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The Resident VIEW in Nursing Homes

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Abstract

This article presents the Resident VIEW (Voicing Importance, Experience, and Well-Being), a measure designed to learn directly from long-term care residents the extent to which they experience support that matters most to them. The Resident VIEW contains 63 items across eight domains developed through cognitive interviews with residents in different types of residential settings (e.g., nursing homes, assisted living, and adult foster care). Residents rate items on both importance and their experience. In total, 258 nursing home residents living in 32 Oregon nursing homes were selected through a two-stage random sampling design and participated in the study. Results demonstrate that what matters most to residents varies, emphasizing the value of asking residents directly about their preferences. The relationship between importance and experience differed by item. Residents who experienced support rated very important within some domains, reported better quality of life and reported lower levels of depressive symptoms than those who did not experience these things. The interaction between importance and experience, however, did not reach statistical significance, suggesting that positive experiences may provide benefit even in some areas that are not perceived as important by residents. Results underscore the value of incorporating the resident perspective into measure development in long-term care.

Keywords

person-centered care, person-directed care, measurement, resident voice, quality of life, long-term care

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Person-centered care (PCC)¹ practices have emerged as the aspirational standard of practice for care of older adults and people with disabilities, including support for those living in residential long-term care (LTC) settings. Over the past three decades, practitioners, advocates, and scholars throughout the world have contributed to conceptualizing, defining, and implementing PCC practices with the aim of partnering with people who require support to preserve their dignity, autonomy, and relationships, and to improve their quality of life. Although definitions and conceptualizations of PCC vary, consensus is developing around some core elements (American Geriatrics Society Expert Panel on Person-Centered Care, 2016; Corazzini et al., 2019; Health Innovation Network, n.d.; Kitson, Marshall, Bassett, & Zeitz, 2012; McGilton, Heath, et al., 2016). These core elements encompass an explicit emphasis on a holistic approach to care that recognizes the worth and dignity of each person; provides support based on individual goals, preferences, and biography; preserves autonomy; promotes social connection; and is planned and carried out in relationship with the person and his or her family (Behrens et al., 2019; Kogan, Wilber, & Mosqueda, 2016; Scales et al., 2017; Washburn & Grossman, 2017). There is also

a growing recognition that the social context of care as well as the organizational and structural characteristics of the care setting influence the ability of an organization to engage in PCC (Kitson et al., 2012; Siegel et al., 2012).

The development of PCC practices has been accompanied by the need for reliable and valid measures that can be used in research to identify and implement evidence-based best practices and to develop interventions to improve resident outcomes. Multiple measures of PCC from the perspectives of providers have been developed and had their psychometric properties evaluated (e.g., Edvardsson & Innes, 2010; Wilberforce et al., 2016). Similarly, an international consortium called “Worldwide Elements To Harmonize Research In LTC Living Environments” (WE-THRIVE) identified common data elements for use in cross-national PCC research—partly in response to the World Health Organization’s call for comparative measurement for use in changing health

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systems (Corazzini et al., 2019). PCC is one of the four domains identified by the WE-THRIVE consortium. The other domains are the organizational context, workforce and staffing, and care outcomes.

In spite of multiple efforts to develop and improve measurement of PCC, relatively little PCC research has involved recipients of LTC services. Applebaum, Uman, and Straker (2006) argued that improvements in quality of services cannot be made without hearing from consumers of services. Harrison and Frampton (2017), among others, note that residents rarely participate in evaluation of efforts to change culture in nursing homes (NHs) in ways that will contribute to PCC. It is particularly important to hear these voices, because preferences and priorities of residents are often quite different than those of staff and family (White et al., 2012; Whitlatch, Piiparinen, & Feinberg, 2009).

To remedy this situation, measures have been developed that directly involve LTC consumers. For instance, measures such as the Preferences for Everyday Living Instrument (PELI; Van Haitsma, Abbott, et al., 2014; Van Haitsma, Curyto, et al., 2012) can be used across different settings to identify areas of importance to residents and to promote individualized care planning that incorporates very specific preferences. Similarly, the Values and Preferences Scale (VPS; Whitlatch et al., 2005) focused on the importance of values and preferences of people with cognitive impairment as well as their family members' perceptions of their ratings of importance. Zimmerman et al. (2015) have developed a measure of Person-Centered Practices in Assisted Living (PC-PAL) which asks residents to rate their experience with various PCC practices identified by residents. What is missing, however, is a measure that incorporates ratings of importance and experience concurrently. Little research has focused on the impact of discrepancies between desired and received support in LTC settings. Research conducted in other areas has found poorer psychological well-being when preferences for support in community settings are not met (e.g., Reynolds & Perrin, 2004; Sutor, Gilligan, & Pillemer, 2012). Similar research is needed in LTC settings focusing specifically on PCC from the perspectives of residents. This requires measures which can be used to determine whether practices thought to be person-centered are felt to be person-centered by the resident who is the recipient of those support practices.

To address this gap in PCC research, the current study introduces the Resident VIEW (Voicing Importance, Experience, and Well-being). It is a measure intended to enable researchers and providers to learn directly from residents what is and what is not important to them, how their experiences in receiving or not receiving support align with those preferences, and the implications of congruence or incongruence between importance and experience for their well-being and satisfaction with care. This article describes the conceptual framework guiding measurement development, the process of generating

and evaluating items, and the initial results from validating the Resident VIEW with a sample of NH residents. We describe the sample and examine the association between importance and experience with resident well-being. For residents to experience support as person-centered, it needs to be provided in a way that is consistent with what matters most to them, or in ways they find to be very important in their daily lives. As such, we hypothesize that congruence in these elements will contribute to resident well-being—that is, receiving an item will be associated more strongly with positive resident outcomes (i.e., depressive symptoms and reported quality of life) among residents who rated that item to be important for their lives.

