated only with general satisfaction. Among AFH residents, it was significantly associated only with higher likelihood of recommending the setting to someone else and general satisfaction. Among AL/RC residents, it was significantly associated with all resident outcomes of interest, except likelihood of recommending the place to others.

Qualitative findings. This question generated about 90 comments. About one-fourth found the question was not relevant or not important. Many of these individuals, mostly in AL/RC, received little or no personal care assistance. Similarly, those who lived in an AFH where they had just one caregiver were not likely to find this item important or relevant. Approximately one-third of the comments were evenly divided between those who indicated that they either experienced the same person or a familiar person (or persons) helping them most days. *"We don't have a problem with that because we have a very regular schedule, and it's very nice to know who is here." "Maybe not the same people, but those who are familiar." "Depends on what shift you're talking about. It's a smaller place, so you get to know everybody."* Some residents pointed out that staff have days off, so others provide support on those days.

About one-quarter of the comments indicated that residents do not experience the same person helping on most days. *"There is a crew of people who help me put my socks on, but I never know who it's going to be." "It changes depending on which hall they are assigned to."* Most of the comments about lack of consistent assignment were connected to staff turnover. *"They've had trouble keeping help in the past, and it was a parade of people for a while, which was annoying and confusing." "There are new caregivers all the time." "We've been short-staffed and lots of change in management."*

d. Do you have a say in who works here?

Quantitative findings. Few residents considered it very important that they have a say in who works at the setting. Overall, only a quarter of all residents (25%) across all settings said that this was very important to them. Residents did not differ by setting type (NH=28%; AFH=24%; AL/RC=23%).

A few residents (9%) reported that they had a say in who worked at the setting. However, AL/RC residents were even less likely to report that they did so compared to NH and AFH residents (NH=11%; AFH=13%; AL/RC=4%).

Two-fifth of all residents (43%) across three settings reported unmet need about this issue and residents from different settings reported similarly high unmet need (NH=41%; AFH=40%; AL/RC=47%).

Among NH residents, this item was associated only with higher quality of life. Among AFH residents, it was significantly associated only with higher likelihood of recommending the setting to someone else and general satisfaction. Finally, among AL/RC residents, this item was significantly associated with higher likelihood of recommending and quality of life.

Qualitative findings. About 100 comments were made in response to this item, and most were related to the question about the importance of having a say. The responses fell into three main categories. About one-third indicated this was not important, mostly because they felt it was not an appropriate role for residents. *"Because they are not working for me. They're working for [owner], so [owner] has to like them." "I would probably make the wrong decision." "It really isn't any of my business . . ." ". . .I'm not qualified. They know more about it than I do." "Just as long as they are competent."* Others indicated this was not important to them because the leaders in their settings made good decisions. *"Everyone that comes in, I get along with." "All the people who work here are wonderful."*

Just over one-fourth of the residents described the importance of or instances in which they or their family members complained about specific staff and saw changes resulting from their complaint. *"I only have an opinion about that because we had a person who worked here for a very short period of time who was not a very caring or kind person. I thought she was borderline abusive and talked to the [provider] and she let her go." 'I think HR has a job to do that, but if they are not doing it, then I will say something." "That's a tricky question, I would probably have a say if there were indiscretions."* A couple of residents pointed to the Resident Council as a forum for expressing their opinion.

Nearly one-quarter simply indicated that they did not have a say, whether because of policy or lack of awareness of how that might work. *"No, but I'd sure like to." "I've never asked." "They don't let that happen." "Could be more, but I have not asked."*

Other comments suggest that the question is not relevant, mostly in AFH where the owner is the sole caregiver or in AL/RC where the resident did not require or receive much support from staff. Others identified other things as being more important, such as appreciating the required background checks, the desire to fire the cook, and the desire to have management introduce new staff.

e. Do you have a say in who helps you?

Quantitative findings. NOT REPORTED. Data on this item not collected for all NH residents.

Qualitative findings. The comments offered by CBC residents described for the item "have a say in who works here," were similar to those made by NH residents. It seems that having a say in hiring decisions was too removed from most residents' experiences or desires and that asking them whether they had a say in who helped them would be

more relevant to them and more in keeping with PCC practices. This question was added part way through data collection for NH residents and included in the CBC study.

This item generated about 75 comments. In contrast to the comments about having a say in who works here, only a few residents indicated that having a say in who helped them was not an appropriate role for them. Similar to the response to having a say in who worked there, a few of the AFH and AL/RC residents were the most likely to find this question not relevant to their experience. AFH residents often had just one caregiver, the owner, and AL/RC residents were the least likely to require personal care.

About one-fourth of the comments suggest that residents either have a say or that they have no preferences for who providers support. *"Not important . . . because they are all excellent workers, they are all caring." "I have a say, but they do good enough for me." "I will not have a man giving me a shower or anything." "I don't need much help, but I have a say in how much help I need." "If somebody was not doing what I ask them, I'd ask that not come again. There's a person in charge of the caregivers and she can take care of anything."*

Similarly, several residents indicated that they did not make requests, but they could if needed. *"I'm sure I would have a say if I didn't want someone to help me, but that's never happened."* A few other comments were related to characteristics caregivers should have, including politeness, industriousness, and competence. *It's important that they know what they're doing, especially in handling medicine."*

About one in five of the comments suggest that residents did not have a say or were accepting of who helped. *"Whoever is available." "It's luck of the draw." "I accept it or I tolerate it." "I don't want to be responsible for somebody getting fired or quitting. I don't want them to feel like they can't help me. That's reciprocal."*

A few said that they did not know if they had a say, that importance depended on the role (i.e., Med Aide vs. Housekeeping), or turnover.

f. Do the people who work here have time to help you when you need it?

Quantitative findings. This question asked if the resident considered it not important, somewhat important, or very important that people worked at the setting had the time to help the resident when the resident needed it. Three-quarters of all residents (76%) responded that this was very important to them. NH residents were significantly more likely to rate this item very important compared to AFH residents (NH=81%; AFH=69%; AL/RC=75%).

When asked if the people who worked at the setting had time to help the resident when the resident needed it, two-third of all residents (67%) responded positively. However,

NH residents were significantly less likely to report that they did so compared to AFH and AL/RC residents (NH=60%; AFH=74%; AL/RC=68%).

While a quarter (26%) of all residents reported unmet need about this issue, NH residents reported a significantly higher unmet need compared to both AFH and AL/RC residents (NH=35%; AFH=17%; AL/RC=24%).

This item was significantly associated with all four resident outcomes across three settings.

Qualitative findings. About 50 comments were made in response to this question. Nearly 30 percent of the comments either stressed the importance of staff time or indicated that this was something they experienced. *"That's why I'm here. That's why they're here." "They make time. That's important, even if it means going off duty later than they should." "They make time."*

Just over one-fourth of the comments connected their response to staffing and busyness of staff. *"They're always so busy." "They don't always have a full staff." "I try not to use anybody if I don't need them. They come in when they can."* As illustrated in some of these comments, many residents were sensitive to staff needs and often did not ask for assistance as a result.

One in five comments said issues related to availability of staff time varied depending on the circumstance and the task at hand. *"Sometimes she has time." "It's situational with me. If my heart monitor goes off, I have to take priority, but otherwise I try to not ask for help." "Generally, it's not important if it does not involve something that is an absolute emergency. That rarely happens." "If it's planned ahead of time, yes [staff have time.]*

Very few individuals indicated that staff did not have time and several people indicated the question was not relevant because they had no need for staff time.

g. Do the people who work here have a good attitude?

Quantitative findings. Staff having a good attitude was considered important by most residents. Eighty-seven percent of all residents said that it was very important that people who worked at the setting had a good attitude. NH residents were slightly more likely to rate this item very important compared to AFH residents (NH=91%; AFH=85%; AL/RC=86%).

Overall, 77 percent of residents across the three settings reported that the people who worked at the setting had a good attitude. However, AFH residents were significantly more likely to report that they did so compared to NH and AL/RC residents (NH=74%; AFH=84%; AL/RC=76%).

Twenty percent of all residents reported unmet need about this issue. AFH residents had a significantly lower unmet need compared to NH and AL/RC residents (NH=24%; AFH=12%; AL/RC=21%).

This item was significantly associated with all four resident outcomes across three settings.

Qualitative findings. This question also generated about 50 comments. Half of the comments stressed the importance of a good attitude, with some providing examples. *"Very, very, very [important]. Boy, top most important." "That's a necessity." "They are so nonchalant when giving me a bath, which I appreciate. They aren't critical of me being overweight or of my messy room. They just want to provide good care."* "*They have a funny attitude, very playful. I like to watch them."*

About one-third of the comments indicated that staff varied in their attitudes. *"It's so hard to put everyone in one basket, so again, I'll average and say 'some' [have good attitudes." "One person in the dining room can be abrupt. Some have a better attitude." "They definitely have favorites."* Staffing and issues related to the job were given as other reasons for poor attitudes. *"If they are not happy working here, they are not going to do a good job." "[Their] attitude isn't toward me, but the job. A lot are frustrated." "Usually the ones with a poor attitude work themselves out, because they have to work as a team. If there is a bad cog in the wheel, they won't last long."*

A few of the residents stressed their own responsibility for having positive attitudes. *"It has to go both ways." "When I got out of a coma, I told my brother that I was going to go forward with a positive attitude."*

h. Do you feel this place is run well?

Quantitative findings. The last question in this domain asked if the resident considered it not important, somewhat important, or very important that the resident felt the place was run well. Most residents (90%) replied that this was very important to them – which was, on average, the most important item in this domain. AL/RC and NH residents were significantly more likely to rate this item very important compared to AFH residents (NH=92%; AFH=84%; AL/RC=93%).

While almost three-quarter of all residents (72%) felt the place was run well, AFH residents were significantly more likely to report so compared to NH and AL/RC residents (NH=65%; AFH=89%; AL/RC=66%).

Overall, 25 percent of all residents across the three settings reported unmet need about this issue. However, a much smaller share of AFH residents reported unmet need compared to NH and AL/RC residents (NH=32%; AFH=8%; AL/RC=32%).

This item was significantly associated with all four resident outcomes across three settings.

In spite of the strength of this item, it was not included in the final Resident VIEW tool. We determined that this item is best considered to be an outcome measure, especially related to resident satisfaction. Importantly, we are interested in what other elements of PCC practices are associated most strongly with resident assessment that the place they are living is run well.

Qualitative findings. This item generated nearly 70 comments. About one-fourth of the comments stressed the importance of the place being run well, with several more describing how the place was run well. *"Well, that's important. You have people's lives here." "It's my life." "The better things operate, the more relaxed the people." "I wouldn't stay here if it wasn't." "I tell everybody about this place. Not because I just live here, but because it is home."*

Nearly half of the comments, however, suggest that the place was not run well, or that residents were equivocal in their ratings. Those who felt the place was not run well made these types of comments: *"Emphatically, no." "Not happening. They don't know their priorities. [They act like] it's more important to get someone orange juice than a pain patch." "I would be lying if I even said 'some.'"* Staffing was given as a reason for the place being run poorly. *"I chose this place because of the established staff here. I thought that would make it a good place. Within three months of moving in, everyone had changed." "I can't see why there is such a big turnover."* For some, it depended on the specific part of the organization, notably areas related to food. *"I wish they would get some new chefs. Some things aren't fit to eat, you can't tell what it is." "Everything is okay except for the kitchen."*

Summary

Table OE3. Selection of items from the Organizational Environment domain for the final tool based on various sources. The item "have a good attitude" met criteria for inclusion across all settings. Staff time to help residents when it was needed met criteria for inclusion in NH and AL/RC settings, and there was some support for this item in AFH. Being able to talk with the administrator or provider when the resident had a problem was generally considered important, but this item met criteria for inclusion only in AL/RC settings.

We want to emphasize that comments made in response to this and other domains provide evidence about the impact of leadership, staffing, and staff attitudes on the experiences of residents across long-term settings. We heard from residents who were very satisfied with the place where they lived. They had relationships with administrators or providers as well as the staff who provided direct care. Many satisfied residents also emphasized the competence of staff. For some, competence and attitude were more

important than consistency of service. However, we also heard that low staffing and high turnover, of both administrators and direct care staff, was challenging. These issues are described in more detail in Part 2: Results, 2.b., “How can this place be run better?”

Table OE3. Selection of items from the Organizational Environment domain for the final tool based on various sources

	NH	AFH	AR
a. Talk to admin/provider if you have a problem?	×	×	✔
b. See admin/provider around this place?	×	×	×
c. Same person help you on most days?	×	×	×
d. Have a say in who works here?	×	×	×
f. People who work here have time to help you?	✔	⇔	✔
g. Have a good attitude?	✔	✔	✔

Results: Part 2: Elevating Resident Voices[3]

Results: 2.A. Creating Home

Introduction. The experience of feeling "at-home" in one's dwelling place is a critical part of wellness throughout the life course, but it is perhaps especially important for older adults who leave their homes and move to a higher level of care (Galvin & Todres, 2011; Gillsjö et al., 2011; Zingmark et al., 1995). Many long-term care (LTC) providers and advocates, regardless of setting, consider providing a homelike environment as an important programmatic goal, often a key feature of culture change initiatives to provide person-centered care (PCC) (Crandall, 2007; Koren, 2010; Tester et al., 2004). Intentionally built home-like settings typically feature the symbolic and functional architecture of home, such as "human-scale" design and layouts that promote both privacy and social interaction (Eijkelenboom et al., 2017; Marsden, 2001). But whether homelike designs ultimately result in improvements in resident quality of life or perceived at-homeness is uncertain (Gray & Farrah, 2019; Verbeek et al., 2009). In addition, regardless of recent efforts to build or remodel congregate living buildings to be more homelike, many older adults will continue to reside in traditionally designed LTC settings with more institutional features (e.g., long corridors, shared bedrooms and bathrooms). What residents think will enhance their experience of at-homeness and how contextual features influence those experiences are critical questions (Rijnaard et al, 2016).

Although many studies have examined residents' experiences of home in LTC settings, none, to our knowledge, have done so across multiple types of care settings and from the voices of a large number of residents. In this section, we will examine what over 800 residents in Nursing Homes (NH), Assisted Living and Residential Care (AL/RC), and Adult Foster Homes (AFH) communities consider to be the factors that contribute to their experience of at-homeness. As described earlier in this report, PCC is conceptualized as multifaceted and items in the Resident VIEW were developed to reflect eight different domains: the physical environment, relationships with staff, autonomy, meaningful activity, personalized care, knowing the person, being treated like a person, and the organizational environment. We also examined the associations between resident experiences of home with various other contextual factors such as length of time living in the setting, payment source, and urban or rural locations.

[3] This section of the report served as the basis for Diana Cater, Ozcan Tunalilar, Diana White, Serena Hasworth, & Jaclyn Winfree. (2021). "'Home is home:' Exploring the meaning of home across long-term care settings. *Journal of Aging and Environment.* https://doi.org/10.1080/26892618.2021.1932012

In this report we explore four major questions using both quantitative and qualitative methods:

- How do residents describe living situations that “feel like home” compared to descriptions of those who do not?
- How are qualitative responses to questions about “feeling like home” associated with different types of settings? (i.e., NH, AL/RCF, AFH)
- How is “feeling like home” related to staff and administrative characteristics?
- How do resident qualitative responses relate to overall resident satisfaction? Length of stay?

Methods. The last item in the Resident VIEW physical environment domain focused on the idea home. First, we asked residents “how important is it to you that it feels like home here?” Response categories were 1=not important, 2=important, and 3=very important. We then asked, “does it feel like home to you here?” Response categories were 1=not at all, 2=some, and 3=yes. If the answer was yes, we asked, “What makes it feel like home here?” and if the answer was no or some, we asked, “What would make it feel more like home?” We also gathered information on resident and setting characteristics such as urban or rural setting, payment type, shared or private room, gender, race, and length of stay.

Quantitative methods were used to examine ratings of home and the variables associated with them. We examined resident characteristics (i.e., gender, race, age, Medicaid or non-Medicaid payment type) and structural/environment characteristics (setting type, shared room, urban/rural) to determine their influence on resident ratings of home. This analysis included responses of 660 residents who had complete data for the analysis (see Table Home-1 for the distribution of residents across settings).

Qualitative analysis was conducted with data provided by the 612 residents who described what made it feel like home and what would make it feel like home. A Grounded Theory approach was used to avoid forcing responses into preconceived concepts (Charmaz, 2006). Using the constant comparative method, a sample of open-ended comments from NH residents were classified independently via open coding by two reviewers who were blinded to the care settings where the comments originated, establishing two separate coding schemes based on the questions answered by respondents (Strauss, 1987; Strauss & Corbin, 1990; Glaser & Strauss, 1967). Similar codes were grouped or collapsed into categories. After three reviewers coded a section of the data independently, the reviewers met with a fourth investigator to resolve interpretive discrepancies. The CBC data were then coded by a single reviewer, with multiple team meetings to discuss the coding process and results. Overarching themes were identified to connect like categories between the two responses (like home vs not

like home). Quotes were reconnected to setting type after analysis. The frequencies of the overarching themes and individual codes were counted and separated by setting to provide a general sense of what themes were most frequently named, or curiously absent, from each setting.

Results

Quantitative findings

Ratings of home did not vary by age, gender, or race/ethnicity. Setting type had the greatest association with feeling at home; AFH residents were significantly more likely to report that living in the setting felt at like home, with NH residents least likely.

As described in Part 1.b. (1) Physical Environment item selection, residents who rated feeling like home in the setting as very important, experienced high levels of unmet need in all settings, especially in NH. With the exception of depressive symptoms in NH residents, experiencing the setting as home was associated outcomes of interest across settings. In addition to depressive symptoms, outcomes included quality of life, resident satisfaction, and residents recommending the setting to others.

Qualitative findings

Five overarching themes emerged from the open-ended responses:

- Whom I'm with: Social Connection
- What I Can Do: Autonomy, Control, and Having a Say
- Where I Am: Engagement with the Physical Environment
- How I'm Treated and How Things Work: Organizational Environment
- How I Feel and What I Think: Perceptions and Coping

1. Whom I'm With: Social Connection.

Not like home. Residents who did not feel at home in their LTC Community missed their family, friends, and pets. *"If I had all my kids back and my wife back, anywhere I go would feel like home."*

Only a handful of residents said they wished they had better relationships with staff or other residents.

Feels like home. More than half of those who did feel at home described how the people in their LTC Community made them feel welcomed and cared for.

"Everybody gets along well, just like a family. I call my sister every morning, and everyone [the other residents, the providers, the resident manager] all talk to her, too. It just feels good."

Comments like these were derived primarily from AFH settings compared to AL/RC and NH settings, perhaps due to the family-like environment inherent in most homes. Some AFH residents' comments reveal the intimacy with which they know the owners, their families, pets, and other residents. As a resident who moved from a larger care setting to an AFH explained,

"It's a house, not a huge building. It's a smaller space. Fewer residents: from 66 to 5. The friendliness of the staff [and] getting to know the other residents [makes it feel like home]."

Take away: These comments demonstrate the breadth of social connections possible in LTC settings, from simply being acknowledged, to experiencing love, belonging, and companionship. LTC communities can help residents stay connected to the important people and pets in their lives while supporting the growth of meaningful relationships within the LTC Community.

2. What I Do: Autonomy.

Not like home. The relationship between personal autonomy and homeness was identified by many residents through different examples of losing choice over one's activities. Examples included pursuing desired activities and interests, controlling their own schedules, having more choice in daily routines (including meal times), privacy, and autonomy in movement.

"[It would feel like home if] I was able to eat when I want to eat and get up when I want to get up."

Barriers prevented residents from enacting preferences including their own physical disabilities, environmental barriers, and staff barriers. For NH residents in particular, there was a sense of being institutionalized, including descriptions of their experiences as "being in Jail" or "mice in cages."

Like home. Residents felt at home when they had control over their activities, routines, and comings and goings. Their choices were supported by the people around them and enabled by the physical environment.

[It feels like home because I]: "Got freedom here--can go outside and [at] night if you want to. Could even walk downtown if I wanted to go."

Beyond personal activities and space, some residents described their ability to contribute to or influence the LTC setting. For some, this looked like reciprocity:

> *"They cook for me and go to the store for me, help me shower. I get to sweep sometimes and clear/wipe the table. Helping with these tasks makes it feel like home."*

Take away: Center control over activities and routines with residents (waking and sleeping, meals, bathing); enable choice and mobility through accessible built environments; respect privacy and personal space (knock and be invited in before entering rooms; be quiet in hallways) while offering a standing invitation to community inclusion.

3. Where I Am: Influence over the Physical Environment.

Not like home. Residents often described how their LTC settings could be more like home if they had, as one resident described, "a space that is totally yours," such as a private room or portion of a garden. Residents often wished they were able to influence the spaces they *did* have through personalizing their rooms and having access to valued objects. This was difficult to obtain, especially for NH residents who typically share a room and have limited storage and furnishings. The layout or attractiveness of residents' living environments hindered their ability to do as they wished, feel comfortable, or enjoy their living space.

> *"If I had a better apartment. I would like to have a kitchen sink so I don't have to wash dishes in the bathroom. I'd like a cabinet for storage. I'd like it to look like it's not beat to death."*

> *"[It would feel more like home if it was] straightened up and put together. I have bags and bags of photos to sort through. I'd like to put them up."*

Feels like home. One of the most frequent comments residents made when asked what made it feel like home was "my things are here." Pictures and paintings, collections, furniture, hobbies and activities, and objects with sentimental attachment had the power to provide emotional comfort and support. Personalizing space was especially important to AL/RC residents, who mentioned the physical environment more than any other theme and much more frequently than AFH and NH residents.

> *"I'm with my family's pictures. I take my daughter [her picture] with me everywhere."*

Residents also felt at home when they enjoyed the appearance and functionality of their LTC Community and had access to nature and places outside.

It feels like home because "I can hear the animals. I can walk around and see things when I want. I like to look at plants and landscapes around here. I sometimes see deer walking through."

Take away: Support residents in personalizing their rooms or apartments and having a space they alone have control over. If there is not much space in their room, are there other spaces residents can have access to? Create ease of access to spaces outside the LTC Community. Provide opportunity for residents to contribute to their community. Listen to resident opinions and acknowledge the value of the resident to the community.

4. How I'm Treated & How Things Work: Organizational Culture and Structure.

Although direct comments about management and practices were less common among residents who did and did not feel the setting was home, this theme was distinct from the others described above. It addresses the fact that residents and staff occupy the same space but have very different functions and relationships with that space. The setting is a workplace for staff, even those providing care in their own homes. Residents occupy the setting as their living environment. As some residents indicated, they do not "go home" at the end of the day. Residents who were interviewed wanted to be respected by staff and receive the support they needed with certain tasks. They also wanted to be seen as valuable community members with opinions and skills to contribute. Furthermore, they valued good food and responsive leadership.

Not like home. Concerns about management and practices were made most often by AL/RC and NH residents. Many decried the quality of food or food choices. To these residents, "food matters," especially when there is little variety or it "tastes like flavored cardboard." Other residents desired more respect from staff members. Residents felt disrespected when staff "treated [them] like children," "intruded" upon personal space, or were loud and disruptive. Problems with organizational structure and personal autonomy intertwined in comments that highlighted how residents felt powerless to affect their LTC setting when they needed support from staff and leadership.

"Being listened to would make it feel more like home. Management being interested in me."

Like home. For residents who did feel at home in their LTC setting, getting meaningful support from staff, like housekeeping or support with activities, contributed to a sense of home. These residents depicted a considerate staff who "go out of their way to help you," "ask you what you need," and "are available to help." Although some residents valued doing homemaking tasks for themselves, others were grateful that staff undertook these activities. As one resident put it, "I don't do my laundry or make my bed. It's like vacation." Feeling respected, or "treat[ed]... like an ordinary person, not like

a commodity to be taken care of" and "people treating you the way you want to be treated," was also an aspect of organizational culture that contributed to homeness. Residents who felt athomeness appreciated "good communication" and "the way things are done." As echoed in the discussion of autonomy, residents who felt at home noted that they could "suggest things" and feel listened to by staff and leadership. "The owner is outspoken and I can be outspoken with her," one resident in an AFH explained. Having "choices about food, activities" (and good food and activities) were also listed as contributors to homeness.

> *"I feel like I have a lot to say that they pay attention to. Like right now we are down an activities director so I am trying to help. For example, I run the candy bingo on Mondays. I was allowed to pick the prizes for that."*

Take away: Recognize power differences between residents and staff. In all encounters, staff need to treat residents as individuals worthy of respect. Include residents meaningfully in community responsibilities, activities, and decision making.

5. How I Feel and What I Think: Perceptions and Coping

Of course, residents, like all of us, come to the LTC community with a lifetime of experiences, attitudes, knowledge and skills for coping and problem solving. Within the structure of the setting, residents act with agency. These personal traits in combination with the social, physical, and organizational environment helped shape the transition of residents to the environment as well as their ability to experience home in these settings.

Not like home. Many residents did not have straightforward feelings about whether their LTC setting felt like home. The idea, that the LTC setting cannot feel like home, was one of the most frequently voiced sentiments across settings, especially for NH residents. As one resident explained, "Right now it feels as good as it can, because it can't be home." Ambivalence, or "it does and it doesn't [feel like home]" was experienced by several residents. These residents pointed out that some aspects were homelike, but others were not: my room feels like home, but outside it doesn't; my wife is here, but I can't do many of the things I like; it feels like an institution, but I still have choices. Others found that they liked where they were living, but that did not mean it was home ("It's not home, but it's satisfactory"), implying that there are aspects beyond pleasantness that constitute home. Residents also demonstrated ways that they were emotionally adapting to or accepting their living environment. Some felt that they were "doing the right thing" by leaving their home and entering LTC, especially on behalf of family. These sentiments were rare among AFH residents compared to AL/RC and NH residents.

Like home. Across all settings, some residents explained how they had adapted mentally and emotionally to see their LTC setting as home. “I decided this is where I’m going to live, might as well get used to it,” one resident explained; another shared, “You have to realize where you are and make the best of it.” Time was an important part of this process for some residents. One AFH resident explained,

> *“When I first came here it was hard because I lived alone for many years. Time. For the first year and a half it did not feel like home, but now it does.”*

Time enabled some residents to develop a feeling of familiarity with the people and environment. Others stated simply that it felt like home because “it’s where I live” or was a “roof over my head” – a sharp contrast compared to those who did not feel at home even as they acknowledged their comfort.

A few comments demonstrated how prior experiences or the circumstances of moving to LTC helped with the transition:

> *“I didn’t have a good home before moving here. There was no one around during the day, and I fell a lot. Here, it’s just peaceful, and the dogs come in the morning to lick my face and beg for food, and I just love being around them. And talk about a view! [gestures out the window].”*

For this AFH resident and others, moving into LTC represented a positive transition, which may have greatly enabled their ability to feel at home.

Discussion

How do residents describe living situations that “feel like home” compared with those that do not? Figure 1 is a compilation of the elements of home described by residents who experience their setting as home. The physical environment is both attractive and functional, which is especially important for people with disabilities. They have enough space and opportunity to have personal things that are meaningful to them and that facilitate autonomy. Easy access to outdoor space, including nature, are also part of the environment.

The physical environment also facilitates social connection and autonomy, two other components of a home. Most of those who talked about social connection as part of feeling like home spoke of meaningful relationships with staff and/or residents. Less frequent were mentions about family and friends from outside the settings. Residents talked about being supported and treated with respect and warmth. Those who felt the setting was like home also described their autonomy within the setting, especially being able to come and go as they wished and being in control of how they spent their time.

Resident characteristics of those who felt the setting was like home exhibited resilience with respect to their ability to cope with and adjust to a congregate living situation. Personal traits with respect to personality, prior life experiences as well as time in the setting were likely to support resilience. The organizational culture was also instrumental in supporting resident abilities. The organization supported staff engagement with residents, inclusion of residents in the community, and empowered residents to control their lives to the extent possible.

It is important to emphasize that many residents, although positive about aspects of the setting, indicated that it could never feel like home. Others who did not feel the setting was like home made similar statements about how the setting could not be home. These individuals, however, were also likely to describe the physical, social, and organizational environments negatively and report a lack of control over their lives.

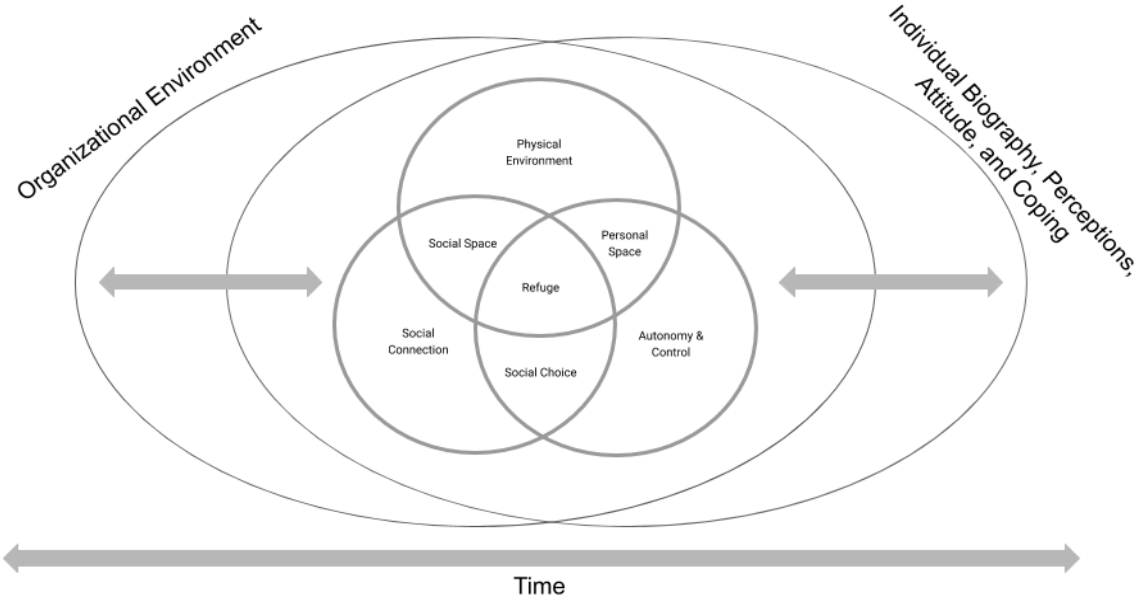


Figure 1. What Makes it Feel Like Home? **Organizational Environment:** *The LTC Organization supports resident choice and engagement; staff are supported to know residents as individuals.* **Individual Biography, Perceptions, Attitude, and Coping:** *Residents' unique experiences and personal features influence what home means to them and how they perceive the LTC setting.* **Physical Environment**: *The setting is attractive and functional. Residents have enough space and access to amenities*. **Social Environment:** *The physical space enables connection, not isolation.* **Social Connection:** *Residents have meaningful relationships within the LTC setting and/or can maintain meaningful relationships with family, friends, and pets.* **Social Choice:** *Residents access privacy or company as they desire.* **Autonomy & Control:** *Residents are primarily in control of what they do and how they spend their time.* **Personal Space:** *The physical environment enables resident-directed activities, preferences, and privacy.* **Refuge:** *The LTC setting feels like a safe, familiar place where one experiences a sense of home.* **Time:** *Generally, time enables the development of familiarity and relationships; feeling at home also becomes more important.*

How are qualitative responses to questions about "feeling like home" associated with different types of settings? (i.e., NH, AL/RC, AFH). Overall, residents in AFH were most likely to report their living situation felt like home. They were more likely to have developed relationships with the providers, had access to common living areas, and more say in how they spent their time. They were more likely to be engaged in contributing to the community.

How is "feeling like home" related to staff and administrative characteristics? From resident comments, we know that relationships with staff are frequently identified as a reason why it feels like home. In comments made by residents throughout the interviews, however, staff busyness, often related to turnover and workload, hindered the development of relationships. More analysis is needed to explore differences in resident responses in relationship to administrator characteristics.

How do resident qualitative responses relate to overall resident satisfaction? Length of stay? The qualitative comments regarding satisfaction with the setting are consistent with the quantitative data. Through the quantitative data, we know that the setting feeling like home is associated with the four outcomes that were measured in this study, including resident satisfaction. The item "does it feel like home here?" has been selected as one of the cross-setting items for the final Resident VIEW measure. Qualitative comments provide important insights into what makes a setting feel like home or not feel like home. A substantial number of residents, including those who express satisfaction with the setting, suggest that a congregate care setting can never be home. For those individuals, optimizing the elements of home identified here are critical to making the experience the best it can be. With time, those individuals may also begin to feel their setting is home.

Results: 2.B. Supporting Autonomy Through Daily Decisions in Community-Based Care (CBC) Settings

After asking residents about the importance of each item in the "Autonomy and Choice" domain, our team asked residents in assisted living, residential care, and adult foster home settings, "what is the most important decision you make here?" Nearly all of the CBC residents (n=449) provided responses to this open-ended question.

Each response was read to identify possible themes and responses were sorted according to those themes. Initial coding of the open-ended responses was completed prior to examining the item analysis responses to the "autonomy and choice" domain (see Part 1.B.(5)). Analysis of the items that comprised the domain, provided additional insight into residents' thinking about this question. As a result, codes were revised and the responses to 'what is the most important decision you make here?" were recoded. This allowed us to more fully capture residents' perspectives. Only four responses did not relate to the question and are not included in this analysis. Ten themes emerged from the process and are described below. Some responses included more than one theme and each theme was noted to capture the full meaning of the response. Based on their responses, we have listed areas where assisted living communities, residential care, and adult foster homes would be able to support decisions that are important based on residents' perspectives.

Decisions about activities meaningful to residents. Just over one in four (n=117) of the residents discussed meaningful activity inside and outside of the care setting as being the most important decision they make. Many residents made references to "how I spend my time," while others explicitly stated outings such as going to church or shopping. One resident stated, "what I watch on tv. I'm pretty flexible." Some residents described navigating transportation especially to leave the facility as an important part of decision making. For example, "calling a cab if I want to go to the store. That's the only decision I make."

Quality and personalized care. Decisions to maximize quality of care in the setting were discussed in various way. Residents described many factors that contributed to quality care from their perspectives. For example, nearly one in four (n=101) residents described decisions related to getting up or waking up from bed, diet, rehabilitation, staying in or leaving a particular setting. These decisions led to general comments about how they are treated by the staff, medication management, showering, and assistance with using the restroom. These comments emphasize the role of staff in facilitating or creating barriers to resident decision-making. One resident described their

most important decision as, “when I get up, if I need my bandages taken care, my showers. We're short-staffed...can't get mad at them for that.” Another resident stated their most important decisions were related to waking up and using the restroom. The resident stated, “I wait until they wake me up, which is about the time I wake up anyway. But sometimes I wake up before 8:15, and I have sat there on the commode, sometimes for 10-20 minutes because I already got my pajamas off and I’m just waiting for them. I have to wait because if I try to get up on my own, I’ll land on my camp.”

General autonomy. About one-fifth (n=82) residents described important decisions related to individualization and general autonomy. These decisions extended from personalizing clothing and decor to privacy. One resident stated, “my food. Being able to choose my own clothes and stuff. I don’t have to wear a uniform.” Another stated more generally, “there's always a decision I can make. All of them.”

Decisions related to food. Similarly, about one-fifth (n=79) residents described decisions related to food as the most important decision that they make in their respective care settings. These responses indicated decisions related to food choices, menu decisions, when to eat, quality of the food, and timing of the food as the most important. One resident stated, “eat the food or not- what I’ll eat. The food isn't that great- sometimes I fix my own or eat with family.” This resident explained their decision to eat as connected to the quality of the food by stating, “I wish I could [make] more decisions about the food we have. I don't like it. Some of it is inedible.”