Conceptual Framework for the Resident VIEW

The Resident VIEW has its roots in the development of the Person-Directed Care Staff Assessment measure (PDC-SA; White, Newton-Curtis, & Lyons, 2008). PDC-SA was created to evaluate changes in person-directed practices in multiple settings, including NHs and assisted living (AL) communities, and through home care (White et al., 2008; Wilberforce et al., 2016). It includes five subscales reflecting dimensions identified in the extant literature (personhood, knowing the person, autonomy and choice, relationships, and care) and three subscales related to the organizational and physical environment context. Building on this background, the conceptual framework used to develop the Resident VIEW is presented in Figure 1. Personhood holds the central focus with the acknowledgment that each person has inherent value and is worthy of respect (e.g., Coyle & Williams, 2001; Crandall, White, Schuldheis, & Talerico, 2007; Kitwood, 1997; White et al., 2008). The framework identifies five areas of practice that directly support and reinforce personhood: knowing the person (e.g., Boise & White, 2004; Talerico, O'Brien, & Swafford, 2003), supporting autonomy and choice (e.g., Burack, Reinhardt, & Weiner, 2012; Crandall et al., 2007), nurturing relationships (e.g., Kane et al., 2003; McGilton, Sidani, Boscart, Guruge, & Brown, 2012; Roberts & Bowers, 2015), personalizing care (e.g., Crandall et al., 2007; Rader, 1995; Sloane et al., 2013), and providing opportunities for meaningful activity (Edvardsson, Petersson, Sjogren, Lundkvist, & Sandman, 2013; Estabrooks et al., 2015; Mansbach, Mace, Clark, & Firth, 2017). This framework also acknowledges the contribution of the environment, both physical and organizational, as well as the social structure within which PCC practices are facilitated or constrained (Casper, Cooke, O'Rourke, & MacDonald, 2013; Chadbury, Hung, & Badger, 2013; Siegel et al., 2012). Drawing from multiple disciplines and approaches to support the populations served in LTC settings, the Resident VIEW seeks to be comprehensive in examining and documenting PCC practices and the context in which they occur.

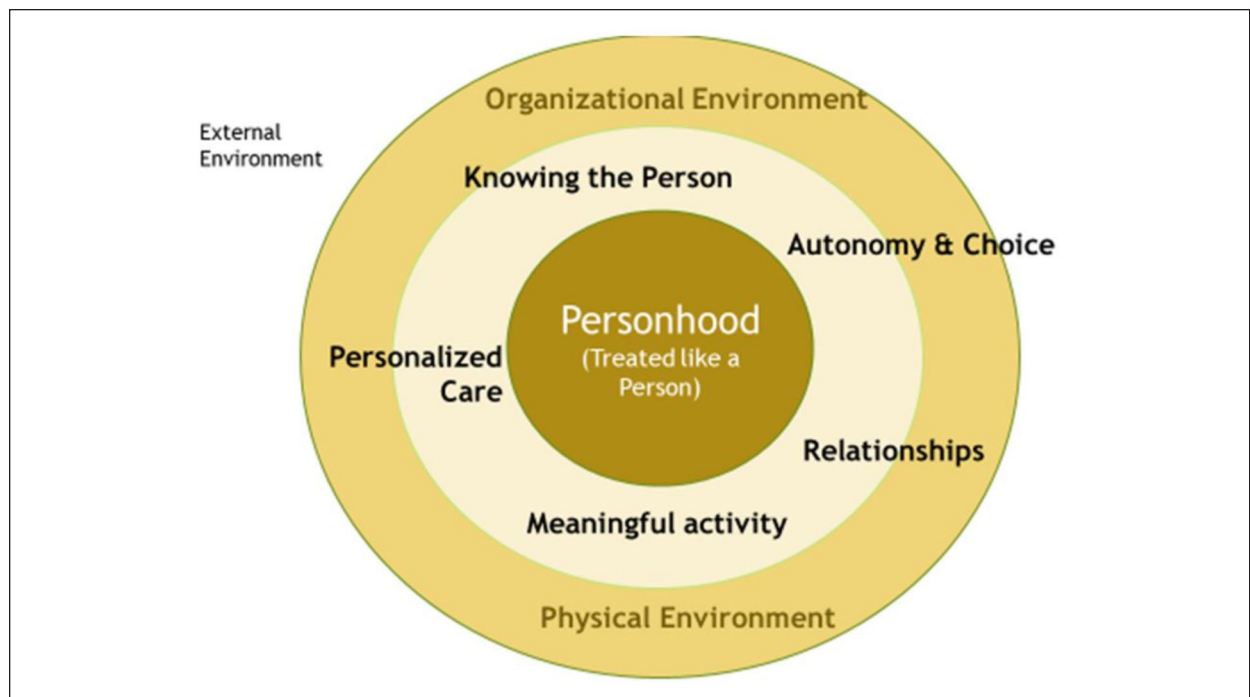


Figure 1. Conceptual framework for the Resident VIEW.

Method

Item Development

To move from the conceptual model to a validated measure, it was critical to engage residents directly, soliciting their insight and expertise as LTC residents in different types of settings. This was accomplished through cognitive interviews. Cognitive interviewing involves asking those who are most knowledgeable about an issue or condition to participate in constructing or evaluating measures related to that issue or condition (Ahmed, Bestall, Payne, Noble, & Ahedzai, 2009; Buers et al., 2014; Peterson, Peterson, & Powell, 2017; Willis, 2011). Cognitive interviewing helps to ensure that items within a measure are comprehensible and meaningful to the person who is asked to respond to them and that the researcher and respondent have a shared understanding of the content and intent of each item. Cognitive interviewing can take many forms. For the Resident VIEW, open-ended questions were used to generate items, and both probing and think-out-loud methods were used to evaluate these proposed items and others proposed by the research team. Each resident answered questions about only one PCC domain. Each domain was reviewed by at least two residents across the three settings. The first set of questions dealt with the domain of interest: “What do you think about when you hear the word [domain name]?” Residents were then given a copy of the definition generated by the research team and asked a series of questions (e.g., “What do you think about this description?” “Does this make sense to you?” “Is this [domain name] important to you?”). “Personhood” was

the domain name that did not make sense to residents. One resident proposed and others agreed that “treated like a person” was a better term.

Next, residents received a list of 10 to 19 items based on the PDC-SA project and the literature to reflect the domain. Participants were asked how they would answer the question, what was a better way of asking the question, how important the question was for understanding the domain, and what other questions should be asked. Several items emerged from this process including “enjoy the view from my window” and staff “having things in common with me.” Finally, residents were asked about response categories to use in the final instrument. They were handed a copy of a 3- and 4-point response category for frequency (i.e., yes, some, no; or all of the time, some of the time, rarely, never). To determine the value of the experience, they were asked whether we should use “importance” or “it matters.” Participants were evenly divided between preferences for these terms. We decided to use “importance” because it was understood by most.

Item development was followed by a feasibility test, which allowed us to determine whether residents could respond to items in all eight domains and whether random sampling of residents was possible in these three types of settings. A convenience sample of care settings was used and residents were randomly sampled from within those settings. Included were six residents living in assisted living or residential care, six in adult foster care, and five in NHs. Additional information about the sample is presented in the final report (White, Elliott, & Hasworth, 2016). In addition to the Resident VIEW, the

research protocol incorporated other established measures critical for obtaining evidence of validity (e.g., predictive and discriminant validity) for the Resident VIEW. These additional measures administered in the feasibility test 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; McCabe, 2019), Patient Health Questionnaire (PHQ-9; Saliba et al., 2012), and satisfaction items based on the work of Kane, Lum, Cutler, Degenholtz, and Yu (2007).

Results indicated that the proposed research protocol was feasible and could be successfully implemented in a larger validation study (White et al., 2016). The feasibility test allowed refinement of items. The resulting Resident VIEW measure totals 63 separate items across the eight domains. Although a 4-point rating was originally used in the feasibility study, it proved too difficult for many residents to rate, especially those in NHs and those with some cognitive impairment. As a result, response categories used in the validation study for rating the importance of these items were "not at all," "somewhat," and "very important." Similarly, response categories for the experience ratings were "no," "some," and "yes."

Sample and Procedures for Validation Testing

Nursing home sample. Ninety-three NHs were selected randomly within a 100-mile radius of Portland State University stratified by rural/urban setting, profit and not-for-profit designation, and quality. Quality was operationalized by regulatory compliance (above or below the median number of survey deficiencies). Recruitment included publicizing the study through the professional associations (e.g., LeadingAge Oregon, Oregon Health Care Association), sending all NH administrators information about the study, and reaching out by phone. We emphasized that the purpose of the study was to evaluate the Resident VIEW and not the NH.

We met our goal to recruit NHs in each stratum, ultimately recruiting 32 NHs where at least one interview was completed. Eighty-five NHs were contacted at least once. Twenty administrators declined to participate and contact was not possible with 19 other NHs despite four to nine attempts. Recruitment stopped within each stratum once the target sample was achieved; eight NHs were not contacted because the stratum was filled. The size of the NHs ranged from a capacity of six to 148 residents, with 53 as the median number of beds. Our analysis comparing facilities in and out of our sample showed few significant differences in terms of NH characteristics (e.g., number of deficiencies, size) or resident characteristics (e.g., percentages of gender, race/ethnicity, Medicaid recipients, long- and short-stay, and quality

measures). The differences that we did observe were in unexpected directions. For instance, responding NHs had a slightly higher prevalence of depression among long-stay residents compared with their nonresponding counterparts (data not shown; available from the first author).

Resident sample. Residents were selected randomly from participating NHs, most often using the resident census or other list provided by the NH. All residents were eligible for participation 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. Residents were not screened for cognitive functioning as part of the eligibility criteria, although interviewers did administer the MoCA as part of the research protocol (Nasreddine et al., 2005). Considering that people with significant cognitive impairment can provide meaningful and consistent responses about their preferences (Feinberg & Whitlatch, 2001; Whitlatch, Feinberg, & Tucke, 2005), our purpose was to determine at what level of cognitive functioning residents are able to respond meaningfully to the Resident VIEW. Interviews were conducted between December 2017 and August 2018.

Ultimately, complete Resident VIEW data were obtained from 258 residents. Additional interviews were initiated, but not completed ($n = 102$). The major reason for incomplete interviews was cognitive impairment (60%) demonstrated through the resident's inability to track questions or respond in meaningful ways (e.g., agreeing with everything, talking about other things in spite of efforts at redirection). About 20% were unable to communicate, typically due to language difficulties, and another 20% of residents elected to discontinue the interview because of fatigue, scheduled therapy, or the person received a visitor.

Results

We start this section by describing the characteristics of the sample, which are presented in Table 1. Both unweighted and weighted statistics are provided. Weights were used to account for stratification and clustering in the study design. As in most LTC settings, this sample was predominantly women. Most residents had lived in the NH for less than a year, but over two thirds were considered long-stay residents. One in five had been in the NH for more than 2 years. Just over half shared rooms and most received financial support through Medicaid. About half were over the age of 75 years, a slightly younger population than Oregon NH residents as a whole (Mendez-Luck, Luck, Larson, & Dyer, 2018). The NH resident sample was somewhat less diverse (94% White-weighted) than the Oregon NH population as a whole (87% White). About 30% of the NH residents lived in rural communities compared with

Table 1. Characteristics of Residents in the Sample ($n = 258$).

| | Observations | Nonmissing unweighted | Nonmissing weighted ^a |
|--------------------------|--------------|-----------------------|----------------------------------|
| Sex | | | |
| Male | 98 | 41.5% | 38.5% |
| Female | 138 | 58.5% | 61.5% |
| Age group (years) | | | |
| <65 | 45 | 19.2% | 17.0% |
| 65-74 | 76 | 32.5% | 32.5% |
| 75-84 | 63 | 26.9% | 28.2% |
| 85 and over | 50 | 21.4% | 22.3% |
| Missing | 24 | | |
| Race/Ethnicity | | | |
| Non-Hispanic White | 217 | 93.1% | 94.0% |
| Other | 16 | 6.9% | 6.0% |
| Medicaid receipt | | | |
| No | 92 | 39.3% | 41.6% |
| Yes | 142 | 60.7% | 58.4% |
| Missing | 24 | | |
| Room type | | | |
| Private | 99 | 42.5% | 46.1% |
| Shared | 134 | 57.5% | 53.9% |
| Stay type | | | |
| Short-stay | 73 | 30.9% | 31.0% |
| Long-stay | 163 | 69.1% | 69.0% |
| Length of stay | | | |
| <6 months | 111 | 47.0% | 50.6% |
| 6-12 months | 35 | 14.8% | 14.4% |
| 1-2 years | 40 | 16.9% | 15.2% |
| More than 2 years | 50 | 21.2% | 19.8% |
| Location | | | |
| Urban | 178 | 69.0% | 71.3% |
| Rural | 80 | 31.0% | 28.7% |

Note. Missing data ranged between 22 and 25 participants for each of these items. Most (22) were from one nursing home where the administrative staff was not available to provide the information in spite of multiple attempts.