No decisions. Sixty-six residents (15%) indicated that they did not make any decisions. Most of these residents made general comments about not making decisions, “I really don't know. There aren't many decisions I have to make here.” One resident noted how his inability to make decisions is related to his change in ability. This resident stated, “I don't make any important decisions here. That's why I’m here. My decision was coming here and giving up my freedom. I will argue if they tell me what to do, but they seldom do that.”

Communication and engagement with others. Decisions regarding communication or interaction with staff or providers, visitors, or pets as an important decision were noted by 59 residents. For example, one resident explained how communication with others impacted his meals by stating, “the most important decision is asking everyone else what their decisions are such as collaborating with other(s) to get dinner.” Other residents explained the value of choosing their friends. Another resident stated, “my choices for friends.” Additionally, one resident described how his previous experiences have impacted his communication with staff, “It's almost like being totally on my own, but I can ask for help when I need it. Sometimes I get told, “when that happens again,

push your button for help." That's hard, because I was raised to do things on my own. But it's nice to ask for help when I need it. Coming here was my choice and I have never regretted it."

Maintaining personhood. Forty-eight residents described decisions related to their personhood as being the most important decision they make. Residents generally discussed how decisions related to their quality of life, sharing their feelings, decisions related to their goals, or embodying a certain characteristic. In addition, some of these residents described decisions related to self-advocacy as important. For example, one resident stated, "if I go to the doctor or not. Not going to the emergency room if I don't want. Because I have palliative care to back me up because some of the people here, I worry won't follow my directive. It's the quality of life. Not the number of days." Another resident explained the decision to "just being myself. Not just sit here and wither up" was the most important decision they make.

Don't know. Forty-two residents responded that they didn't know what the most important decision was that they made in a particular care community. One resident said, "I've never thought about it before. I don't know."

Accepting others as decision makers. Thirty-one residents alluded to acceptance of making fewer choices, sometimes indicating their own flexibility. These residents generally described structured routines in which resident decision making was not an option, or expressed a lack of confidence in their own abilities. For example, one resident stated, "everything is the same, go to bed at the same time, eat meals at the same time. Don't really have a say to change them." Another resident described doubting their ability to make decisions by stating, "I don't really make decisions. I don't really understand most of the time so I don't know if my decisions would be good or not." Additionally, some residents stated that other people make decisions for them. One resident stated, "one is...the reason I'm here is that I was falling. I don't have the freedom to go where I want to go. I could walk to the pool, but they're not going to let me. When all this started, my daughter put me in [this] assisted living. When I went out, all I did was sign out. But I don't have that freedom here. I understand why, but I miss having freedom."

Contributing to or fully participating in the community. Twenty-one residents described decisions related to the overall structure of a community as their most important decision. For example, one resident stated," I get recycle materials ready to go out, so they recycle instead of throwing in the garbage. I look at every bin of recyclables as a tree that doesn't need to be cutdown." Other residents mentioned resident council meetings, in particular by stating, "probably with resident council and

new residents and showing them around. I like to be less responsible for different things. I also spent a lot of time doing secretarial stuff for resident council. And Saturday is the only day of the free activities and then we are all in a room without breaks, but I do them anyway. I would like to see more breaks. The other activities have a charge. They say it's only 75 cents but to me, that is a lot." Another resident explained how having a say in the administration would be an important decision by stating, "it would be nice if we had a say in who runs [this] place. We had a lady who was a real neat freak. You couldn't leave anything out. I want to live in a home, not a showroom."

Financial decisions. Twenty-one residents described financial decisions as the most important decision. Some residents mentioned finances generally, while others were more specific, such as mentioning bills or rent. One resident plainly stated, "I guess on a whole, financial." Another resident explained, "I just don't know. I guess that my money holds out."

Take away

Residents mostly make decisions about their daily lives – what to do, what to eat, and how to spend their time. A small proportion also manage their finances. This reinforces the importance of staff understanding the daily routines and ways that each resident finds as meaningful ways to live and spend their time. Staff can also explore what beyond the modest decisions that residents make would also provide meaning. Residents also had things to say about how they received support from staff, made decisions to ensure quality of life (personhood) and quality care as they defined them. Residents are living in congregate settings because they require and/or desire assistance. Residents should be engaged as full partners in teaching about and experiencing care that meets their needs as they define it. Dignity of the resident must be at the forefront.

Decisions related to community life, captured by the themes contributing to the community, communication, and engaging with others (communication), were most important to some, but account for only 15% of decisions. Most residents have a lot to offer to a community. Although some residents prefer to be by themselves (see item qualitative comment descriptions), staff should explore, with residents, ways to facilitate engagement in community life. About a quarter of the comments made were related to meaningful activities and how residents choose to spend their time. Future research may want to investigate more fully which kinds of activities, inside and outside of care settings, enhance or impact residents' quality of life. A large proportion (31%) of residents reported making no decisions, didn't know if they made decisions, or had relinquished decision making to others.

Results: 2.C. Improving Quality and the Organizational Environment

As a follow-up to the Resident VIEW item, “Do you feel this place is run well?” in the *Organizational Environment* domain, we asked participants the open-ended question, “How could this place be run better?” We conducted a thematic analysis of the N=644 responses (n=208 in AL/RC; n=186 in AFH; n=250 in NH) as described in Methods. Responses were wide ranging and although many did not have specific suggestions for improvement, the key themes emerging among those that did included: staffing, responsiveness and quality care, administrator qualities and organizational factors, the physical environment, relationships and meaningful engagement, and food/dining.

Staffing

The top suggestions from residents in assisted living, residential care, and nursing homes were centered around staffing. The number one issue reported by more than a quarter of ALRC residents (n=56) and 37.6% (n=94) of nursing home residents was that there were not enough staff or staff were too busy. Comments about staffing were often coupled with other issues that occur as a consequence of overstretched staff, such as long wait times, lack of follow-through, and little time to bond or visit with their care partners.

> *More staff. We are on a low streak right now so I know we are low. When the state was here, we had to hire temps to come in and it was much better run then.*
> – Residential care resident

> *Honey, that would go into another hour of wishing. A lot of it is just the little things that are getting sloppy and not tidy. We all know that the answer is more people. They are working double shifts. I love this place and what happened and where the breakdown was, I don't know. Some things are lovely. Like the courtyard.*
> – Residential care resident

> *More staff, better pay for current staff. These places should not be for profit.*
> – Nursing home resident

> *CNAs don't have enough time to spend with patient, or get to them in a timely manner. Same with the nurses, they want to, but can't – they're understaffed.*
> – Nursing home resident

Although a much smaller proportion of AFH residents reported staffing as an issue (10.2%), it remained the most frequent suggestion.

> *I would like to see [the owner] hire qualified people so the load on her less. She holds onto a lot of responsibilities.* – Adult foster home resident

> *I think they need more help. The caregiver who does the personal care works 11 hours a day, 5 days a week. She's in her 50s, and that's way too long for somebody to be working and be happy at the end of the day.* – Adult foster home resident

> *That's a hard one. If [the owner] had more help but she can't afford that. She doesn't have time to enjoy herself. If she wanted to make money she wouldn't do this.* – Adult foster home resident

Other staffing issues mentioned included hiring the right people who are qualified for and committed to the job, and addressing challenges related to turnover of caregivers and administrators.

> *More education and training. Decrease turnover, I don't think they are asking the right questions when interviewing people.* – Assisted living resident

> *Need to be more selective in their staff. Hire people… more professionals. Currently they hire anyone off the street. I'd rather have CNAs, because they have to pay for their training- they'll be more professional, more caring about their job, more knowledgeable.* – Residential care resident

> *Find a person who really cared about people who are in here. Every person who comes in new wants to slap a coat of paint on everything- a coat of paint don't do nothing. We need plumbing and everything else down here. Hire people who are more interested in the patients than the paycheck. I know we all work for a paycheck- but give them some incentive to do better.* – Nursing home resident

A number of residents called for higher wages for direct care workers, expressing that they are not adequately compensated for the work that they do; some noted how this contributes to staff burnout and turnover.

> *They have higher turnover of employees, especially caregivers and med techs- because they don't feel they're being treated fairly and underpaid.* -Assisted living resident

If they treated their staff with dignity and respect, paid them well, there wouldn't be as much turnover. They could make better decisions about how this place is run. – Residential care resident

That's kind of hard to answer. Mainly because we have a new administrator on the campus. I think he is going to be very good. They could have less turnover in employees which would make it easier for us, if someone was here for a while consistently. – Assisted living resident

I've never had anybody ask me anything. Am I comfortable? Am I not comfortable? They don't think about the patients because they are so busy. Staff changes often. Would be nice to have the same people. – Nursing home resident

Pay a decent wage, project ahead and not let too many people go on vacation at the same time. They need a larger staff. – Assisted living resident

What they need is caregivers that stay here instead that they work a while and then quit. And the administrator, this is the fifth administrator since living here. We had a girl here for a while and then she left. It wasn't smooth. Once the new one gets going, it'll be alright. – Residential care resident

A few talked about issues on the weekend and evenings, noting that the community is frequently short-handed. This was predominantly reported by those living in nursing homes, with only one assisted living resident mentioning weekends.

When the boss is away, they play. The weekends, it's terrible.
– Assisted living resident

When everybody goes home, there's no one in charge. They all leave at the same time, no one here for noc shift- they should endure what the rest of us have to. – Nursing home resident

Hire more people, more staff. [There is only] one person per weekend. Weekends are extremely understaffed. They just care about their bottom line. [They need] double the staff at least. -Nursing home resident

Responsiveness and quality care

One co-occurring theme with staffing was the issue of responsiveness and follow-through on requests. Many residents wanted their preferences honored, to be involved in decision-making, and to have solid communication between staff and residents.

> *When they converse with each other more and let each other know what's going on. They're very disorganized. One hand doesn't know what the other's doing. When you ask a question, you're just left there. You don't know if they're coming back or not.* – Assisted living resident

> *They could have more contact between administrators and residents, and pay attention to what we say. Feel as if they would listen and act on what we said.* – Assisted living resident

At the heart of many comments about responsiveness, there seemed to be a call for dignity and to feel that the staff and administrator truly care.

> *They need much more help. They don't have nearly enough help in any place. Decisions are made...we have a meeting each month. We talk about things we'd like to change. Mostly food, better food. It's always "we're working on it". Things never change. There are some people here who run this whole floor. We feel like second class citizens, the whole third floor. We ask for things and they never get done. We asked flowers on the tables like the second floor- it took four months. If you're in independent living this place couldn't be better. You get to assisted living and it falls apart.*

> *We'd have better response times. Sometimes I've waited an hour and a half. We could have more laughter. We definitely need that. A better attitude. If I give respect, I expect it back. I don't need to be talked down to.*

Residents noted how staff busyness at times impacted their health and safety, most frequently mentioning medication, but other care needs, such as showers.

> *I guess maybe [being] more on top of getting showers regularly. It's not that they don't want you to have them. It's just that when things get busy, it's the first thing that falls to the bottom of the list.* – Adult foster home resident

Some residents (n=23) emphasized the importance of supporting autonomy, with desires to be able to do more for themselves independently, have more privacy, and

have greater access to transportation. About half of these comments came from nursing home residents.

> *From my standpoint, the more autonomy, the better. I don't like people watching what I do. I like my freedom. For the most part, I can do that.* – Assisted living resident

Adjusting to the setting can be really challenging for many people. One resident who lived most of their life on a farm longed for the responsibility and satisfaction. They also took issue with the term “foster” for the setting.

> *Be on 10 acres and have goats and chickens. I want some more room and more responsibility to live a more full life. I want some goats to take care of and fresh eggs every morning. Also, change the name from "foster" care because the perception of that is bad.* – Adult foster home resident

Administrator qualities and organizational factors

Some residents (n=42) called for administrators to be more involved, more hands on, and more authentic. These comments were most common among assisted living and residential care residents, with about 9.6% of AL/RC responses discussing administrator qualities. These comments also co-occurred with those about responsiveness, calling for administrators to be more organized and effective.

> *[The administrator] could be more hands on, greet residents and others more often and be more aware of residents as people and environment. There are dead roses, safety concerns, and she doesn't notice them.* – Residential care resident

> *If administrator had more association with residents – gives talk and leaves abruptly, no chance for question and answer.* – Assisted living resident

Residents also noted the role of the management company or owner, which have different meanings in the various care contexts.

> *A little bit better with communication staff and management.* – Adult foster home resident

> *We are in transition...we have a new manager. You kind of have to wait and see. Our last manager said "oh, I’ll help with that." and would never do a dang thing.*

How? I'm not sure. We get the impression they can't do anything until corporate decides. – Residential care resident

Physical environment

Some residents had suggestions about the physical environment at the community and these often co-occurred with discussion of follow-through, responsiveness, and the role of the administrator. The majority of remarks about the physical environment were centered around the need for maintenance and general upkeep for a clean and safe space. Residents also talked about their desires for more personal space, especially in settings where they were more likely to have a shared room. This was also related for a desire for a more peaceful environment, with some comments about excessive noise. There were also a few comments about the need for more accessibility features and for inviting common spaces, most notably outdoor areas.

Perhaps a better outdoor setup. The dryer vent opens into the back patio and the detergent/softener fragrance can be a bit too much. Not much sheltered space to sit outside when it rains.

Relationships and meaningful engagement

A small number of residents across all settings (n=29) talked about how their experience could be improved if they had better relationships with staff, other residents, family and friends, or pets. They expressed the desire to engage with staff outside of their care duties, but often coupled those comments with caveats indicating acceptance and coping (e.g., “They do their best.”)

More conversation. I'm lonely most of the time. – Adult foster home resident

Maybe more personal contact, interactions...but everything else is fine. The meals are good, it's clean, it's consistent. – Adult foster home resident

Having admin/staff build rapport with residents, take trips outside of the facility. – Assisted living resident

Some were dissatisfied with other residents living at the community. Some didn’t feel like they could relate to or connect with others, and some had negative views toward people with behavioral health needs.

Get a few people more my age to live here. There aren't a lot of people my age to associate with. – Residential care resident

Get rid of the beast [another resident]. She screams, morning, noon, and night. She has abused everyone who works here, calls them nasty names. – Adult foster home resident

People who are really mentally unstable. They should be in certain section, not mixed in. Hard when you have your door open, someone screaming. – Nursing home resident

A similar proportion of residents across settings (n=24) made comments about activities, engagement, and socialization. The most common request was for more outings and meaningful activities that they actually want to do.

Listen to the residents more and really take it to heart, instead of just passing the buck. Take into consideration the range of ages that are in here. Bingo is fine once in a while, but not everybody likes bingo. In fact, a lot of older people don't. – Nursing home resident

One person noted the value of encouraging people to engage:

More encouragement for people who stay in their room, get them out to go to various programs. – Assisted living resident

Another remarked the intersection between activities and social engagement with the desire for more autonomy and follow-through from staff:

The access, social life, care, help arranging your room, it all could be better… I think the thing that frustrates me the most is the lack of the social activities and how I can't go outside without their help. Sometimes they will offer to take me somewhere, but then they won't. They need to follow through on what they say. – Adult foster home resident

Food and dining

Aside from staffing-related issues, the other top recommendations from residents across settings had to do with food and dining, although this was a lot less common for adult foster home residents (5.4%) than it was for AL/RC (15.4%) and NH (12%) residents. Participants called for better tasting foods, more variety and options, different meal times, and for requests and dietary preferences to be honored.

Well, I am not always pleased with the food, but they try. I don't always like what they have on the menu. – Assisted living resident
Kitchen, number one. The food becomes more important than anything in senior's life. We wait for the food, if we are served the same thing over and over again, we don't like it. We get tired of it. – Assisted living resident

They are all pushed but I do believe, I'll tell you what happens. They forget some of my food items, like honey with my tea. Sometimes the food served here is cold- they try. They also forget to put things on my tray. Inefficiency in the kitchen is my only problem. – Residential care resident

I don't really know. Change the food a bit… it's good food, but it's like anything else. Sometimes you just want something different. Some things you like and somethings you don't. – Adult foster home resident

No suggestions

A large proportion of respondents (43% overall) did not have suggestions for improvement. Among those, most expressed general satisfaction or did not provide commentary. This was the most common response among AFH residents, with 58.6% reporting that they were content or couldn't think of anything that could be improved. In comparison, only about one-third (33.6%) of nursing home residents and 40.9% of ALRC residents offered no suggestions for improvement. Some felt "unqualified" to comment or that it wasn't their responsibility (e.g., "I wouldn't know. That's their work, not mine.").

Don't think it could be run better. I like living here. It's excellent. – Assisted living resident

I wouldn't know. They're all run the same. – Residential care resident

Nothing, great place to be in, we all get along. We do things together. – Adult foster home resident

I don't think it could because they have a lot of staff here and they are kind and gentle. They make sure I have things my way. – Nursing home resident

My mother stayed in another [community in the same company] and it was not well run. I was nervous about coming here, but this has been a four-star hotel.

– Nursing home resident

I think they do a good job, but there is always room for improvement. That's all I'll say. – Adult foster home resident

Take away

Staffing is a major issue. Residents know it is a challenge to recruit and retain staff, but from their experiences, low staffing means long wait times, lack of follow-through, poorer care, and difficulty forming relationships. As we saw in the item qualitative analysis, staffing issues are related to low expectations with respect to care, forming bonds, and, for those with physical disabilities, navigating their space and engaging in meaningful activities.

Hiring the right people defined as those who are qualified and committed to the job speaks to the importance of staff recruitment procedures, but also speaks to the need for ongoing training, staff development, and coaching supervision. This is particularly true in areas of staff interaction with residents – being able to "treat residents like people," get to know them individually, and personalizing their care while completing job tasks. Some residents recognized systemic issues of direct care workers' wages as a factor in recruitment and job turnover. Residents value an administrator or owner who is present and visibly engaged with staff and residents. Some residents found that the physical environment could be improved by providing more personal space (e.g., private rooms), maintaining common areas, and having outdoor space that could be accessed without relying on staff, is easily navigable, and provides sheltered space.