^aWeights were used to account for stratification and clustering in the study design, allowing for generalization of findings to coverage area (see text for details).

20% of Oregon's general population (U.S. Census Bureau, 2010).

All except five residents completed additional measures, including the satisfaction items, QOL-AD, and the PHQ-9. With respect to the satisfaction measures, well over 80% of the residents reported they were satisfied (51.5% weighted) or very satisfied (34.1% weighted) with the NH as a place to live. Similar weighted ratings were given to the NH as a place to receive care (49.7% satisfied; 39.6% very satisfied), and most residents (83.3%) would recommend the NH to someone else. The PHQ-9 contains nine symptoms of depression with ratings from 0 = *not at all*, 1 = *several days*, 2 = *more than half the days*, to 3 = *nearly every day*. The mean item score ($n = 257$) was .80 ($SD = .61$), which indicates mild levels of depression for the sample (Cronbach's alpha = .79). Eleven items from the QOL-AD scale were used (1 = *poor*, 2 = *fair*, 3 = *good*, 4 = *excellent*). Quality of life related to marriage was not used because of high rates of widowhood and unmarried

status of NH residents. The mean score per item ($n = 257$) was 2.6 ($SD = .53$) suggesting that residents rated their quality of life between "fair" and "good." See Supplemental Tables 1 and 2 for more details on these measures.

Less than half (46%) of the residents completed the MoCA form. It was the final standardized measure administered and some were fatigued by that time in the interview. Many residents refused to complete all or parts of the MoCA. Others were not physically able to complete the visuospatial/executive portion of the MoCA due to physical disability, including blindness resulting in 45% missing data for this domain. Other domains had completion rates ranging from 76% (orientation) to 68% (attention). Of the 119 residents who completed all parts of the MoCA, 75% showed some form of cognitive impairment. The median score was 21, indicating mild cognitive impairment, and 25% percentile was 16, indicating moderate cognitive impairment (<https://www.mocatest.org/faq/>).

Table 2. Distribution of Resident VIEW-NH Items in the Sample.

| Item | Obs. | Importance | | | Experience | | | Rho ^a |
|--|------|------------|-----------|-----------|------------|-------------|------------|------------------|
| | | NI, % (n) | SI, % (n) | VI, % (n) | No, % (n) | Some, % (n) | Yes, % (n) | |
| Domain 1: Physical environment (Alpha: Imp. (.63) Exp. (.60)) | | | | | | | | |
| a. Your room is arranged and decorated the way you want it? | 252 | 13 (38) | 33 (86) | 54 (128) | 17 (43) | 26 (67) | 57 (142) | .23** |
| b. You enjoy the view from your window? | 254 | 20 (51) | 29 (77) | 51 (126) | 23 (66) | 17 (42) | 60 (146) | .36*** |
| c. You feel welcome in areas outside of your room? | 252 | 7 (22) | 28 (69) | 65 (161) | 5 (14) | 10 (28) | 85 (210) | .10 |
| d. You easily get around outside of your room? | 254 | 4 (11) | 24 (66) | 72 (177) | 14 (38) | 12 (33) | 74 (183) | .23*** |
| e. You got outdoors? | 253 | 18 (48) | 29 (72) | 53 (133) | 27 (69) | 14 (47) | 58 (137) | .21*** |
| f. It is peaceful here? | 256 | 3 (8) | 19 (51) | 78 (197) | 8 (24) | 26 (64) | 65 (168) | -.05 |
| g. It feels like home here? | 252 | 18 (51) | 33 (83) | 49 (118) | 50 (130) | 23 (56) | 28 (66) | .46*** |
| Domain 2: Meaningful activity (Alpha: Imp. (.75) Exp. (.72)) | | | | | | | | |
| a. Do the things you care about? | 250 | 7 (15) | 27 (70) | 66 (165) | 23 (60) | 30 (74) | 47 (116) | .19** |
| b. Do things with other people who live here? | 254 | 38 (98) | 35 (88) | 27 (68) | 40 (106) | 27 (64) | 34 (84) | .54*** |
| c. Do things just for fun? | 252 | 15 (41) | 35 (84) | 50 (127) | 22 (56) | 23 (56) | 54 (140) | .37*** |
| d. Do physical activities (e.g., exercise classes, go on walks, work on strength)? | 253 | 22 (58) | 26 (64) | 51 (131) | 27 (74) | 23 (58) | 50 (121) | .55*** |
| e. Take care of plants? | 255 | 53 (141) | 19 (48) | 28 (66) | 78 (202) | 6 (12) | 16 (41) | .51*** |
| f. Spend time with animals? | 253 | 34 (87) | 18 (52) | 48 (114) | 62 (159) | 17 (41) | 21 (53) | .50*** |
| g. Listen to or make music that you like? | 254 | 24 (61) | 28 (76) | 48 (117) | 41 (104) | 18 (38) | 41 (112) | .36*** |
| h. Do things to help others who live or work here? | 251 | 22 (55) | 36 (92) | 42 (104) | 36 (86) | 23 (63) | 41 (102) | .53*** |
| i. Share your wisdom with the people who work here (e.g., advice)? | 251 | 24 (59) | 39 (99) | 37 (93) | 27 (63) | 32 (86) | 41 (102) | .57*** |
| j. Have a purpose in life? | 247 | 8 (23) | 17 (33) | 74 (191) | 18 (45) | 18 (41) | 64 (161) | .43*** |
| Domain 3: Personalized care (Alpha: Imp. (.80) Exp. (.84)) | | | | | | | | |
| a. Take into account your health needs? | 254 | 1 (4) | 7 (15) | 91 (235) | 6 (17) | 14 (31) | 80 (206) | .25*** |
| b. Respond quickly to your requests (e.g., to ease your pain, to use the toilet?) | 256 | 2 (7) | 16 (48) | 81 (201) | 15 (39) | 31 (82) | 54 (135) | .04 |
| c. Make you feel at ease when they are helping you (e.g., to get dressed, in the bathroom)? | 255 | 2 (7) | 11 (28) | 87 (220) | 4 (12) | 18 (44) | 78 (199) | .28*** |
| d. Tell you how long you have to wait if they can't help you right away? | 248 | 9 (24) | 25 (64) | 66 (160) | 26 (65) | 27 (65) | 47 (118) | -.01 |
| e. Take the time with you that you need? | 255 | 2 (5) | 18 (45) | 81 (205) | 8 (27) | 24 (56) | 68 (172) | .09 |
| f. Make you feel comfortable asking for help? | 256 | 3 (9) | 15 (40) | 82 (207) | 8 (21) | 16 (36) | 76 (199) | .26*** |
| g. Make sure that you can hear what they say? | 251 | 2 (5) | 13 (31) | 85 (215) | 4 (11) | 17 (35) | 79 (205) | .03 |
| h. Are gentle when they are helping you or doing things for you (e.g., to get dressed, in the bathroom)? | 256 | 3 (8) | 9 (25) | 88 (223) | 3 (9) | 20 (52) | 77 (195) | .01 |
| Domain 4: Knowing the person (Alpha: Imp. (.82) Exp. (.82)) | | | | | | | | |
| a. How you like to have things done? | 251 | 5 (15) | 27 (65) | 68 (171) | 14 (31) | 27 (68) | 60 (152) | .18** |
| b. The kinds of things you are interested in? | 254 | 17 (44) | 41 (109) | 42 (101) | 26 (63) | 29 (73) | 46 (118) | .33*** |
| c. How you like to spend your time? | 252 | 19 (46) | 33 (90) | 47 (116) | 21 (57) | 27 (61) | 52 (134) | .28*** |
| d. What makes a good day for you? | 240 | 14 (32) | 30 (81) | 56 (127) | 25 (58) | 26 (62) | 49 (120) | .33*** |
| e. Who is important to you (e.g., family, friends)? | 249 | 11 (30) | 22 (58) | 66 (161) | 12 (33) | 19 (49) | 69 (167) | .39*** |
| f. What you worry about? | 239 | 31 (75) | 32 (78) | 36 (86) | 50 (118) | 22 (53) | 28 (68) | .31*** |
| g. What you like to be called? | 255 | 19 (39) | 24 (66) | 57 (150) | 4 (11) | 7 (17) | 89 (227) | .22*** |
| Domain 5: Autonomy/choice (Alpha: Imp. (.74) Exp. (.70)) | | | | | | | | |
| a. Get up when you want to? | 257 | 6 (16) | 15 (41) | 79 (200) | 21 (53) | 13 (37) | 66 (167) | .15* |
| b. Eat meals when you want to? | 253 | 21 (49) | 31 (85) | 47 (119) | 34 (91) | 18 (46) | 48 (116) | .18** |
| c. Take a shower or a bath when you want to? | 255 | 10 (28) | 24 (66) | 66 (161) | 43 (106) | 13 (37) | 44 (112) | .12* |