Low staffing was often coupled with concerns about quality of care – including the lack personalized care. This includes responsiveness, demonstrating caring, and following through. Staff busyness means that things like showers do not get done. Many residents stressed the importance of an organizational environment where they were full partners in planning, organizing, and supervising their own care. Although AFH residents generally had fewer suggestions for improvement than residents in other settings, it is important to emphasize that residents in all settings made suggestions for improvement and even as other residents across those same settings expressed contentment with the organizational environment.

Next steps

Additional analysis is needed to learn more about the residents who had no suggestions for improvement. For those with positive comments, what was the characteristic of the

setting? What were the characteristics of residents who were satisfied with the setting as is (e.g., length of stay, quality indicators, quality of life, social connection, cognitive status)? How did these residents respond overall to the Resident VIEW? These same questions need to be explored for those who said they did not know or chose not to answer the question.

Discussion and Next steps

The Resident VIEW projects included interviews with nearly 700 residents living in 32 NH, 31 AL/RC and 150 AFH. Results from the analysis to validate the Resident VIEW are presented below for each of the project's research questions. We conclude with a discussion of next steps in analysis and for using the Resident VIEW to improve care of those living in long-term care residential settings.

1. **What are the best items for predicting key outcomes, including quality of life (QOL), quality of care (QOC), and resident satisfaction?**

Seven items reflecting seven of the eight domains of person-centered care met criteria for inclusion in the short form of the Resident VIEW. This meant that they met criteria in all three settings (NH, AFH, AL/RC). These items are:

1. Does this place feel like home? *(Physical environment)*
2. Do you do things you care about? *(Meaningful activity)*
3. Do the people who work here take the time with you that you need?[a] *(Personalized care)*
4. Do the people who work here make you feel comfortable asking for help?[a] *(Personalized care)*
5. Do the people who work here know how you like to spend your time? *(Knowing the person)*
6. Do the people who work here laugh with you? *(Relationship with staff)*
7. Do the people who work here have a good attitude? *(Organizational environment)*

[a]Note: No items met criteria of sufficient evidence for inclusion for personalized care across all settings. However, these Items had sufficient evidence for inclusion across 2 settings, and ambiguous support in one setting for personalized care. No items for the domain *autonomy and choice* met these standards for inclusion.

Additional items listed below (Research question 4) met the criteria for inclusion in specific settings and can be used in combination with the seven items presented above.

2. **How do residents respond to individual items of the Resident VIEW? That is, which items appear to resonate most? Which items are confusing? Which items are difficult to answer?**

In general, the items of the Resident VIEW resonated with most participants. Some residents had difficulty with the concept of rating "importance" and instead would describe their experience. With some coaching and reminders, most participants were

able to understand and provide their opinions. This was especially true for items in the "Personalized Care" domain, which most residents felt were very important.

Very few residents, usually no more than five, would express confusion about an item. However, some did not find some items to be relevant. This occurred with some of the items in Physical Environment, Meaningful Activity, and Personalized Care domains. For example, those without need for support for care related to ADL needs (usually in AL/RC) were not sure how to answer the questions, because at the time those items were not important to them and they did not experience them because they did not need them.

Overall, responses to the Resident VIEW items showed variation across residents. Some residents would find an item to be very important and other residents would not. Examples include items about being around animals, being outside, or sharing things in common with the people who worked in the setting. Similarly, some residents would experience a PCC practice and others would not. This included doing things with other residents, having care partners let them know how long they would have to wait, and having a say in who helped them. This suggests that the items can be used to distinguish preferences and experiences among residents.

Responses to some items indicate the items may be problematic for assessing PCC practices. For example, in the domain of Meaningful Activities, "doing things for fun" did not resonate as much as "doing things you care about." "Having fun" seemed an odd phrase to several residents. Similarly, the "sharing your wisdom" item was often met with laughter, *"what wisdom?"* "Having a purpose" seemed to be something internal to the person rather than something generated by the setting. At the same time, comments from some residents illustrate how organizational practices can facilitate or hinder feelings of purpose or usefulness. As a final example here, we asked residents whether it was important for the people who worked in the setting to "understand what it is like for you to live here" and whether the staff did understand. A large proportion of residents indicated that staff could not understand because they did not have the life experience to understand, whether because of age or lack of personal experience with disability.

Staff busyness emerged as a factor in residents' ratings of importance. We found evidence through many comments that residents will lower ratings of importance because the item reflects a PCC practice they perceive that they cannot experience. For example, many residents had no expectations that staff would spend time just talking and being with them, or that staff could listen to them share stories about their lives. This is not to say that these practices were truly unimportant to a subset of residents, but it is also true that some residents would say things like, "it would be very important if it could happen."

3. **How well does the Resident VIEW perform for people living with cognitive impairment?**

We did not screen out residents for cognitive impairment unless they were unable to speak. If a resident expressed interest in participating and trained interviewers judged the person understood the informed consent process, we proceeded with interviews. As described earlier, interviewers would sometimes conclude the interviews if residents were not able to track questions or became uncomfortable with the interviews. For the most part, these interviews were concluded because of cognitive impairment. At the same time, many residents with mild to moderate levels of cognitive impairment were able to complete the interviews and the interviewers felt confident in their responses. As has been demonstrated in other research, most residents with significant cognitive impairment can state their preferences for services as well as their perceptions of services.

4. **Is there a common measure that performs well in all settings or are separate measures needed for each LTC setting type? That is, which items, if any, perform well across all types of settings? Which items are unique to each setting?**

As describe above (Research question 1), seven items performed well in all settings. We also found additional items that performed well in one or two settings only. More research is needed to determine whether all or a subset of items will work best to evaluate and improve PCC practices in each setting.

<u>Additional items for Nursing home residents</u>

1. Is your room arranged and decorated the way you want it? *(Physical environment)*
2. Is it peaceful here? *(Physical environment)*
3. Do you feel you have a purpose? *(Meaningful activities)*
4. Do the people who work here know who is important to you? *(Knowing the person)*
5. Do you have privacy when you want it? *(Autonomy and choice)*
6. Do you do things for yourself when you want to? *(Autonomy and choice)*
7. Do you feel free to express your opinions about the things you do not like here? *(Autonomy and choice)*
8. Are the people who work here gentle when they are helping you? *(Personalized care)*
9. Do the people who work here show that your needs are important to them? *(Treated like a person)*
10. Do the people who work here answer your questions? *(Treated like a person)*
11. Do the people who work here have time to help you when you need it? *(Organizational environment)*

Additional items for Adult Foster Care Residents

1. Can you easily get around outside of your room? *(Physical environment)*
2. Do you spend your time the way you want it? *(Autonomy and choice)*
3. Do you feel you have a purpose? *(Meaningful activities)*
4. Do the people who work here take into account your health needs? *(Personalized care)*
5. Do the people who work here know the kinds of things you are interested in? *(Knowing the person)*
6. Do the people who work here know what makes a good day for you? *(Knowing the person)*

Additional items for Assisted Living and Residential Care Residents

1. Do you feel welcome in areas outside of your room? *(Physical environment)*
2. Do the people who work here know how you like to have things done? *(Knowing the person)*
3. Do the people who work here know what you worry about? *(Knowing the person)*
4. Do you spend your time the way you want to? *(Autonomy and choice)*
5. Do the people who work here show that your needs are important to them? *(Treated like a person)*
6. Can you talk to the administrator when you have a problem? *(Organizational environment)*
7. Do the people who work here have time to help you when you need it? *(organizational environment)*

5. What is the relationship between Resident VIEW ratings and facility characteristics (e.g., facility type, quality, size, Medicaid population), administrator (e.g., tenure, educational background), and staff (e.g., job satisfaction, assessment of person-directed care)?

As shown through analysis of quantitative and qualitative data reported for each item of the Resident VIEW, residents often rated areas of greatest importance and experiences with PCC practices differently based on the setting type in which they lived. For example, compared to residents in other settings, NH residents rated privacy as having greater importance while AL/RC residents rated getting around outside their rooms and doing things with other residents as more important. Overall, those living in AFH settings had lower levels of unmet need with respect to personalized care and they were more likely to experience staff who knew them, feel they were treated like a person, and to rate relationships with staff more positively. In contrast, NH residents had the highest levels of unmet need across all domains. Overall, residents were most likely to experience PCC in AFH, least likely in NH, with those in AL/RC somewhere in between.

Beyond setting type, we have not yet conducted the analysis to determine the association of the Resident VIEW ratings with various organizational or leadership characteristics. As described below in discussion about next steps, we will be analyzing interview data from leadership and linking those results to Resident VIEW responses. A manuscript describing staff perceptions of PCC practices and the work environment in NH is nearing completion. In the future we will compare staff and resident responses to PCC items within each setting.

6. **How do Resident VIEW interviewer assessments of quality compare to other quality indicators (i.e., 5-star rating, number of deficiencies)? How can qualitative data provided by interviewers augment understanding of quality as measured by quality indicators?**

Although we have data to do these analyses, we have not yet been able to conduct those analyses. This question will be answered in later publications.

7. **Feeling like home:**
    f. **What do residents say makes a residential setting feel like home? Not feel like home?**

Residents who said the setting felt like home described the physical environment and personal space, social connections, and autonomy and choice. The physical environment in a place that feels like home is both attractive and functional; this is especially important for people with disabilities. Residents who feel at home also have enough space and have personal things that are meaningful to them and that facilitate their autonomy. Easy access to outdoor space, including nature, are also part of the environment.

The physical environment also facilitates social connection and autonomy, two other components of a home. Most of those who talked about social connection as part of feeling like home spoke of meaningful relationships with staff and/or residents. Less frequent were mentions about family and friends from outside the settings. Residents talked about being supported and treated with respect and warmth. Those who felt the setting was like home also described their autonomy within the setting, especially being able to come and go as they wished and being in control of how they spent their time.

Resident characteristics of those who felt the setting was like home exhibited resilience with respect to their ability to cope with and adjust to a congregate living situation. Some of the qualitative data suggest that personal traits with respect to personality, prior life experiences as well as time in the setting were likely to support resilience. The

organizational culture was also instrumental in supporting these personal traits and abilities. In a place that felt like home, the organization supported staff engagement with residents, inclusion of residents in the community, and empowered residents to control their lives to the extent possible.

It is important to emphasize that many residents, although positive about aspects of the setting, indicated that it could never feel like home. However, others who did not feel the setting was like home and stated that it could not be home, described the physical, social, and organizational environments negatively and reported a lack of control over their lives.

g. What can residential settings do to help residents feel more like home?

In short, organizations can focus on what home means to residents in their setting and identify practices and environmental characteristics that are facilitating or serving as barriers to feeling at home. Organizational systems, including staff training, should promote practices found to be supportive of home. The residents who shared their thoughts and experiences through this research provide important guidelines to shape these efforts.

h. How is "feeling like home" related to facility, staff (e.g., job satisfaction, assessment of person-centered care), and administrative characteristics?

Our analyses of organizational and resident characteristics showed that residents living in rural settings, those with longer length of stay, and those who paid primarily using Medicaid funds were significantly more likely to report feeling at home. In contrast, those residents who shared a room with others were significantly less likely to report that they did. Age, gender, and race/ethnicity of resident was not significantly associated with reporting feeling like home. As noted above, we were able to collect staff data from a smaller subset of AFH and AL/RC staff. As such, we have not yet been able to conduct the analyses to examine feelings of home related to staff characteristics and staff perceptions of PCC practices.

i. How are qualitative responses to questions about "feeling like home" associated with different types of settings? (i.e., NH, AL/RCF, AFH)

Overall, AFH residents were most likely to report their living situation felt like home. They were more likely to have developed relationships with the providers, had access to

common living areas, and had more say in how they spent their time. They were more likely to be engaged in contributing to the community. The NH residents were the least likely to describe the setting as home and experienced the most restrictions in terms of personal space, autonomy, and social relationships.

8. **Important decisions**
    a. **What do residents say are the most important decisions they make at the facility?**

Ten themes were identified through resident comments about their most important decisions. Many decisions are related to residents' daily lives, including what to eat and how they spend their time. Other residents described decisions they made to direct their care, guiding and teaching staff how to provide support that they need in the way that they want it. Decisions about engaging in the community, whether with other residents or with staff, were central to some residents. At the same time, nearly one-third of the residents did not know what decisions they made or could not identify them. More analysis is needed to understand more about the characteristics of those who do and do not make decisions as well as the characteristics of the settings in which they live.

    b. **How do these responses relate to level of resident reported autonomy, quality indicators, overall satisfaction, and quality of life?**

The responses to the question about important decisions residents made, were consistent with the items in the Autonomy and Choice domain. Of the 9 items analyzed for this report, NH residents identified more unmet need – in seven of the nine items – compared to those living in AFH and AL/RC settings. Items most predictive of outcomes of interest (i.e., recommending the place, satisfaction, quality of life, and depressive symptoms) across settings were "feel free to express your opinions about things you do not like" and "spend your time the way you want to." Analysis has not yet been done to identify the association between important decisions identified by residents and quality indicators for the setting in which they live.

9. **Improving organizations**
    a. **What do residents suggest as ways for improving the way facilities are run?**
    b. **How do suggestions relate to characteristics of the facility (e.g., quality, size, Medicaid population), administrator (e.g., tenure, educational background), and staff (e.g., job satisfaction, assessment of person-directed care)?**

When asked how the place could be run better, staffing emerged as a major theme and was at the center of resident recommendations for improvement. Residents know it is challenging to recruit and retain staff, but from their experiences, low staffing means long wait times, lack of follow-through, poorer care, and difficulty forming relationships. As we saw in the qualitative analysis of individual items, staffing issues are related to low expectations with respect to care, forming bonds, and, for those with physical disabilities, navigating their space and engaging in valued activities.

Hiring the right people is related to staffing and is defined as hiring those who are qualified and committed to the job. This speaks to the importance of staff recruitment procedures, but also speaks to the need for ongoing training, staff development, and coaching supervision. The need for training within the context of multiple job responsibilities is particularly urgent in areas of staff interaction with residents. Effective and caring staff need to have the necessary skills to “treat residents like people” and get to know residents individually so that they can personalize their care while completing job tasks.

Some residents recognized systemic issues of direct care workers’ wages as a factor in recruitment and job turnover.

Residents value an administrator or owner who is present and visibly engaged with staff and residents.

Some residents found that the physical environment could be improved by providing more personal space (e.g., private rooms), maintaining common areas, and having outdoor space that can be accessed by residents without relying on staff. Furthermore, outdoor space should be easily navigable and provide sheltered space.

Low staffing was often coupled with concerns about quality of care – including the lack personalized care. This includes deficits in responsiveness, demonstrating caring, and following through on resident requests. Staff busyness means that things like showers do not get done. Many residents stressed the importance of an organizational environment where they were full partners in planning, organizing, and supervising their own care.

Although AFH residents generally had fewer suggestions for improvement than residents in other settings, it is important to emphasize that residents in all settings made suggestions for improvement, even as other residents across those same settings expressed contentment with the organizational environment.

Next steps

Publications. One paper has been published, one submitted, and two other manuscripts are in preparation.

- *Diana Cater, Ozcan Tunalilar, Diana White, Serena Hasworth, & Jaclyn Winfree. (2021).* "Home is home:" Exploring the meaning of home across long-term care settings. *Journal of Aging and Environment.* *https://doi.org/10.1080/26892618.2021.1932012*.
- *Person-Centered Care Practices in Nursing Homes: Staff Perceptions and Work Environment,* Sarah Dys, PhD candidate, first author. (Submitted August 2021). This paper examines NH staff perceptions of person-centered care, individual and NH characteristics, and the association with job satisfaction and organizational commitment.
- *Is Asking about Importance Important?* Ozcan Tunalilar, PhD, and co-investigator is first author. This manuscript examines the added value of asking residents whether a specific issue/service is important to them alongside whether they experience it in predicting their overall well-being.
- *The Resident VIEW in Community-Based Care Residential Settings.* This paper is a companion to a previous publication, *The Resident VIEW In Nursing Homes,"* that was published in the *Gerontology and Geriatric Medicine* in 2019.

***Another Look,* The Donaghue Foundation.** As described above, this project yielded a wealth of data that have a lot to teach us but have not been analyzed fully. The Research Team has received a two-year grant from The Donaghue Foundation through their "Another Look" program which supports secondary data analysis. This grant enables us to continue data analysis to answer questions we were not able to answer for this report. Data to be analyzed include interviews with administrators, providers, and nurse leaders; interviewer notes about each setting; administrative data including quality ratings; and staff surveys. Additional resident data to be analyzed include measures of physical functioning, cognitive status, and social support. Additional qualitative analysis of resident comments will be completed that includes NH resident data. The research questions guiding our analysis include:

- To what extent do resident, provider, interviewer, and regulatory perspectives of process and outcome measures related to quality of life (QoL) and quality of care (QoC) differ across types of LTC settings?

- What is the role of context (e.g., setting, rural/urban, ownership type, quality ratings) in explaining observed differences and similarities in components of quality from different points of view?
- What are the implications of resident perspectives for organizational system change, including staff training and guidelines for personalizing and improving care?

The Resident VIEW and Quality Improvement. Oregon's Quality Care Fund and funds from the CMS Civil Monies Penalty program supported development of the Resident VIEW. As revealed in this report, residents provided a wealth of information that should be used to inform practice. We have developed a short form of the Resident VIEW that include items that can be used across settings as well as setting-specific items. This short form has the potential to be easily administered and provide important information to providers and to DHS about the state of PCC in Oregon's LTC system and to identify areas for improvement.