(continued)

Table 2. (continued)

| Item | Obs. | Importance | | | Experience | | | Rho ^a |
|---|------|------------|-----------|-----------|------------|-------------|------------|------------------|
| | | NI, % (n) | SI, % (n) | VI, % (n) | No, % (n) | Some, % (n) | Yes, % (n) | |
| 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)? | 248 | 3 (9) | 19 (49) | 78 (190) | 15 (41) | 21 (44) | 63 (163) | .31*** |
| e. Spend your time the way you want to? | 258 | 3 (9) | 24 (67) | 73 (182) | 12 (35) | 20 (49) | 68 (174) | .13* |
| f. Have privacy when you want it? | 258 | 7 (18) | 12 (33) | 81 (207) | 11 (29) | 17 (44) | 73 (185) | -.0 |
| g. Can do things for yourself? | 255 | 3 (7) | 14 (36) | 83 (212) | 7 (19) | 19 (45) | 74 (191) | .30*** |
| h. Have a say in how this place works (e.g., meal schedules, decorating communal areas, planning social events, hiring & evaluating staff)? | 253 | 24 (65) | 35 (90) | 41 (98) | 65 (167) | 16 (42) | 19 (44) | .28*** |
| i. Feel free to express your opinions about things you do not like here? | 250 | 9 (22) | 16 (44) | 75 (184) | 11 (30) | 15 (35) | 73 (185) | .27*** |
| Domain 6: Treated like a person (Alpha: Imp. (.81) Exp. (.88)) | | | | | | | | |
| a. Pay attention to your opinions? | 237 | 3 (9) | 23 (58) | 74 (170) | 11 (27) | 29 (70) | 60 (140) | .09 |
| b. Show that they are interested in you as a person? | 254 | 6 (17) | 21 (59) | 72 (178) | 10 (24) | 28 (71) | 62 (159) | .24*** |
| c. Listen to you without interrupting? | 253 | 4 (12) | 26 (68) | 70 (173) | 11 (25) | 19 (52) | 70 (176) | .18** |
| d. Show that your needs are important to them? | 250 | 5 (13) | 16 (42) | 79 (195) | 8 (24) | 27 (59) | 65 (167) | .23*** |
| e. Understand what it is like for you to live here? | 236 | 7 (20) | 20 (50) | 72 (166) | 28 (70) | 26 (59) | 45 (107) | .25*** |
| f. Answer your questions? | 254 | 1 (5) | 16 (42) | 82 (207) | 9 (19) | 19 (50) | 72 (185) | .10 |
| g. Treat you with respect? | 256 | 1 (3) | 6 (16) | 93 (237) | 3 (8) | 15 (37) | 82 (211) | .19** |
| h. Treat you with kindness? | 257 | 2 (5) | 9 (22) | 89 (230) | 3 (8) | 13 (33) | 84 (216) | .26*** |
| Domain 7: Relationship with staff (Alpha: Imp. (.85) Exp. (.79)) | | | | | | | | |
| a. Listen to you share stories about your life? | 255 | 24 (64) | 43 (109) | 33 (82) | 26 (62) | 24 (66) | 50 (127) | .40*** |
| b. Tell you about their personal lives? | 257 | 29 (79) | 45 (112) | 26 (66) | 28 (73) | 45 (108) | 27 (76) | .44*** |
| c. Talk to you about things you are interested in? | 247 | 18 (41) | 42 (108) | 40 (98) | 25 (61) | 31 (78) | 44 (108) | .41*** |
| d. Spend time with you just talking or being with you? | 253 | 19 (49) | 42 (108) | 40 (96) | 32 (82) | 38 (96) | 30 (75) | .29*** |
| e. Know what you have done in your life? | 250 | 34 (85) | 42 (106) | 24 (59) | 39 (91) | 35 (91) | 27 (68) | .26*** |
| f. Have things in common with you? | 241 | 35 (88) | 42 (99) | 23 (54) | 32 (76) | 46 (113) | 21 (52) | .17* |
| g. Laugh with you? | 255 | 13 (36) | 26 (67) | 62 (152) | 7 (20) | 21 (53) | 71 (182) | .33*** |
| Domain 8: Organizational environment (Alpha: Imp. (.61) Exp. (.57)) | | | | | | | | |
| a. You can talk to the [owner/ manager/ administrator] if you have a problem? | 246 | 5 (14) | 13 (34) | 82 (198) | 31 (71) | 8 (19) | 61 (156) | .33*** |
| b. You see the [owner/manager/ administrator] around the home? | 251 | 20 (54) | 26 (71) | 54 (126) | 33 (78) | 15 (38) | 52 (135) | .27*** |
| c. The same people help you on most days? | 252 | 10 (31) | 32 (77) | 58 (144) | 32 (80) | 17 (44) | 52 (128) | .20** |
| d. You have a say in who works here? | 245 | 44 (113) | 25 (61) | 31 (71) | 79 (199) | 8 (18) | 12 (28) | .30*** |
| e. The people who work here have time to help you when you need it? | 252 | 1 (4) | 16 (42) | 83 (206) | 11 (28) | 28 (73) | 60 (151) | -.01 |
| f. The people who work here have a good attitude? | 257 | 1 (2) | 8 (22) | 92 (233) | 3 (9) | 22 (59) | 76 (189) | .10 |
| g. This place is run well? | 248 | 2 (5) | 6 (14) | 92 (229) | 13 (36) | 22 (53) | 65 (159) | .24*** |