The final phase of the development of the Resident VIEW short form requires a series of pilot projects. Examples include:

- Use the Resident VIEW to identify and measure success of various intervention projects to improve quality of care and quality of life.
- Testing the feasibility of using the short form measure in Memory Care Communities
- Using technology to collect resident responses (e.g., tablets)

References

Anderson, K., Bird, M., MacPherson, S., & Blair, A. (2016). How do staff influence the quality of long-term dementia care and the lives of residents? A systematic review of the evidence. *International Psychogeriatrics, 28*, 1263-1281. doi:10.1017/S1041610216000570

Anderson, R. A., Corazzini, K. N., & McDaniel, Jr. R. R. (2004). Complexity science and the dynamics of climate and communication: Reducing nursing home turnover. *The Gerontologist, 44,* 378-388.

Banaszak-Holl, J. Castle, N.G., Lin, M.K., Shrivastwa, N., & Spreitzer, G. (2013). The role of organizational culture in retaining nursing workforce. *The Gerontologist, doi:10.1093/geront/gnt129*

Bergland, A., & Kirkevold, M. (2005). Resident-caregiver relationships and thriving among nursing home residents. *Research in Nursing & Health, 28,* 365-375. https://doi-org.proxy.lib.pdx.edu/10.1002/nur.20097

Bowers, B.J., Fibich, B., & Jacobson, N. (2001). Care-as-service, care-as-relating, care-as-comfort: Understanding nursing home residents' definitions of quality. *The Gerontologist, 41,* 539-545.

Bowers, B., Nolet, K., Roberts, T., Esmond, S. (no date). *Implementing change in long-term care: A practical guide to transformation.* Supported by The Commonwealth Fund, [Grants #20020672; 9/1/02-12/31/03& #20070611; 6/1/07-9/1/07]

Burack, O. R., Reinhardt, J. P., & Weiner, A. S. (2012). Person-centered care and elder choice: A look at implementation and sustainability. *Clinical Gerontologist*, *35*, 390-403.

Burke, R. E., & Werner, R. M. (2019). Quality measurement and nursing homes: Measuring what matters. *British Medical Journal Quality & Safety, 28*. 520-523. doi:10.1136/bmjqs-2019-009447

Calkins, M. P. (2018). From research to application: Supportive and therapeutic environments for people living with dementia. *The Gerontologist, 58, Supplement 1*, S114-S128. https://doi.org/10.1093/geront/gnx146

Castle, N. G., & Ferguson, J. C. (2010). What is nursing home quality and how is it measured? *The Gerontologist, 50,* 426-442.

Cassie, K. M., & Cassie, W. E. (2012). Organizational and individual conditions associated with depressive symptoms among nursing home residents over time. *The Gerontologist, 52,* 812-821. *doi:10.1093/geront/gns059*

Centers for Medicare and Medicaid, Minimum Data Set (MDS) 3.0. (https://www.in.gov/isdh/files/Section_F_MDS_3.0.pdf)

Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis.* Sage Publications: Thousand Oaks, CA.

Chaudhury, H., Cooke, H. A., Cowie, H., & Razaghi, L. (2018). The influence of the physical environment on residents with dementia in LTC settings: A review of empirical literature. *The Gerontologist, 58,* e325-e337. doi:10.1093/geront/gnw259.

Conney, A. (2011). 'Finding home': A grounded theory on how older people 'find home' in long-term care settings. *International Journal of Older People Nursing, ??,* 188-199.

Corbin, J. M., & Strauss, A. (1990). Grounded theory research: Procedures, canons, and evaluative criteria. *Qualitative Sociology, 13*(1), 3–21. https://doi.org/10.1007/BF00988593

Crandall, L. G., White, D. L., Schuldheis, S., & Talerico, K. A. (2007). Initiating Person-Centered Care Practices in Long-Term Care Facilities. *Journal of Gerontological Nursing*, *33*(11), 47–56. https://doi.org/10.3928/00989134-20071101-08

Drageset, J., Haugan, G., Tranvåg, (2017). Crucial aspects promoting meaning and purpose in life: perceptions of nursing home residents. *BMC Geriatrics, 17,* 254. DOI 10.1186/s12877-017-0650-x

Ejaz., F. K.., Noelker, L. S., Menne, H. L., & Bagaka, J. G. (2008). The impact of stress and support on direct care workers' job satisfaction. *The Gerontologist, 48,* Special issue 1, 60-70.

Eijkelenboom, A., Verbeek, H., Felix, E., & van Hoof, J. (2017). Architectural factors influencing the sense of home in nursing homes: An operationalization for practice. *Frontiers of Architectural Research*, *6*(2), 111–122. https://doi.org/10.1016/j.foar.2017.02.004

Frankl, V. (1963). *Man's search for meaning.* Beacon Press: Boston

Galvin, K., & Todres, L. (2011). Kinds of well-being: A conceptual framework that provides direction for caring. *International Journal of Qualitative Studies on Health and Well-Being*, *6*(4), 10362. https://doi.org/10.3402/qhw.v6i4.10362

Gillsjö, C., Schwartz-Barcott, D., & von Post, I. (2011). Home: The place the older adult cannot imagine living without. *BMC Geriatrics*, *11*, 10. https://doi.org/10.1186/1471-2318-11-10

Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research.* Aldine de Gruyter.

Gray, C., & Farrah, K. (2019). *Homelike Models in Long Term Care: A Review of Clinical Effectiveness, Cost-Effectiveness, and Guidelines*. Canadian Agency for Drugs and Technologies in Health. http://www.ncbi.nlm.nih.gov/books/NBK545819/

Groenendaal, M., Loor, A., Trouw, M., Achterberg, W. P., Caljouw, M.A.A. (2019). Perspectives of healthcare professionals on meaningful activities for persons with dementia in transition from home to a nursing home: An explorative study. *Healthcare, 9*, 98. doi:10.3390/healthcare7030098.

Hartigen, I. (2007). A comparative review of the Katz ADL and the Barthel Index in assessing the activities of daily living of older people. *International Journal of Older People Nursing, 2,* 204-212.

Hoeffer, B., Talerico, K. A., Rasin, J., Mitchell, C. M., Stewart, B. J., McKenzie, D., Barrick, A. L., Rader, J., & Sloane, P. D. (2006). Assisting cognitively impaired nursing home residents with bathing: Effects of two bathing interventions on caregiving. *The Gerontologist, 46,* 524-532.

Hunter, P. V., Hadjistavropoulos, T., Thorpe, L., Lix, L. M., & Malloy, D. (2016). The influence of individual and organizational factors on person-centred dementia care. *Aging and Mental Health, 20,* 700-708.

Joseph, A., Choi, Y-S, & Quan, X (2016). Impact of the physical environment on residential health, care and support facilities (RHCSF) on staff and residents: A systematic review of the literature. *Environment and behavior, 48,* 1203-1241. DOI: 10.1177/0013916515597027

Kane, R. A., Kane, R. L., Illston, L. H., Nyman, J. A., & Finch, M. D. (1991). Adult foster care for the elderly in Oregon: a mainstream alternative to nursing homes? *American Journal of Public Health, 81,* 1113-1120. *doi/abs/10.2105/AJPH.81.9.1113*

Kane, R. A., Kling, K. C., Bershadsky, B., et al. (2003). Quality of life measures for nursing home residents. Journal of Gerontology, 58A, 240–248.

Kane, R. A., Lum, T. Y., Cutler, L. J., Degenholtz, H. B., & Yu, T. C. (2007). Resident Outcomes in Small-House Nursing Homes: A Longitudinal Evaluation of the Initial Green House Program. *Journal of the American Geriatrics Society*, *55*(6), 832-839.

Kitwood, T. (1997). *Dementia reconsidered: The person comes first.*
London: Open University Press.

Koehn, S. D., Mahmood, A. N., & Stott-Eveneshen, S. (2016). Quality of life for diverse older adults in assisted living: The centrality of control. *Journal of Gerontological Social Work, 59,* 512-536. http://dx.doi.org/10.1080/01634372.2016.1254699.

Koren, M. J. (2010). Person-Centered Care For Nursing Home Residents: The Culture-Change Movement. *Health Affairs*, *29*(2), 312–317. https://doi.org/10.1377/hlthaff.2009.0966

Lawton, M. P., & Nahemow, L. (1973). Ecology and the aging process. In C. Eisdorfer & M. P. Lawton (Eds.), The psychology of adult development and aging (p. 619–674). American Psychological Association. https://doi.org/10.1037/10044-020

Logsdon, R. G., Gibbons, L. E., McCurry, S. M., & Teri, L. (2002). Assessing quality of life in older adults with cognitive impairment. *Psychosomatic medicine*, *64*(3), 510-519.

Lustbader, W. (2014). Fostering culture change: What can social workers do? In A. S. Weiner & J. L. Ronch (Eds.). *Models and pathways for person-centered elder care. (pp.* 397-411). Baltimore: Health Professions Press.

Lyons, S. S. (2010). How do people make continence care happen? An analysis of organizational culture in two nursing homes. *The Gerontologist, 50,* 327-339.

Mansbach, W. E., Mace, R. A., Clark, K. M., & Firth, I. M. (2017). Meaningful activity for long-term care residents with dementia: A comparison of activities and raters. *The Gerontologist, 57,* 461-488.

Marsden, J. (2001). Chapter 6 A Framework for Understanding Homelike Character in the Context of Assisted Living Housing. *Journal of Housing For the Elderly*, *15*(1–2), 79–96. https://doi.org/10.1300/J081v15n01_07

Martínez, T., Suárez-Álvarez, J., Yanguas, J., Mu˜niz, J. (2016). The person centered approach in gerontology: New validity evidence of the staff assessment person-directed care questionnaire. *International Journal of Clinical and Health Psychology. http://dx.doi.org/10.1016/j.ijchp.2015.12.001*

McCormack B., Roberts, T., Meyer, J., Morgan, D., & Boscart V. (2012). Appreciating the 'person' in long-term care. *International Journal of Older People Nursing, 7,* 284-294. doi:10.1111/j.1748-3743.2012.00342.x

McGilton, K. S., Sidani, S., Boscart, V. M., Guruge, S., & Brown, M. (2012). The relationship between care providers' relational behaviors and residents' mood and behavior in long-term care settings. *Aging & Mental Health, 16,* 507-515. https://doi.org/10.1080/13607863.2011.628980

McGilton, K.S., & Boscart, V.M. (2007). Close care provider-resident relationships in long-term care environments. *Journal of Clinical Nursing, 16,* 2149-2157. *https://doi-org.proxy.lib.pdx.edu/10.1111/j.1365-2702.2006.01636.x*

Miller, S. C., Schwartz, M. L., Lima, L. C., Shield, R. R., Tyler, D. A., Berridge, C. W., Gozalo, P. L., Lepore, M. J., & Clark, M. A. (2018). The prevalence of culture change

practice in US nursing homes: Findings from a 2016/2017 nationwide survey. *Medical Care, 56,* 985-993.

Milte, R., Shulver, W., Killington, M., Bradley, C., Ratcliffe, J., & Crotty, M. (2016). Quality in residential care from the perspective of people living with dementia: The importance of personhood. *Archives of Gerontology and Geriatrics, 63,* 9-17. http://dx.doi.org/10.1016/j.archger.2015.11.007

Nasreddine, Z. S., Phillips, N. A., Bedirian, V., Charbonneau, S., Whitehead, V., Collin, I., Cummings, J. L., & Chertkow, H. (2005). The Montreal cognitive assessment, MoCA: A brief screening tool for mild cognitive impairment. *Journal of the American Geriatrics Society, 53,* 695-699.

NASUAD & HSRI (2017). *National Core Indicators: Aging and Disability Adult Consumer Survey.* 2015-2016 National Results. National Association of States United for Aging and Disabilities, and Human Services Research Institute.

National Quality Forum (2020, July). *Person-centered planning and practice.* Final Report. Report to the Department of Health and Human Services under contract HHSM-500-2017-00060I, 75FCMC19F0001.

Rader, J. (1995). *Individualized dementia care*. New York: Springer.

Rijnaard, M. D., van Hoof, J., Janssen, B. M., Verbeek, H., Pocornie, W., Eijkelenboom, A., Beerens, H. C., Molony, S. L., & Wouters, E. J. M. (2016). The Factors Influencing the Sense of Home in Nursing Homes: A Systematic Review from the Perspective of Residents. *Journal of Aging Research*, *2016*, 1–16. https://doi.org/10.1155/2016/6143645

Roberts, T.J. (2018). Nursing home resident relationship types: What supports close relationships with peers & staff? *Journal of Clinical Nursing, 27,*4361-4372*.*

Saliba, D., DiFilippo, S., Edelen, M. O., Kroenke, K., Buchanan, J., & Streim, J. (2012). Testing the PHQ-9 interview and observational versions (PHQ-9 OV) for MDS 3.0. *Journal of the Medical Director Association, 13,* 618-625.

Scales, K., Lepore, M., Anderson, R. A., McConnell, E. S., Song, Y., Kang, B., Porter, K., Thach, T., & Corazzini, K. N. (2017). Person-directed care planning in nursing homes: Resident, family and staff perspectives. *Journal of Applied Gerontology, 1-26.* https://doi.org/10.1177%2F0733464817732519

Strauss, A. L. (1987). *Qualitative analysis for social scientists*. Cambridge University Press.

Sullivan, J. L., Meterko, M., Baker, E., Stolzmann, K., Adjognon, O., Ballah, K., & Parker, V. A., (2012). Reliability and validity of a person-centered care staff survey in Veterans health administration community living centers. *The Gerontologist, 53,* 596-607.

Talerico, K.A., O'Brien, J., & Swafford, K. (2003). Aging matters: Person-centered care: An important approach for 21st century health care*. Journal of Psychosocial Nursing and Mental Health Services, 41(11),* 12-16.

Tester, S., Hubbard, G., Downs, M., MacDonald, C., & Murphy, J. (2004). Frailty and Institutional Life. In W. Alan (Ed.), *Growing Older: Quality Of Life In Old Age: Quality of Life in Old Age* (pp. 209–224). McGraw-Hill Education (UK).

Van Haitsma, K., Curyto, K., Spector, A., Towsley, G., Kleban, M., Carpenter, B., Ruckdeschel, K., Feldman, P. H., & Koren, M. J. (2012). The Preferences for Everyday Living Inventory: Scale development and description of psychosocial preferences responses in community-dwelling elders. *The Gerontologist*, *53,* 582–595.

Verbeek, H., van Rossum, E., Zwakhalen, S. M., Ambergen, T., Kempen, G. I., & Hamers, J. P. (2009). The effects of small-scale, homelike facilities for older people with dementia on residents, family caregivers and staff: Design of a longitudinal, quasi-experimental study. *BMC Geriatrics*, *9*, 3. https://doi.org/10.1186/1471-2318-9-3

White, D., Elliott, S., & Hasworth (2016). *Development of the Resident VIEW.* Final Report Submitted to the Oregon Department of Human Services, IGA #146846. Portland State University Institute on Aging: Portland, OR

White, D. L., Newton-Curtis, L., & Lyons, K. S. (2008). Development and initial testing of a measure of person-directed care. *The Gerontologist, 48, Special Issue 1,* 114-123.

White, D. L., Tunalilar, O., Hasworth, S., & Winfree, J. (2019). The Resident VIEW in Nursing Homes. *Gerontology & Geriatric Medicine, 5,* 1-13. *https://doi.org/10.1177/2333721419877975*

Wilson, K. B. (2007). Historical evolution of assisted living in the United States, 1979 to the present. *The Gerontologist, 47, Special Issue III,* 8-22.

Zimmerman, S., Bowers, B. J., Cohen, L. W., Grabowski, D. C., Horn, S. D., Kemper, P. (2016). New evidence on the Green House Model of nursing home care: Synthesis of findings and implications for Policy, Practice, and research. *Health Services Research, 51, Part II, Special Issue,* 475-496. DOI: 10.1111/1475-6773.12430.

Zingmark, K., Norberg, A., & Sandman, P.-O. (1995). The experience of being at home throughout the life span: Investigation of persons aged from 2 to 102. *The International Journal of Aging & Human Development*, *41*(1), 47–62. https://doi.org/10.2190/N08L-42J5-31D2-JUQA

Appendices: Survey Instruments

Appendix A

Validation of the Resident VIEW in Nursing Homes, Survey Instrument

Appendix B

Validation of the Resident VIEW in Community-Based Care Settings, Survey instrument

The Resident VIEW

A survey for people living in nursing homes

Portland State UNIVERSITY

Resident Name: _____

Remove and destroy this page when interview is complete.

Appendix B. Final Report: Validation of the Resident VIEW in CBC

Interviewer Initials: _____ Date (MM/DD): _____ ID: _____

Facility: _____ Time started: _____

Thank you very much for our time. Your participation in this research will help us to develop a questionnaire that will help us to learn more about what residents think about living or spending time in nursing facilities and learn more about how to improve services.

I am going to start by asking you how important different things are to you and I want you to tell me if these things are "Not important," "Somewhat important," or "Very important" to you. *[Hand resident response card #1.]* I will have different cards throughout the survey for the different types of questions.