Note. All percentages are weighted and all ns in parentheses are unweighted. Row percentages may not add up to 100 due to rounding. VIEW: Voicing Importance, Experience, and Well-Being; NH: nursing home; NI = not important; I = somewhat important; VI = very important.

^aRho refers to Pearson's correlation coefficient between responses to importance and experience questions for each item based on unweighted responses, and measures the strength of the linear relationship in the sample.

* $p < .05$. ** $p < .01$. *** $p < .001$.

We now report on the univariate distribution of the Resident VIEW items. Table 2 presents all 63 items by domain with the distribution of ratings for both importance and experience. In addition, Cronbach's alpha

coefficients are reported for each of the subscales. The alpha coefficients for the domains of personalized care, knowing the person, treated like a person, and relationship with staff are high, indicating that the items within

Table 3. Differences in Average of Measures of Depressive Symptoms (PHQ-9) and Quality of Life (QOL-AD) by Reported Experience.

| Item | PHQ-9 | | QOL-AD | |
|---|-------|---------|--------|---------|
| | N-S | Yes | N-S | Yes |
| Domain 1: Physical environment | | | | |
| a. Your room is arranged and decorated the way you want it? | 1.00 | 0.69*** | 2.46 | 2.77*** |
| b. You enjoy the view from your window? | 0.92 | 0.76 | 2.55 | 2.69 |
| c. You feel welcome in areas outside of your room? | 1.15 | 0.77 | 2.42 | 2.68** |
| d. You easily get around outside of your room? | 0.92 | 0.79 | 2.45 | 2.70** |
| e. You go outdoors? | 0.87 | 0.79 | 2.47 | 2.75** |
| f. It is peaceful here? | 0.97 | 0.73* | 2.41 | 2.76*** |
| g. It feels like home here? | 0.86 | 0.72 | 2.55 | 2.86*** |
| Domain 2: Meaningful activity | | | | |
| a. Do the things you care about? | 0.94 | 0.69** | 2.46 | 2.85*** |
| b. Do things with other people who live here? | 0.86 | 0.74 | 2.55 | 2.83*** |
| c. Do things just for fun? | 0.90 | 0.75 | 2.46 | 2.79*** |
| d. Do physical activities (e.g., exercise classes, go on walks, work on strength)? | 0.93 | 0.72* | 2.57 | 2.72 |
| e. Take care of plants? | 0.81 | 0.84 | 2.63 | 2.73 |
| f. Spend time with animals? | 0.81 | 0.88 | 2.61 | 2.73 |
| g. Listen to or make music that you like? | 0.85 | 0.79 | 2.57 | 2.74* |
| h. Do things to help others who live or work here? | 0.82 | 0.82 | 2.56 | 2.76* |
| i. Share your wisdom with the people who work here (e.g., advice)? | 0.80 | 0.86 | 2.58 | 2.71 |
| j. Have a purpose in life? | 1.01 | 0.73** | 2.39 | 2.78*** |
| Domain 3: Personalized care | | | | |
| a. Take into account your health needs? | 1.13 | 0.75** | 2.22 | 2.74*** |
| b. Respond quickly to your requests (e.g., to ease your pain, to use the toilet)? | 0.95 | 0.71* | 2.47 | 2.78*** |
| c. Make you feel at ease when they are helping you (e.g., to get dressed, in the bathroom)? | 1.11 | 0.74** | 2.30 | 2.73** |
| d. Tell you how long you have to wait if they can't help you right away? | 0.95 | 0.71* | 2.48 | 2.80*** |
| e. Take the time with you that you need? | 1.07 | 0.71** | 2.40 | 2.75** |
| f. Make you feel comfortable asking for help? | 1.08 | 0.74* | 2.31 | 2.75** |
| g. Make sure that you can hear what they say? | 1.24 | 0.72*** | 2.33 | 2.72** |
| h. Are gentle when they are helping you or doing things for you (e.g., to get dressed, in the bathroom)? | 1.02 | 0.76 | 2.31 | 2.73*** |
| Domain 4: Knowing the person | | | | |
| a. How you like to have things done? | 0.93 | 0.75 | 2.51 | 2.73* |
| b. The kinds of things you are interested in? | 0.89 | 0.74 | 2.50 | 2.81*** |
| c. How you like to spend your time? | 0.94 | 0.72* | 2.47 | 2.79*** |
| d. What makes a good day for you? | 0.94 | 0.73* | 2.45 | 2.82*** |
| e. Who is important to you (e.g., family, friends)? | 0.93 | 0.78 | 2.43 | 2.73** |
| f. What you worry about? | 0.83 | 0.85 | 2.58 | 2.76* |
| g. What you like to be called? | 0.91 | 0.80 | 2.62 | 2.64 |
| Domain 5: Autonomy/choice | | | | |
| a. Get up when you want to? | 0.98 | 0.73* | 2.46 | 2.73** |
| b. Eat meals when you want to? | 0.83 | 0.81 | 2.60 | 2.69 |
| c. Take a shower or a bath when you want to? | 0.89 | 0.74 | 2.50 | 2.82*** |
| 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)? | 0.96 | 0.75* | 2.50 | 2.71* |
| e. Spend your time the way you want to? | 0.98 | 0.74** | 2.47 | 2.72** |
| f. Have privacy when you want it? | 0.93 | 0.78 | 2.49 | 2.69* |
| g. Can do things for yourself? | 1.05 | 0.73** | 2.40 | 2.73** |
| h. Have a say in how this place works (e.g., meal schedules, decorating communal areas, planning social events, hiring & evaluating staff)? | 0.85 | 0.69 | 2.57 | 2.93*** |
| i. Feel free to express your opinions about things you do not like here? | 0.95 | 0.78 | 2.48 | 2.69* |
| Domain 6: Treated like a person | | | | |
| a. Pay attention to your opinions? | 0.91 | 0.78 | 2.46 | 2.77** |
| b. Show that they are interested in you as a person? | 0.97 | 0.74* | 2.41 | 2.78*** |
| c. Listen to you without interrupting? | 1.09 | 0.71** | 2.41 | 2.74** |

(continued)

Table 3. (continued)

| Item | PHQ-9 | | QOL-AD | |
|--|-------|---------|--------|---------|
| | N-S | Yes | N-S | Yes |
| d. Show that your needs are important to them? | 1.06 | 0.69*** | 2.41 | 2.76** |
| e. Understand what it is like for you to live here? | 0.95 | 0.68** | 2.49 | 2.81*** |
| f. Answer your questions? | 1.11 | 0.71** | 2.38 | 2.74** |
| g. Treat you with respect? | 1.17 | 0.74** | 2.23 | 2.73*** |
| h. Treat you with kindness? | 1.09 | 0.77 | 2.29 | 2.70* |
| Domain 7: Relationship with staff | | | | |
| a. Listen to you share stories about your life? | 0.90 | 0.75 | 2.53 | 2.74* |
| b. Tell you about their personal lives? | 0.81 | 0.85 | 2.59 | 2.76* |
| c. Talk to you about things you are interested in? | 0.89 | 0.74 | 2.51 | 2.81*** |
| d. Spend time with you just talking or being with you? | 0.83 | 0.76 | 2.54 | 2.83** |
| e. Know what you have done in your life? | 0.86 | 0.73 | 2.60 | 2.73 |
| f. Have things in common with you? | 0.85 | 0.77 | 2.56 | 2.90*** |
| g. Laugh with you? | 0.94 | 0.77 | 2.39 | 2.74** |
| Domain 8: Organizational environment | | | | |
| a. You can talk to the [owner/ manager/administrator] if you have a problem? | 0.97 | 0.73* | 2.49 | 2.73* |
| b. You see the [owner/manager/ administrator] around the home? | 0.88 | 0.78 | 2.52 | 2.74* |
| c. The same people help you on most days? | 0.76 | 0.88 | 2.62 | 2.66 |
| d. You have a say in who works here? | 0.84 | 0.72 | 2.60 | 2.87* |
| e. The people who work here have time to help you when you need it? | 0.96 | 0.72* | 2.43 | 2.78*** |
| f. The people who work here have a good attitude? | 1.03 | 0.76** | 2.39 | 2.72*** |
| g. This place is run well? | 1.01 | 0.73* | 2.33 | 2.80*** |

Note. All means are weighted. N-S: no (not at all) or some receipt.

Difference tests are based on ordinary least squares (OLS) linear regression results incorporating design weights.

* $p < .05$. ** $p < .01$. *** $p < .001$.

these domains work together well (Pedhazur & Schmelkin, 1991). The domains of meaningful activity and autonomy and choice are satisfactory for research purposes ranging from .70 to .75. The items in the domains for physical and organizational environments work less well together as indicated by alpha coefficients ranging from .57 to .63.

As expected ratings of importance for items varied, from just 23% of the sample saying that having things in common with the staff was very important to almost all (93%) of residents rating being treated with respect as very important (Table 2). Overall, items within the personalized care and being treated as a person domains received the highest ratings of importance, and items in the knowing the person and meaningful activities domains received the lowest. The large variation in the percentages of individual items indicates that what residents find important differs. Some things, such as that the place is run well or that staff have time to help residents when they need help, were rated to be very important by almost all NH residents. Other things were found very important by only a minority of residents. For example, only about one quarter (23%) of residents found it very important for them to have things in common with staff, an indicator of relationships with staff. Similarly, less than half of the residents identified staff knowing how they like to spend their time as very important. These findings illustrate the importance of

asking residents' preferences and not presuming to know what they may or may not want.

We next examined experience and again found substantial variation. Most residents reported that the staff treated them with kindness (84%) and that they felt welcome in areas outside of their room (85%). In contrast, fewer than 30% of residents reported that they experienced support such as staff knowing what they worried about, spent time just talking or being with them, had things in common with them, or the resident had a say in who worked in the NH. Actual experience can affect self-reported well-being as measured by average QOL-AD and PHQ-9 scores (Table 3). Many of the items across all domains were significantly associated with QOL-AD and several items within the personalized care and treated like a person domains were also significantly associated with lower levels depression.