1. Our first question is about the physical environment. How important is it to you that . . .

	[physical environment]	Not important	Somewhat important	Very important	DK, NA [DO NOT READ]
a.	Your room is arranged and decorated the way you want it?	1	2	3	9
b.	You enjoy the view from your window?	1	2	3	9
c.	You feel welcome in areas outside of your room?	1	2	3	9
d.	You easily get around outside of your room?	1	2	3	9
e.	You go outdoors?	1	2	3	9
f.	It is peaceful here?	1	2	3	9
g.	It feels like home here?	1	2	3	9

2. Think about the things that you like to do. Living here, how important is it to you that you:

	[meaningful activity]	Not important	Somewhat important	Very important	DK, NA [DO NOT READ]
a.	Do the things you care about?	1	2	3	9
b.	Do things with other people who live here?	1	2	3	9
c.	Do things just for fun?	1	2	3	9
d.	Do physical activities (e.g., exercise classes, go on walks, work on strength)?	1	2	3	9
e.	Take care of plants?	1	2	3	9
f.	Spend time with animals?	1	2	3	9
g.	Listen to or make music that you like?	1	2	3	9
h.	Do things to help others who live or work here?	1	2	3	9
i.	Share your wisdom with the people who work here (e.g., advice)?	1	2	3	9
j.	Have a purpose in life?	1	2	3	9

3. Next are questions about the kind of care that you receive. How important is it to you that the people who work here:

	[personalized care]	Not important	Somewhat important	Very important	DK, NA [DO NOT READ]
a.	Take into account your health needs?	1	2	3	9
b.	Respond quickly to your requests (e.g., to ease your pain, to use the toilet)?	1	2	3	9
c.	Make you feel at ease when they are helping you (e.g., to get dressed, in the bathroom)?	1	2	3	9
d.	Tell you how long you have to wait if they can't help you right away?	1	2	3	9
e.	Take the time with you that you need?	1	2	3	9
f.	Make you feel comfortable asking for help?	1	2	3	9
g.	Make sure that you can hear what they say?	1	2	3	9
h.	Are gentle when they are helping you or doing things for you (e.g., to get dressed, in the bathroom)?	1	2	3	9

4. The next set of questions have to do with how well the people who work here know you. How important is it to you that the people who work here know:

	[knowing the person]	Not important	Somewhat important	Very important	DK, NA [DO NOT READ]
a.	How you like to have things done?	1	2	3	9
b.	The kinds of things you are interested in?	1	2	3	9
c.	How you like to spend your time?	1	2	3	9
d.	What makes a good day for you?	1	2	3	9
e.	Who is important to you (e.g., family, friends)?	1	2	3	9
f.	What you worry about?	1	2	3	9
g.	What you like to be called?	1	2	3	9

5. The next questions have to do with the choices and decisions that you want to make living here. How important is it to you that you:

	[autonomy/choice]	Not important	Somewhat important	Very important	DK, NA [DO NOT READ]
a.	Get up when you want to?	1	2	3	9
b.	Eat meals when you want to?	1	2	3	9
c.	Take a shower or a bath when you want to?	1	2	3	9
d.	Make your own decisions even if others don't approve (e.g., eating foods not on your diet, taking or not taking some medications)?	1	2	3	9
e.	Spend your time the way you want to?	1	2	3	9
f.	Have privacy when you want it?	1	2	3	9
g.	Can do things for yourself?	1	2	3	9
h.	Have a say in how this place works (e.g., meal schedules, decorating communal areas, planning social events, hiring & evaluating staff)?	1	2	3	9
i.	Feel free to express your opinions about things you do not like here?	1	2	3	9

j. What are the most important decisions you make here? [WRITE RESPONSE.]

6. These questions have to do with how the people who work here relate to you as a person. How important is it to you that the people who work here:

	[treated like a person]	Not important	Somewhat important	Very important	DK, NA [DO NOT READ
a.	Pay attention to your opinions?	1	2	3	9
b.	Show that they are interested in you as a person?	1	2	3	9
c.	Listen to you without interrupting?	1	2	3	9
d.	Show that your needs are important to them?	1	2	3	9
e.	Understand what it is like for you to live here?	1	2	3	9
f.	Answer your questions?	1	2	3	9
g.	Treat you with respect?	1	2	3	9
h.	Treat you with kindness?	1	2	3	9

7. I would like to ask you some questions about the people who work here. How important is it to you that the people who work here:

	[relationships with staff]	Not important	Somewhat important	Very important	DK, NA [DO NOT READ]
a.	Listen to you share stories about your life?	1	2	3	9
b.	Tell you about their personal lives?	1	2	3	9
c.	Talk to you about things you are interested in?	1	2	3	9
d.	Spend time with you just talking or being with you?	1	2	3	9
e.	Know what you have done in your life?	1	2	3	9
f.	Have things in common with you?	1	2	3	9
g.	Laugh with you?	1	2	3	9

8. These questions have to do with how this place is run. How important is it to you that

	[organizational environment]	Not important	Somewhat important	Very important	DK, NA [DO NOT READ]
a.	You can talk to the [owner/manager/administrator] if you have a problem?	1	2	3	9
b.	You see the owner [owner/manager/administrator] around the home?	1	2	3	9
c.	The same people help you on most days?	1	2	3	9
d.	You have a say in who works here?	1	2	3	9
e.	The people who work here have time to help you when you need it?	1	2	3	9
f.	The people who work here have a good attitude?	1	2	3	9
g.	This place is run well?	1	2	3	9

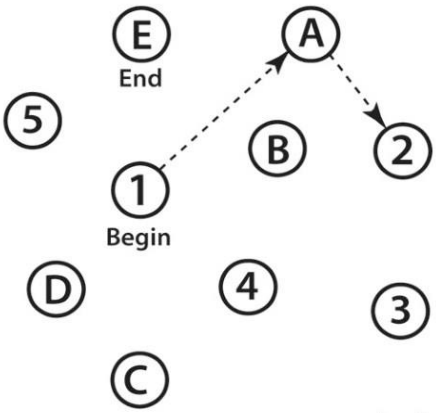
9. MOCA

Now we are going to move on to some brain games. [Pull out MOCA Administration and Scoring Instructions and use language to administer screening, turn to next page and show clipboard to resident.]

MONTREAL COGNITIVE ASSESSMENT (MOCA)

Version 7.1 Original Version

VISUOSPATIAL / EXECUTIVE



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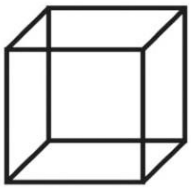

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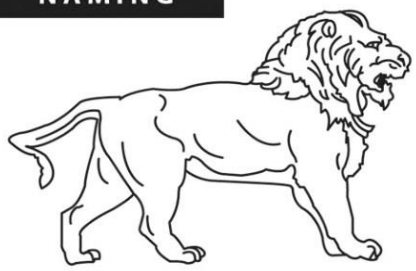

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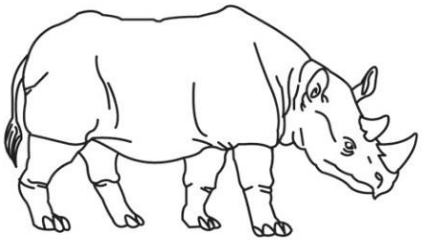

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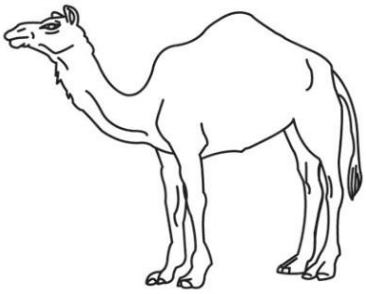

[ ] ___/3

MEMORY

Read list of words, subject must repeat them. Do 2 trials, even if 1st trial is successful. Do a recall after 5 minutes.

	FACE	VELVET	CHURCH	DAISY	RED
1st trial					
2nd trial					

No points

ATTENTION

Read list of digits (1 digit/ sec.).

Subject has to repeat them in the forward order [ ] 2 1 8 5 4

Subject has to repeat them in the backward order [ ] 7 4 2 ___/2

Read list of letters. The subject must tap with his hand at each letter A. No points if ≥ 2 errors

[ ] F B A C M N A A J K L B A F A K D E A A A J A M O F A A B ___/1

Serial 7 subtraction starting at 100 [ ] 93 [ ] 86 [ ] 79 [ ] 72 [ ] 65

4 or 5 correct subtractions: **3 pts**, 2 or 3 correct: **2 pts**, 1 correct: **1 pt**, 0 correct: **0 pt** ___/3

LANGUAGE

Repeat : I only know that John is the one to help today. [ ]

The cat always hid under the couch when dogs were in the room. [ ] ___/2

Fluency / Name maximum number of words in one minute that begin with the letter F [ ] _____ (N ≥ 11 words) ___/1

ABSTRACTION

Similarity between e.g. banana - orange = fruit [ ] train – bicycle [ ] watch - ruler ___/2

DELAYED RECALL

	Has to recall words **WITH NO CUE**	FACE [ ]	VELVET [ ]	CHURCH [ ]	DAISY [ ]	RED [ ]	Points for UNCUED recall only
Optional	Category cue						
	Multiple choice cue						

___/5

ORIENTATION

[ ] Date [ ] Month [ ] Year [ ] Day [ ] Place [ ] City ___/6

Normal ≥ 26 / 30

TOTAL ___/30

Add 1 point if ≤ 12 yr edu

Did you graduate from high school? ___ No ___ Yes

[IF NO, ADD 1 POINT TO TOTAL SCORE]

Earlier we asked you questions about what is important to you about living here. Now we want to know what it is like for you to live here. These questions are going to sound very familiar but now we want to know if you experience these things here. *[Hand response card #2.]* **For these questions use the responses "No (or not at all)," "Some," or "Yes."**

10. First we will be asking you about the physical environment.

	[physical environment]	No (not at all)	Some	Yes	DK, NA [DO NOT READ]
a.	Is your room arranged and decorated the way you want it?	1	2	3	9
b.	Do you enjoy the view from your window?	1	2	3	9
c.	Do you feel welcome in areas outside of your room?	1	2	3	9
d.	Can you easily get around outside of your room when you want to?	1	2	3	9
e.	Do you go outdoors [when you want to]?	1	2	3	9
f.	Is it peaceful here?	1	2	3	9
g.	Does it feel like home to you here?	1	2	3	9

10h. [PROBE: FOLLOW-UP] [WRITE RESPONSE.]

[If "Yes" ask "What makes it feel like home here?"]

[If "No" or "Some" ask "What would make it feel more like home?"]

11. For these next questions, think about the way you spend your time. Living here:

	[meaningful activity]	No (not at all)	Some things	Yes	DK, NA [DO NOT READ]
a.	Can you do things that you care about?	1	2	3	9
b.	Do you do things with other people who live here?	1	2	3	9
c.	Do you do things just for fun?	1	2	3	9
d.	Do you do physical activities (e.g., exercise classes, go on walks, work on strength)?	1	2	3	9
e.	Do you take care of plants?	1	2	3	9
f.	Do you spend time with animals?	1	2	3	9
g.	Do you listen to or make music that you like?	1	2	3	9
h.	Do you do things to help others who live or work here?	1	2	3	9
i.	Do you share your wisdom with the people who work here (e.g., advice)?	1	2	3	9
j.	Do you [feel you] have a purpose in life?	1	2	3	9

12. Next are questions about the kind of care that you receive. Do the people who work here:

	[personalized care]	No (not at all)	Some	Yes	DK, NA [DO NOT READ]
a.	Take into account your health needs?	1	2	3	9
b.	Respond quickly to your requests (e.g., to ease your pain, to use the toilet)?	1	2	3	9
c.	Make you feel at ease when they are helping you (e.g., to get dressed, in the bathroom)?	1	2	3	9
d.	Tell you how long you have to wait if they can't help you right away?	1	2	3	9
e.	Take the time with you that you need?	1	2	3	9
f.	Make you feel comfortable asking for help?	1	2	3	9
g.	Make sure that you can hear what they say?	1	2	3	9
h.	Are the people who work here gentle when they are helping you or doing things for you (e.g., to get dressed, in the bathroom)?	1	2	3	9

13. The next set of questions have to do with how well the people who work here know you. Do the people who work here know:

	[knowing the person]	No (not at all)	Some	Yes	DK, NA [DO NOT READ]
a.	How you like to have things done?	1	2	3	9
b.	The kinds of things you are interested in?	1	2	3	9
c.	How you like to spend your time?	1	2	3	9
d.	What makes a good day for you?	1	2	3	9
e.	Who is important to you (e.g., family, friends)?	1	2	3	9
f.	What you worry about?	1	2	3	9
g.	What you like to be called?	1	2	3	9

14. The next questions have to do with the choices and decisions that you make here.

	[autonomy/choice]	No (not at all)	Some	Yes	DK, NA [DO NOT READ]
a.	Do you get up when you want to?	1	2	3	9
b.	Do you eat meals when you want to?	1	2	3	9
c.	Do you take a shower or a bath when you want to?	1	2	3	9
d.	Do you make your own decisions even if others don't approve (e.g., eating foods not on your diet, taking or not taking some medications)?	1	2	3	9
e.	Do you spend your time the way you want to?	1	2	3	9
f.	Do you have privacy when you want it?	1	2	3	9
g.	Do you do things for yourself?	1	2	3	9
h.	Do you have a say in how this place works (e.g., meal schedules, decorating communal areas, planning social events, hiring & evaluating staff)?	1	2	3	9
i.	Do you feel free to express your opinions about things you do not like here?	1	2	3	9

15. These questions have to do with how the people who work here relate to you as a person. Do they:

	[treated like a person]	No	Some	Yes	DK, NA [DO NOT READ
a.	Pay attention to your opinions?	1	2	3	9
b.	Show that they are interested in you as a person?	1	2	3	9
c.	Listen to you without interrupting?	1	2	3	9
d.	Show that your needs are important to them?	1	2	3	9
e.	Understand what it is like for you to live here?	1	2	3	9
f.	Answer your questions?	1	2	3	9
g.	Treat you with respect?	1	2	3	9
h.	Treat you with kindness?	1	2	3	9

16. I would like to ask you some questions about the people who work here. Do they:

	[relationships with staff]	No	Some	Yes	DK, NA [DO NOT READ]
a.	Listen to you share stories about your life?	1	2	3	9
b.	Tell you about their personal lives?	1	2	3	9
c.	Talk to you about things you are interested in?	1	2	3	9
d.	Spend time with you just talking or being with you?	1	2	3	9
e.	Know what you have done in your life?	1	2	3	9
f.	Have things in common with you?	1	2	3	9
g.	Laugh with you?	1	2	3	9

17. These questions have to do with how this home is run.

	[organizational environment]	No	Some	Yes	DK, NA [DO NOT READ]
a.	Do you talk to the [owner/manager/administrator] if you have a problem?	1	2	3	9
b.	Do you see the [owner/manager/administrator] around the home?	1	2	3	9
c.	Does the same person help you on most days?	1	2	3	9
d.	Do you have a say in who works here?	1	2	3	9
e.	Do the people who work here have time to help you when you need it?	1	2	3	9
f.	Do the people who work here have a good attitude?	1	2	3	9
g.	Do you feel this place is run well?	1	2	3	9

17h. How could this home be run better? [WRITE RESPONSE.]

Cognitive and Behavioral Health Assessment

18. Quality of Life-AD (QOL-AD)

Now I'm going to ask you some questions about your quality of life. Please rate different aspects of your life using one of these words: "poor," "fair," "good," or "excellent." *[Hand resident response card #3].*

When you think about your life, there are different aspects, like your physical health, energy, family, money, and others. I'm going to ask you to rate each of these areas. We want to find out how you feel about your current situation in each area.

If you're not sure what a question means, you can ask me about it. If you have difficulty rating any item, just give it your best guess.

[If resident says that some days are better than others, ask them to rate how they have been feeling most of the time lately]

	Poor	Fair	Good	Excellent
a. Physical health	1	2	3	4
b. Energy (If the participant says that some days are better than others, ask them to rate how they have been feeling most of the time lately.)	1	2	3	4
c. Mood	1	2	3	4
d. Living situation	1	2	3	4
e. Memory	1	2	3	4
f. Family (If the respondent says they have no family, ask about brothers, sisters, children, nieces, nephews.)	1	2	3	4
g. Friends (If the respondent answers that they have no friends, or all their friends have died, probe further. **Do you have anyone you enjoy being with besides your family? Would you call that person a friend?** If the respondent still says they have no friends, ask **how do you feel about having no friends—poor, fair, good, or excellent?)**	1	2	3	4
h. Self as a whole	1	2	3	4
i. Ability to do things for fun	1	2	3	4
j. Money	1	2	3	4

(If the respondent hesitates, explain that you don't want to know what their situation is (as in amount of money), just how they feel about it.)				
k. Life as a whole	1	2	3	4

19. The Patient Health Questionnaire (PHQ-9)

Now I would now like to ask you some questions about your health and daily activities. I am going to read a list and ask you how often you have been bothered by any of the following problems in the past **two weeks**. *[Hand copy of response card #4.]* For these questions, use the responses "Not at all," "Several days," "More than half the days," or "Nearly every day."

	Not at all	Several days	More than half the days	Nearly every day
a. Little interest or pleasure in doing things	0	1	2	3
b. Feeling down, depressed or hopeless	0	1	2	3
c. Trouble falling asleep, staying asleep, or sleeping too much	0	1	2	3
d. Feeling tired or having little energy	0	1	2	3
e. Poor appetite or overeating	0	1	2	3
f. Feeling bad about yourself – or that you're a failure to have let yourself or your family down	0	1	2	3
g. Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
h. Moving or speaking slowly that other people could have noticed. Or, the opposite – being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3
i. Thoughts that you would be better off dead or hurting yourself in some way	0	1	2	3

20. Katz Index of Independence in Activities of Daily Living

Now I would like to learn about some of your daily activities and whether you do these things by yourself or whether you have some help from the people who work here. *[Hand response card #5.]* For these questions, use the responses "No difficulty," "A little difficulty," "Some difficulty," "A lot of difficulty," or "Unable to do."

Activity	No difficulty	A little difficulty	Some difficulty	A lot of difficulty	Unable to do
a. How much difficulty, if any, do you have with bathing? (*Bathing includes rinsing or drying the body from the neck down (excluding the back) and may be either tub, shower, or sponge bath, getting into or out of tub or shower)*	0	1	2	3	4
Activity	**No difficulty**	**A little difficulty**	**Some difficulty**	**A lot of difficulty**	**Unable to do**
b. How much difficulty, if any, do you have with dressing? *(can include putting on clothes, getting clothes from closet or drawer, using fasteners, tying shoes)*	0	1	2	3	4
c. How much difficulty, if any, do you have with using the toilet *(getting to, on and off, cleaning up afterward)*	0	1	2	3	4
d. How much difficulty, if any, do you have with getting into or out of a bed, chair or wheelchair*? (can be difficulty with any of these)*	0	1	2	3	4
e. How much difficulty, if any, do you have with grooming? *(Grooming includes brushing teeth, combing or brushing hair, washing hands, washing face and either shaving or applying makeup.)*	0	1	2	3	4

21. General Satisfaction Measures

Now I am going to ask you to rate your satisfaction with this [AL, AFC, NH]. *[Hand response card #6]*. For these questions use the responses "Not at all satisfied," "Dissatisfied," "Satisfied," or "Very satisfied."