The current study was also aimed to explore the relationship between the importance and experience ratings. The last column of Table 2 presents the rho coefficient for each item, which refers to Pearson's correlation coefficient between responses to importance and experience questions for each item. Experience and importance relationships between many of these items were quite strong, indicating that for these items, there is substantial congruence between what people want and what they receive. Examples include doing physical activities, taking care of plants, sharing your wisdom with the

people who live here, and doing things to help others. At the same time, items that were very important to some residents were not received by many of those same residents (e.g., staff responding quickly to your needs, taking a shower or bath when you want to, the people who work here have a good attitude). In contrast, some residents experienced support that they had not rated as very important (e.g., you feel welcome in areas outside of your room). Discrepancies between items rated as very important and actual experience indicate areas of unmet need, a situation shared by many of the participants in this study. For example, a substantial proportion of residents who found it very important to get up or bathe when they wanted, did not experience those things. Similarly, many residents did not fully experience staff with good attitudes, or staff who knew who was important to them or how they liked to spend their time.

Finally, the Resident VIEW was developed with the assumption that the lack of a particular service or item can hurt most those who find it important for their lives and well-being. Therefore, when we examine importance and experience together, we expected to find the lowest scores in well-being among those who rated an item very important but were not getting it. To test this expectation, we calculated PHQ-9 and QOL-AD scores for four groups of respondents (very important vs. all others and those who responded yes to the experience question vs. all others) for each item. On the whole, those who rated something as very important and experienced it had higher QOL-AD and lower PHQ-9 scores (Supplemental Tables 3 and 4). The strongest association between experience and outcomes was for those who rated an item as very important. However, experience was also beneficial for those who rated it less important or not important at all. Therefore, these findings suggest that receiving support associated with PCC may be beneficial regardless of ratings of importance assigned by residents.

Discussion

Implications for Research

This article presents initial analysis of data collected to validate the Resident VIEW in NH. The research team was able to recruit a representative sample of Oregon NHs located within a 100-mile radius from the university and complete 258 interviews with residents who were not initially screened for cognitive impairment but were able to complete the interview successfully. This survey design was not particularly efficient and slowed data collection, but it did allow us to successfully include the voices of many cognitively impaired residents who otherwise might not have been heard.

In the course of this study, we identified new items (e.g., “how important is it for you to have a say in who helps you?”) as well as a few problematic ones. Accordingly, the Resident VIEW underwent minor revisions and is currently being tested in community-based care (CBC) settings across Oregon (Resident

VIEW-CBC). CBC settings include assisted living, residential care, and adult foster care homes. Adult foster homes are small (one to five residents) residential settings licensed to provide support to frail and disabled adults (Carder, Tunalilar, Elliott, & Dys, 2018). We will repeat these analyses using the CBC data to identify similarities and differences across setting type. We may find core items that work well across settings as well as items that are setting specific.

Further analysis is needed to finalize the Resident VIEW measure for use in NH. A priority is to reduce the number of items included in the measure. The median time to complete an interview was almost an hour (58 min). This is similar to the time it takes to complete the Minimum Data Set (MDS) for each resident (Saliba & Buchanan, 2012). Considering the high acuity levels of NH residents (and also adult foster care residents), the Resident VIEW in its current form is clearly too long to be used extensively in research or practice. For example, several items appear redundant and others have little variability. We continue analysis to identify the empirically and conceptually strongest items. As part of this process, we will explore the value of asking both about importance and experience or whether questions about experience are sufficient.

In the future, we plan to examine whether aggregate Resident VIEW scores within facilities are associated with various quality indicators at the organizational level as well as with staffing and the environmental context. Such information could help guide policy and practice with the aim of increasing PCC resident experiences by prioritizing and providing the support that matters the most to them.

Given the cross-sectional nature of the data, we are limited in our analysis to examining contemporaneous associations between variables denoting importance, experience, and well-being. Increasingly, longitudinal designs are examining the change and stability in preferences of NH residents (Feinberg & Whitlatch, 2001; Van Haitsma, Crespy, et al., 2014). Within-resident variation in preferences potentially can be linked to dissatisfaction with an NH, especially if care plans are not updated to ensure residents' changing needs and desires are taken into account.

Finally, we were unable to collect data on several resident characteristics that we expect play an important role in the formation of preferences. For instance, we excluded items pertaining to personality traits, especially as they relate to resilience and adaptability to the environment, due to concerns with respondent burden. Similarly, we did not collect extensive data on our respondents' external social support outside of the NH—such as from family, relatives, and friends—nor did we capture information about social visits. Even with these limitations, we contend that studies such as ours continue to increase our understanding regarding LTC residents' preferences and experiences as well as how the interaction of these two dimensions may affect their well-being and quality of life.

Conclusion

This research was initiated to develop a measure that elevates the voices of residents in LTC residential settings about what is important to them and what they experience in their daily lives, addressing a major gap in PCC research. We were able to successfully interview residents with multiple levels of physical and cognitive abilities in a representative sample of Oregon NHs. We found that ratings of importance vary which reemphasizes to providers that in many areas assumptions cannot be made about what an individual resident will find important. We also identified areas of congruence and incongruence in ratings of importance and experience and learned that congruence of ratings of “very important” with what the person experiences is often predictive of well-being, although not statistically significant. When completed, the Resident VIEW can be used in future research to examine whether specific practices contribute to individualized support and well-being among residents with diverse experiences, preferences, and needs.

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Supplemental Material

Supplemental material for this article is available online.

Note

1. In this article, we use the term “person-centered care,” although the term “person-directed care” is used in our work. These concepts are related, but different (Lines, Lepore, & Weiner, 2015; Pioneer Network, no date, <https://www.pioneernetwork.net/culture-change/continuum-person-directed-culture/>). “Person-centered” puts the whole person at the center of care. That is, it is a biopsychosocial approach to thinking about and planning care for and with an individual. “Person-directed” care goes a step further, emphasizing that the individual is in charge of decisions about his or her care, nonmedical issues are paramount in decision-making and empowerment of the person and family is very high (Lines et al., 2015; Scales et al., 2017). With the Resident VIEW, “person-directed” emphasizes the importance of the person receiving support in directing and making decisions about their daily life regardless of their physical and cognitive abilities and environmental constraints.

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