	Not at all satisfied	Dissatisfied	Satisfied	Very satisfied
a. How satisfied are you with this place as a place to live?	1	2	3	4
b. How satisfied are you with this place as a place to receive care?	1	2	3	4

21c. Would you recommend this facility to someone else? ___No ___Yes ___DK

22. Those are all of my questions. Is there anything else we should know about living here?

Thank you so much for your time! **Time ended: _____**

COMPLETE THIS SECTION AFTER RESIDENT HAS BEEN INTERVIEWED OR INTERVIEW HAS BEEN ATTEMPTED

A. OUTCOME of interview with resident:

1. Interview was successfully completed
2. Resident was seen, but was sound asleep and not interviewed
3. Interview attempted, but did not pass MoCA, OR resident could not track questions or made inappropriate responses
4. Interview attempted, resident chose not to continue (Specify: _____)
5. Resident refused to begin the interview
6. Resident was not on site because _____
7. Resident unable to speak/language issue (Specify: _____)
8. Resident unable to hear/hearing issue
9. Resident very ill or dying
10. Other (Specify: _____)

B. Overall, how much difficulty did the resident have in understanding the survey?

1. No difficulty
2. A little difficulty
3. A moderate amount of difficulty
4. A great deal of difficulty

C. Describe items that were difficult for the person to answer.

D. How engaged was the resident in the interview?

1. Very engaged
2. Moderately engaged
3. A little engaged
4. Not at all engaged

E. How distracted was the resident?

1. Very distracted
2. Moderately distracted
3. A little distracted
4. Not at all distracted

F. Summarize your interview. Include some take-home messages with your impressions and a relevant quote if it seems appropriate.

The Resident VIEW
Voicing Importance and Experience for Well-being

A survey for people living in long-term care settings

Resident's first name: _____ Room/apartment number: _____
(If applicable)

STATUS OF SURVEY
(MM/DD)

_____ Survey complete

_____ Resident VIEW complete, other completed measures include (check all that apply):
◯QOL-AD◯PHQ-9◯Katz IADL◯Satisfaction◯ Demographic◯ MoCA

_____ Survey incomplete, follow-up needed

_____ Survey incomplete, no follow-up needed.
Check one: ◯ Case (5+ domains importance) ◯ Non-case (<5 domains importance)

_____ Other (describe): _____

Remove and destroy this page when survey is scanned.

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TIME STARTED

Interviewer initials: _____ Date (MM/DD): _____
Face sheet ID: _____ AFH / AL / RC ID: _____

Thank you very much for your time. This survey has three main sections. First, I am going to start by asking you how important different things are to you. Then, we will go through these things again and I will ask you whether or not you get them. The last section of the survey will focus on your health and daily activities. We know we have a lot of questions, and your responses will help us to make this survey much shorter with all the best questions. This is a very in-depth survey, and we appreciate your time in telling us about what it is like for you to live here.

For this first section, I want you to think about what is important to you while you are living here. I will ask you several questions about different aspects of this place, and I want you to tell me if these things are "Not important," "Somewhat important," or "Very important" to you. You can also rate it "1, 2, or 3." I will have different cards throughout the survey for the different types of questions. Here's the first card. *[Response card #1.]*

1. Our first questions are about the physical environment. How important is it to you that . . .

	[physical environment]	Not important	Somewhat important	Very important	DK, NA [DO NOT READ]
a.	Your [room/apartment] is arranged and decorated the way you want it?	1	2	3	9
b.	You enjoy the view from your window?	1	2	3	9
c.	You feel welcome in areas outside of your [room/apartment]?	1	2	3	9
d.	You easily get around outside of your [room/apartment]?	1	2	3	9
e.	You go outdoors [when you want to]?	1	2	3	9
f.	It is peaceful here?	1	2	3	9
g.	It feels like home here?	1	2	3	9

1OE. COMMENTS (Note corresponding item letter next to comment)

2. Think about the things that you like to do. Living here, how important is it to you that you:

	[meaningful activity]	Not important	Somewhat important	Very important	DK, NA [DO NOT READ]
a.	Do the things you care about?	1	2	3	9
b.	Do things with other people who live here?	1	2	3	9
c.	Do things just for fun?	1	2	3	9
d.	Do physical activities (e.g., exercise classes, go on walks, work on strength)?	1	2	3	9
e.	Take care of plants?	1	2	3	9
f.	Spend time with animals?	1	2	3	9
g.	Listen to or make music that you like?	1	2	3	9
h.	Do things to help others who live or work here?	1	2	3	9
i.	Share your wisdom with the people who work here (e.g., advice)?	1	2	3	9
j.	Have a purpose?	1	2	3	9
k.	Feel useful?	1	2	3	9

2OE. COMMENTS (Note corresponding item letter next to comment)

3. Next are questions about the kind of care that you receive. How important is it to you that the people who work here:

	[personalized care]	Not important	Somewhat important	Very important	DK, NA [DO NOT READ]
a.	Take into account your health needs?	1	2	3	9
b.	Respond quickly to your requests (e.g., to ease your pain, to use the toilet)?	1	2	3	9
c.	Make you feel at ease when they are helping you (e.g., to get dressed, in the bathroom)?	1	2	3	9
d.	Tell you how long you have to wait if they can't help you right away?	1	2	3	9
e.	Take the time with you that you need?	1	2	3	9
f.	Make you feel comfortable asking for help?	1	2	3	9
g.	Make sure that you can hear what they say?	1	2	3	9
h.	Are gentle when they are helping you or doing things for you (e.g., to get dressed, in the bathroom)?	1	2	3	9

3OE. COMMENTS (Note corresponding item letter next to comment)

4. The next set of questions have to do with how well the people who work here know you. How important is it to you that the people who work here know:

	[knowing the person]	Not important	Somewhat important	Very important	DK, NA [DO NOT READ]
a.	How you like to have things done?	1	2	3	9
b.	The kinds of things you are interested in?	1	2	3	9
c.	How you like to spend your time?	1	2	3	9
d.	What makes a good day for you?	1	2	3	9
e.	Who is important to you (e.g., family, friends)?	1	2	3	9
f.	What you worry about?	1	2	3	9
g.	What you like to be called?	1	2	3	9

4OE. COMMENTS (Note corresponding item letter next to comment)

5. The next questions have to do with the choices and decisions that you want to make living here. How important is it to you that you:

	[autonomy/choice]	Not important	Somewhat important	Very important	DK, NA [DO NOT READ]
a.	Get up when you want to?	1	2	3	9
b.	Choose what you eat?	1	2	3	9
c.	Eat meals when you want to?	1	2	3	9
d.	Take a shower or a bath when you want to?	1	2	3	9
e.	Make your own decisions even if others don't approve (e.g., eating foods not on your diet, taking or not taking some medications)?	1	2	3	9
f.	Spend your time the way you want to?	1	2	3	9
g.	Have privacy when you want it?	1	2	3	9
h.	Can do things for yourself?	1	2	3	9
i.	Have a say in how this place works (e.g., meal schedules, decorating communal areas, planning social events, hiring & evaluating staff)?	1	2	3	9
j.	Feel free to express your opinions about things you do not like here?	1	2	3	9

k. Now, this next question is open-ended. From your perspective, what are the most important decisions you make here? [WRITE RESPONSE.]

5OE. COMMENTS (Note corresponding item letter next to comment)

IF RESPONDENT FATIGUES OR WISHES TO END THE INTERVIEW, NOTE TIME AND ATTEMPT SATISFACTION AND DEMOGRAPHIC QUESTIONS (PAGES 17 & 21)

6. These questions have to do with how the people who work here relate to you as a person. How important is it to you that the people who work here:

	[treated like a person]	Not important	Somewhat important	Very important	DK, NA [DO NOT READ
a.	Pay attention to your opinions?	1	2	3	9
b.	Show that they are interested in you as a person?	1	2	3	9
c.	Listen to you without interrupting?	1	2	3	9
d.	Show that your needs are important to them?	1	2	3	9
e.	Understand what it is like for <u>you</u> to live here?	1	2	3	9
f.	Answer your questions?	1	2	3	9
g.	Treat you with respect?	1	2	3	9
h.	Treat you with kindness?	1	2	3	9

6OE. COMMENTS (Note corresponding item letter next to comment)

IF RESPONDENT FATIGUES OR WISHES TO END THE INTERVIEW, NOTE TIME AND ATTEMPT SATISFACTION AND DEMOGRAPHIC QUESTIONS (PAGES 17 & 21)

7. Now I would like to ask you some questions about your relationships with the people who work here. How important is it to you that the people who work here:

	[relationships with staff]	Not important	Somewhat important	Very important	DK, NA [DO NOT READ]
a.	Listen to you share stories about your life?	1	2	3	9
b.	Tell you about their personal lives?	1	2	3	9
c.	Talk to you about things you are interested in?	1	2	3	9
d.	Spend time with you just talking or being with you?	1	2	3	9
e.	Know what you have done in your life?	1	2	3	9
f.	Have things in common with you?	1	2	3	9
g.	Laugh with you?	1	2	3	9

7OE. COMMENTS (Note corresponding item letter next to comment)

IF RESPONDENT FATIGUES OR WISHES TO END THE INTERVIEW, NOTE TIME AND ATTEMPT SATISFACTION AND DEMOGRAPHIC QUESTIONS (PAGES 17 & 21)

8. These questions have to do with how this place is run. How important is it to you that:

	[organizational environment]	Not important	Somewhat important	Very important	DK, NA [DO NOT READ]
a.	You can talk to the [provider/owner/administrator] if you have a problem?	1	2	3	9
b.	You see the [provider/owner/administrator] around this place?	1	2	3	9
c.	The same people help you on most days?	1	2	3	9
d.	You have a say in who works here?	1	2	3	9
e.	You have a say in who helps you?	1	2	3	9
f.	The people who work here have time to help you when you need it?	1	2	3	9
g.	The people who work here have a good attitude?	1	2	3	9
h.	This place is run well?	1	2	3	9

8OE. COMMENTS (Note corresponding item letter next to comment)

IF RESPONDENT FATIGUES OR WISHES TO END THE INTERVIEW, NOTE TIME AND ATTEMPT SATISFACTION AND DEMOGRAPHIC QUESTIONS (PAGES 17 & 21)

Those are all of my questions about what is important to you living here. Now, the next section of the survey asks about what it is like for you to live here. These questions are going to sound very familiar but now we want to know if you experience these things here. **For these questions use the responses "No (or not at all)," "Some," or "Yes."** *[Response card #2.]*

9. First we will be asking you about the physical environment.

	[physical environment]	No (not at all)	Some	Yes	DK, NA [DO NOT READ]
a.	Is your [room/apartment] arranged and decorated the way you want it?	1	2	3	9
b.	Do you enjoy the view from your window?	1	2	3	9
c.	Do you feel welcome in areas outside of your [room/apartment]?	1	2	3	9
d.	Can you easily get around outside of your [room/apartment] when you want to?	1	2	3	9
e.	Do you go outdoors [when you want to]?	1	2	3	9
f.	Is it peaceful here?	1	2	3	9
g.	Does it feel like home to you here?	1	2	3	9

9h. [9g follow up] If 9g "Yes" ask "What makes it feel like home here?"
If 9g "No" or "Some" ask "What would make it feel more like home?"

9OE. COMMENTS (Note corresponding item letter next to comment)

IF RESPONDENT FATIGUES OR WISHES TO END THE INTERVIEW, NOTE TIME AND ATTEMPT SATISFACTION AND DEMOGRAPHIC QUESTIONS (PAGES 17 & 21)

10. For these next questions, think about the way you spend your time. Living here:

	[meaningful activity]	No (not at all)	Some things	Yes	DK, NA [DO NOT READ]
a.	Can you do things that you care about?	1	2	3	9
b.	Do you do things with other people who live here?	1	2	3	9
c.	Do you do things just for fun?	1	2	3	9
d.	Do you do physical activities (e.g., exercise classes, go on walks, work on strength)?	1	2	3	9
e.	Do you take care of plants?	1	2	3	9
f.	Do you spend time with animals?	1	2	3	9
g.	Do you listen to or make music that you like?	1	2	3	9
h.	Do you do things to help others who live or work here?	1	2	3	9
i.	Do you share your wisdom with the people who work here (e.g., advice)?	1	2	3	9
j.	Do you [feel you] have a purpose?	1	2	3	9
k.	Do you feel useful?	1	2	3	9

10OE. COMMENTS (Note corresponding item letter next to comment)

IF RESPONDENT FATIGUES OR WISHES TO END THE INTERVIEW, NOTE TIME AND ATTEMPT SATISFACTION AND DEMOGRAPHIC QUESTIONS (PAGES 17 & 21)

11. Next are questions about the kind of care that you receive. Do the people who work here:

	[personalized care]	No (not at all)	Some	Yes	DK, NA [DO NOT READ]
a.	Take into account your health needs?	1	2	3	9
b.	Respond quickly to your requests (e.g., to ease your pain, to use the toilet)?	1	2	3	9
c.	Make you feel at ease when they are helping you (e.g., to get dressed, in the bathroom)?	1	2	3	9
d.	Tell you how long you have to wait if they can't help you right away?	1	2	3	9
e.	Take the time with you that you need?	1	2	3	9
f.	Make you feel comfortable asking for help?	1	2	3	9
g.	Make sure that you can hear what they say?	1	2	3	9
h.	Are the people who work here gentle when they are helping you or doing things for you (e.g., to get dressed, in the bathroom)?	1	2	3	9

11OE. COMMENTS (Note corresponding item letter next to comment)

IF RESPONDENT FATIGUES OR WISHES TO END THE INTERVIEW, NOTE TIME AND ATTEMPT SATISFACTION AND DEMOGRAPHIC QUESTIONS (PAGES 17 & 21)

12. The next set of questions have to do with how well the people who work here know you. Do the people who work here know:

	[knowing the person]	No (not at all)	Some	Yes	DK, NA [DO NOT READ]
a.	How you like to have things done?	1	2	3	9
b.	The kinds of things you are interested in?	1	2	3	9
c.	How you like to spend your time?	1	2	3	9
d.	What makes a good day for you?	1	2	3	9
e.	Who is important to you (e.g., family, friends)?	1	2	3	9
f.	What you worry about?	1	2	3	9
g.	What you like to be called?	1	2	3	9

12OE. COMMENTS (Note corresponding item letter next to comment)

IF RESPONDENT FATIGUES OR WISHES TO END THE INTERVIEW, NOTE TIME AND ATTEMPT SATISFACTION AND DEMOGRAPHIC QUESTIONS (PAGES 17 & 21)

13. The next questions have to do with the choices and decisions that you make here.

	[autonomy/choice]	No (not at all)	Some	Yes	DK, NA [DO NOT READ]
a.	Do you get up when you want to?	1	2	3	9
b.	Do you choose what you eat?	1	2	3	9
c.	Do you eat meals when you want to?	1	2	3	9
d.	Do you take a shower or a bath when you want to?	1	2	3	9
e.	Do you make your own decisions even if others don't approve (e.g., eating foods not on your diet, taking or not taking some medications)?	1	2	3	9
f.	Do you spend your time the way you want to?	1	2	3	9
g.	Do you have privacy when you want it?	1	2	3	9
h.	Do you do things for yourself?	1	2	3	9
i.	Do you have a say in how this place works (e.g., meal schedules, decorating communal areas, planning social events, hiring & evaluating staff)?	1	2	3	9
j.	Do you feel free to express your opinions about things you <u>do not like</u> here?	1	2	3	9

13OE. COMMENTS (Note corresponding item letter next to comment)

IF RESPONDENT FATIGUES OR WISHES TO END THE INTERVIEW, NOTE TIME AND ATTEMPT SATISFACTION AND DEMOGRAPHIC QUESTIONS (PAGES 17 & 21)

14. These questions have to do with how the people who work here relate to you as a person. Do they:

	[treated like a person]	No	Some	Yes	DK, NA [DO NOT READ
a.	Pay attention to your opinions?	1	2	3	9
b.	Show that they are interested in you as a person?	1	2	3	9
c.	Listen to you without interrupting?	1	2	3	9
d.	Show that your needs are important to them?	1	2	3	9
e.	Understand what it is like for you to live here?	1	2	3	9
f.	Answer your questions?	1	2	3	9
g.	Treat you with respect?	1	2	3	9
h.	Treat you with kindness?	1	2	3	9

14OE. COMMENTS (Note corresponding item letter next to comment)

IF RESPONDENT FATIGUES OR WISHES TO END THE INTERVIEW, NOTE TIME AND ATTEMPT SATISFACTION AND DEMOGRAPHIC QUESTIONS (PAGES 17 & 21)

15. Now I would like to ask you some questions about your relationships with the people who work here. Do they:

	[relationships with staff]	No	Some	Yes	DK, NA [DO NOT READ]
a.	Listen to you share stories about your life?	1	2	3	9
b.	Tell you about their personal lives?	1	2	3	9
c.	Talk to you about things you are interested in?	1	2	3	9
d.	Spend time with you just talking or being with you?	1	2	3	9
e.	Know what you have done in your life?	1	2	3	9
f.	Have things in common with you?	1	2	3	9
g.	Laugh with you?	1	2	3	9

15OE. COMMENTS (Note corresponding item letter next to comment)

IF RESPONDENT FATIGUES OR WISHES TO END THE INTERVIEW, NOTE TIME AND ATTEMPT SATISFACTION AND DEMOGRAPHIC QUESTIONS (PAGES 17 & 21)

16. These questions have to do with how this place is run.

	[organizational environment]	No	Some	Yes	DK, NA [DO NOT READ]
a.	Do you talk to the [provider/owner/administrator] if you have a problem?	1	2	3	9
b.	Do you see the [provider/owner/administrator] around this place?	1	2	3	9
c.	Does the same person help you on most days?	1	2	3	9
d.	Do you have a say in who works here?	1	2	3	9
e.	Do you have a say in who helps you?	1	2	3	9
f.	Do the people who work here have time to help you when you need it?	1	2	3	9
g.	Do the people who work here have a good attitude?	1	2	3	9
h.	Do you feel this place is run well?	1	2	3	9

16i. In your opinion, how could this place be run better? [WRITE RESPONSE.]

17. Would you recommend this place to someone else? □ No □ Yes □ DK/NA

16OE. COMMENTS (Note corresponding item letter next to comment)

IF RESPONDENT FATIGUES OR WISHES TO END THE INTERVIEW, NOTE TIME AND ATTEMPT SATISFACTION AND DEMOGRAPHIC QUESTIONS (PAGES 17 & 21)

18. General Satisfaction Measures

Now I am going to ask you to rate your satisfaction for a few different aspects of this place. For these questions use the responses "Not at all satisfied," "Dissatisfied," "Satisfied," or "Very satisfied." *[Response card #6.]*

	Not at all satisfied	Dissatisfied	Satisfied	Very satisfied
c. How satisfied are you with the food here?	1	2	3	4
d. How satisfied are you with this place as a place to live?	1	2	3	4
e. How satisfied are you with this place as a place to receive care?	1	2	3	4

18OE. COMMENTS (Note corresponding item letter next to comment)

19. Before we move on to the final section about your health and daily activities, is there anything else we should know about living here?

IF RESPONDENT FATIGUES OR WISHES TO END THE INTERVIEW, NOTE TIME AND ATTEMPT SATISFACTION AND DEMOGRAPHIC QUESTIONS (PAGES 17 & 21)

20. Quality of Life-AD (QOL-AD)

Now that we've talked about what it's like for you to live here, the final section of the survey asks about your quality of life and daily activities. As a reminder, these questions are voluntary. Are you ready to begin?

When you think about your life, there are different aspects, like your physical health, energy, family, money, and others. I'm going to ask you to rate each of these areas. We want to find out how you feel about your current situation in each area. Please rate different aspects of your life using one of these words: "poor," "fair," "good," or "excellent." *[Response card #3]*. If you're not sure what a question means, you can ask me about it. If you have difficulty rating any item, think about how you have been feeling most of the time lately.

How would you rate your…	Poor	Fair	Good	Excellent
l. Physical health	1	2	3	4
m. Energy (If the participant says that some days are better than others, ask them to rate how they have been feeling most of the time lately.)	1	2	3	4
n. Mood	1	2	3	4
o. Living situation	1	2	3	4
p. Memory	1	2	3	4
q. Family (If the respondent says they have no family, ask about brothers, sisters, children, nieces, nephews.)	1	2	3	4
r. Friends (If the respondent answers that they have no friends, or all their friends have died, probe further. **Do you have anyone you enjoy being with besides your family? Would you call that person a friend?** If the respondent still says they have no friends, ask **how do you feel about having no friends—poor, fair, good, or excellent?)**	1	2	3	4
s. Self as a whole	1	2	3	4
t. Ability to do things for fun	1	2	3	4
u. Money (If the respondent hesitates, explain that you don't want to know what their situation is (as in amount of money), just how they feel about it.)	1	2	3	4
v. Life as a whole	1	2	3	4

20OE. COMMENTS (Note corresponding item letter next to comment)

IF RESPONDENT FATIGUES OR WISHES TO END THE INTERVIEW, NOTE TIME AND ATTEMPT SATISFACTION AND DEMOGRAPHIC QUESTIONS (PAGES 17 & 21)

IF RESPONDENT FATIGUES OR WISHES TO END THE INTERVIEW, NOTE TIME AND ATTEMPT SATISFACTION AND DEMOGRAPHIC QUESTIONS (PAGES 17 & 21)

21. The Patient Health Questionnaire (PHQ-9)

Now I am going to read a list of problems and challenges, and I want you to tell me how often you have been bothered by any of them in the past **two weeks**. Some of these questions are very personal. For these questions, the options are "Not at all," "Several days," "More than half the days," or "Nearly every day." You can also use the numbers one through four. *[Response card #4.]*

In the past two weeks, how often have you…	Not at all	Several days	More than half the days	Nearly every day
j. Had little interest or pleasure in doing things	1	2	3	4
k. Been feeling down, depressed or hopeless	1	2	3	4
l. Had trouble falling asleep, staying asleep, or sleeping too much	1	2	3	4
m. Been feeling tired or having little energy	1	2	3	4
n. Had a poor appetite or been overeating	1	2	3	4
o. Been feeling bad about yourself – or that you're a failure to have let yourself or your family down	1	2	3	4
p. Had trouble concentrating on things, such as reading the newspaper or watching television	1	2	3	4
q. Been moving or speaking slowly that other people could have noticed. Or, the opposite – being so fidgety or restless that you have been moving around a lot more than usual	1	2	3	4
r. Had thoughts that you would be better off dead or hurting yourself in some way	1	2	3	4

[If resident responds "Yes" to thoughts they would be better off dead or hurting themselves in some way, ask: *"Do you have a plan to hurt yourself or take your own life?"*]

21OE. COMMENTS (Note corresponding item letter next to comment)

IF RESPONDENT FATIGUES OR WISHES TO END THE INTERVIEW, NOTE TIME AND ATTEMPT SATISFACTION AND DEMOGRAPHIC QUESTIONS (PAGES 17 & 21)

22. Katz Index of Independence in Activities of Daily Living

Now I am going to read through a list of some daily activities, and I want you to tell me whether you do these things by yourself or whether you receive supervision, direction, or personal assistance from the people who work here. For these questions use the responses "No," "Some," or "Yes."
[Response card #2. If a resident responds with "Some," please mark '0' points or use the descriptions to determine their level. List all activities (e.g., "Bathing") and use descriptions of each activity as probes if clarification is needed.]

Do you receive supervision, direction, or personal assistance with [*activity*]?

Activities Points (1 or 0)	**Independence (1 Point)** **NO** supervision, direction or personal assistance.	**Dependence (0 Points)** **WITH** supervision, direction, personal assistance or total care.
A. BATHING Points: _____	**(1 POINT)** Bathes self completely or needs help in bathing only a single part of the body such as the back, genital area or disabled extremity.	**(0 POINTS)** Need help with bathing more than one part of the body, getting in or out of the tub or shower. Requires total bathing.
B. DRESSING Points: _____	**(1 POINT)** Get clothes from closets and drawers and puts on clothes and outer garments complete with fasteners. May have help tying shoes.	**(0 POINTS)** Needs help with dressing self or needs to be completely dressed.
C. TOILETING Points: _____	**(1 POINT)** Goes to toilet, gets on and off, arranges clothes, cleans genital area without help.	**(0 POINTS)** Needs help transferring to the toilet, cleaning self or uses bedpan or commode.
D. TRANSFERRING Points: _____	**(1 POINT)** Moves in and out of bed or chair unassisted. Mechanical transfer aids are acceptable.	**(0 POINTS)** Needs help in moving from bed to chair or requires a complete transfer.
E. CONTINENCE Points: _____	**(1 POINT)** Exercises complete self-control over urination and defecation.	**(0 POINTS)** Is partially or totally incontinent of bowel or bladder.
F. EATING Points: _____	**(1 POINT)** Gets food from plate into mouth without help. Preparation of food may be done by another person.	**(0 POINTS)** Needs partial or total help with feeding or requires parenteral feeding.

22G. Families and friends often help one another in different ways. In the last month, did you regularly receive unpaid help from your family members or friends with any of the activities we just talked about? □ No □ Yes/Some *[If yes]* which activities? *[Check all]*

□ A. Bathing □ B. Dressing □ C. Toileting □ D. Transferring □ E. Continence □ F. Eating

22H. In the last month, did you regularly receive unpaid help from your family members or friends getting to medical or dental appointments?

□ No □ Yes/Some

IF RESPONDENT FATIGUES OR WISHES TO END THE INTERVIEW, NOTE TIME AND ATTEMPT SATISFACTION AND DEMOGRAPHIC QUESTIONS (PAGES 17 & 21)

23. These next questions have to do with your social support. For these questions use the responses "No (or not at all)," "Some," or "Yes." *[Response card #2.]*

	No	Some	Yes	DK, NA [DO NOT READ]
a. Are there plenty of people you can rely on when you have problems?	1	2	3	9
b. Are there many people you can trust completely?	1	2	3	9
c. Are there enough people you feel close to?	1	2	3	9

23OE. COMMENTS (Note corresponding item letter next to comment)

Personal and demographic information

Our last questions are about you and your background. We ask everybody these questions so that we can describe the kind of people who completed the survey. Some of these questions might seem obvious, but we want to ask everyone in the same way. *[Do not read response categories except where noted.]*

Check one: □ **Self-report from resident** □ **Observed by interviewer**

24. First, what is your race? (Circle all that apply) 1. White (includes Middle Eastern) 2. Black or African American 3. Hispanic or Latino 4. Asian 5. Native Hawaiian or Other Pacific Islander 6. American Indian or Alaska Native 7. Other: _____ 8. Prefer not to answer	25. What is your gender? 1. Female 2. Male 3. Non-binary 4. Questioning 5. Transfeminine (Transwoman) 6. Transmasculine (Transman) 7. Other: _____ 8. Prefer not to answer
26. What is the highest degree or level of education you have completed? (*Add 1 point to MoCA for 1 & 2) 1. Less than high school* 2. High school graduate / GED* 3. Some college 4. Associate / technical degree 5. Bachelor's degree 6. Advanced degree 7. Prefer not to answer	27. What is your marital status? 1. Single (never married) 2. Married 3. Partnered 4. Widowed 5. Divorced 6. Separated 7. Prefer not to answer
28. Do you have any children? By children, we mean biological, step- or adopted children. 1. No, never 2. Yes, ever – survived all of them 3. Yes, currently have children 4. Prefer not to answer *[Confirm response category with participant if not explicitly stated.]*	29. Do you consider yourself to be: *[READ]* 1. Heterosexual or straight; 2. Gay or lesbian; 3. Bisexual; or 4. Something else? *Describe if offered:* _____ 5. *[Do not read]* Don't know 6. *[Do not read]* Prefer not to answer

IF RESPONDENT FATIGUES OR WISHES TO END THE INTERVIEW, NOTE TIME AND ATTEMPT SATISFACTION AND DEMOGRAPHIC QUESTIONS (PAGES 17 & 21)

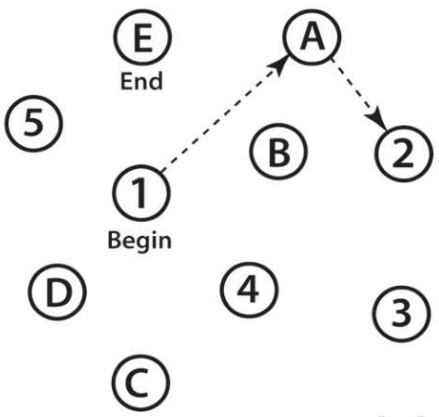
30. MOCA. Those are all of my questions for you. Since you made it through the survey the last thing I have for you is a cognitive screen. We do this with everyone who is able to understand the survey and it helps us describe the people in our study. It takes about 5 to 10 minutes. Are you ready to begin?

IF RESPONDENT FATIGUES OR WISHES TO END THE INTERVIEW, NOTE TIME AND ATTEMPT SATISFACTION AND DEMOGRAPHIC QUESTIONS (PAGES 17 & 21)

Did you <u>omit</u> any items to accommodate a physical disability? ☐ **No** ☐ **Yes**

If yes, describe:

VISUOSPATIAL / EXECUTIVE



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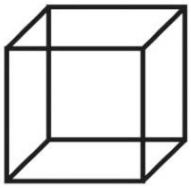


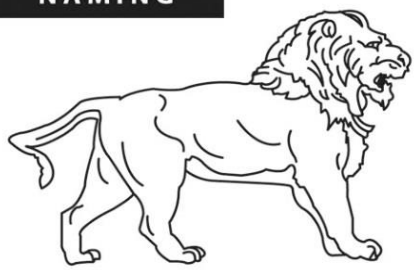
[ ] [ ]

Draw CLOCK (Ten past eleven)
(3 points)

[ ] Contour [ ] Numbers [ ] Hands

POINTS ___/5

NAMING



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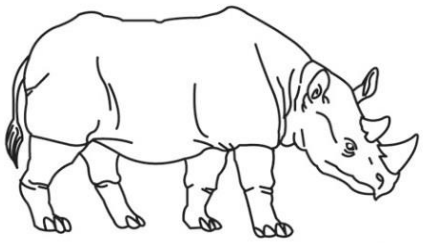

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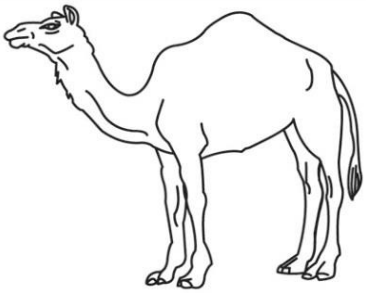

[ ] ___/3

MEMORY

Read list of words, subject must repeat them. Do 2 trials, even if 1st trial is successful. Do a recall after 5 minutes.

	FACE	VELVET	CHURCH	DAISY	RED
1st trial					
2nd trial					

No points

ATTENTION

Read list of digits (1 digit/ sec.).

Subject has to repeat them in the forward order [ ] 2 1 8 5 4

Subject has to repeat them in the backward order [ ] 7 4 2 ___/2

Read list of letters. The subject must tap with his hand at each letter A. No points if ≥ 2 errors

[ ] F B A C M N A A J K L B A F A K D E A A A J A M O F A A B ___/1

Serial 7 subtraction starting at 100 [ ] 93 [ ] 86 [ ] 79 [ ] 72 [ ] 65

4 or 5 correct subtractions: **3 pts**, 2 or 3 correct: **2 pts**, 1 correct: **1 pt**, 0 correct: **0 pt** ___/3

LANGUAGE

Repeat : I only know that John is the one to help today. [ ]

The cat always hid under the couch when dogs were in the room. [ ] ___/2

Fluency / Name maximum number of words in one minute that begin with the letter F [ ] _____ (N ≥ 11 words) ___/1

ABSTRACTION

Similarity between e.g. banana - orange = fruit [ ] train – bicycle [ ] watch - ruler ___/2

DELAYED RECALL

	Has to recall words **WITH NO CUE**	FACE [ ]	VELVET [ ]	CHURCH [ ]	DAISY [ ]	RED [ ]	Points for UNCUED recall only
Optional	Category cue						
	Multiple choice cue						

___/5

ORIENTATION

[ ] Date [ ] Month [ ] Year [ ] Day [ ] Place [ ] City ___/6

☐ **Check if ≤ 12 year education (Q26 options 1 & 2) & add 1 point to score**

TOTAL ___/30

Add 1 point if ≤ 12 yr edu

Scoring: add "-9" to all items that were not asked, "0" for failure, "1" for success

COMPLETE THIS SECTION AFTER RESIDENT HAS BEEN INTERVIEWED OR INTERVIEW HAS BEEN ATTEMPTED

TIME ENDED

BREAK TIME START	BREAK TIME END

31. Outcome of interview with resident:
_____ Survey complete

_____ Resident VIEW complete, other completed measures include (check all that apply):
□ QOL-AD □ PHQ-9 □ Katz IADL □ Satisfaction □ Demographic □ MoCA

_____ Survey incomplete, follow-up needed

_____ Survey incomplete, no follow-up needed

32. Resident impressions: Please rate the following items.

	Very inaccurate	Somewhat inaccurate	Neither	Somewhat accurate	Very accurate
a. The resident was engaged during the interview.	1	2	3	4	5
b. The resident seemed to answer questions honestly.	1	2	3	4	5
c. The resident seemed happy or content.	1	2	3	4	5
d. The resident seemed sad, down, or depressed.	1	2	3	4	5
e. The resident seemed angry or irritable.	1	2	3	4	5
f. The resident seemed lethargic.	1	2	3	4	5
g. The resident seemed afraid of the people who work there.	1	2	3	4	5
h. The resident seemed uncomfortable with some questions.	1	2	3	4	5
i. The resident's room/apartment was clean and tidy.	1	2	3	4	5

IF RESPONDENT FATIGUES OR WISHES TO END THE INTERVIEW, NOTE TIME AND ATTEMPT SATISFACTION AND DEMOGRAPHIC QUESTIONS (PAGES 17 & 21)

33. Did resident appear to understand the difference between importance and experience?

No	Unclear	Yes, resident appeared to understand	Yes, resident explicitly stated understanding
1	2	3	4

34. Please rate the following items.

	Not at all/None	A little	Moderate	Very
a. How much difficulty did the resident have understanding the survey?	1	2	3	4
b. How distracted was the resident?	1	2	3	4
c. How well were you able to establish rapport with this resident?	1	2	3	4
d. How often were staff present during the interview?	1	2	3	4

35. a. Was anyone present during an extended period of the interview? □ No □ Yes

b. If so, how many people? _____

c. Relation to the resident? _____

d. Note any relevant interaction during interview:

36. Do you feel these data should be used? (i.e., are you confident in the validity of these responses?)

□ No □ Yes

Additional comments: Provide any additional information that has not yet been captured. Include any particularly positive and/or negative comments or interactions. Include any specific comments the resident made about the tool or the interview not already noted in comments. Please note if multiple interviewers interviewed a resident, and if so, relevant information. *Do not include any repetitive information (e.g., quotes, resident affect, etc.).*

IF RESPONDENT FATIGUES OR WISHES TO END THE INTERVIEW, NOTE TIME AND ATTEMPT SATISFACTION AND DEMOGRAPHIC QUESTIONS (PAGES 17 & 21)