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Using Spontaneous Commentary of Nursing Home Residents to Develop Resident-Centered Measurement Tools: A Case Study

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Abstract

Nursing home (NH) residents routinely complete surveys that assess their health, well-being, preferences, and care needs. Such surveys reveal important information, however, are largely based on the concerns of providers as opposed to the concerns of residents. Thus, researchers must enhance efforts to ensure that these surveys are guided by the priorities, needs, and concerns of residents. We present a case study to demonstrate how spontaneous commentary of NH residents holds particular efficacy for ensuring that measurement tools are guided by the needs, concerns, and priorities of residents. Spontaneous comments from NH residents ($N=370$) collected as part of a study developing the Preferences for Everyday Living Inventory for NH residents (PELI-NH) were used to refine the PELI-NH across key phases of measurement development. This work demonstrates how the spontaneous commentary of NH residents may contribute to the refinement of NH measurement tools, and allow researchers to base these tools on the needs and priorities of NH residents.

Keywords

Measurement Development; Nursing Home Resident; Spontaneous Commentary

Instruments that assess nursing home (NH) residents' mental and physical health, well-being, and preferences for everyday care are routinely utilized in long-term care facilities. For example, the minimum data set (MDS) is a standardized assessment of resident health and function, services being provided to the resident, and changes in resident status, completed at all Medicare certified nursing homes in the US.¹ Measures that assess resident

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satisfaction with care are widely used for the purpose of facilitating better recognition of each resident's needs and satisfaction with their care.² The majority of instruments used to gather data from NH residents are objective, direct measures of satisfaction. Yet, previous research has identified limitations of this approach, which tends to be restricted by ceiling effects skewed towards greater satisfaction.^{3,4} Moreover, the meaning and specificity behind residents' responses to these surveys is not understood through quantitative measures, therefore limiting what can be gained through this form of inquiry.

Residents typically complete these surveys verbally, with the assistance of a trained interviewer or researcher, and in doing so often elicit spontaneous commentary to contextualize and provide further depth to item responses. The tendency for older adults to voluntarily elicit spontaneous comments is consistent with related work that shows older adults readily disclose indirect and subjective content to enhance their own narratives.⁵ Thus, it is perhaps not surprising that elder NH residents would also elicit spontaneous commentary in order to enhance their responses to closed-ended questions about their personal health, needs, and preferences. Such commentary may be attributed to the idea that, compared to younger adults, older adults have communicative goals that require more subjective and indirectly relevant information,⁵ these goals cannot be met solely by closed-ended questions typically included in NH surveys. Thus, it is quite likely that survey data is capturing a limited perspective, and that this data could be enhanced by systematically assessing the spontaneous commentary of NH residents during survey completion.

Limited research has explored the content of spontaneous comments in older adult populations, particularly within the NH setting. One exception found that NH residents do in fact produce spontaneous comments at a high frequency; 95% of residents sampled (N=69) elicited spontaneous commentary while answering open and closed-ended questions.⁴ This work argues that NH residents' spontaneous commentary is elicited at a high frequency and is a valuable mechanism for understanding residents' unmet needs. Moreover, standard content analysis procedures can be used to meaningfully analyze such comments.⁴ In lieu of the relatively small research base, this study sought to address the broad issue of close ended survey methodology in NH research. Using a case study methodology, we demonstrate the role that NH residents' spontaneous commentary played in developing the Preferences for Everyday Living Inventory for NH residents (PELI-NH)^{6,7} a 72-item instrument that examines the content, and importance of psychosocial preferences among NH residents.

Methods

Participants

The purpose of the study was to adapt the PELI Home Care Version (PELI-HC) developed for frail, community dwelling elders, for use with NH residents (PELI-NH). Cognitively capable residents were referred by facility staff (i.e., administrators, directors of nursing, and/or activity directors). Residents who met the eligibility criteria (English speaking, had been at their facility for at least one week and were expected to remain at the facility for at least 3 months) were referred by staff to the study. Residents were excluded from the study for the following reasons: they lacked capacity to consent for self, had a life limiting illness, did not speak English, resided in the facility for less than a week, was projected to remain in

the facility for less than a week, lacked the cognitive capacity to consent for his/her self. Once residents were identified, the director of nursing verified that the resident had either the capacity to consent and/or had a family member that could consent for the resident. In addition, participants were cleared by their physician for cognitive capacity to consent and medical stability. A total of 760 residents from 32 NHs in the greater Philadelphia area were referred to participate in the study; the final sample consisted of 370 residents (49% completion rate). See Table 1 for demographic information.

Informed consent for participation in the study was established in-person by iterative questioning according to institutional review board approved procedures and protocol. After a resident consented, participants were screened for cognitive impairment using the Mini-Mental State Examination (MMSE ranges from 0–30, with lower scores indicating greater cognitive impairment). Residents who scored 13 or below were not eligible for participation in the study creating a sample with mild to moderate levels of cognitive impairment, but excluding those with more severe levels of impairment.

Measures

Preference Interview

The PELI-HC is a 55-item assessment of preferences spanning five major domains: social contact, growth activities, diversionary activities, self-dominion, and enlisting others in care.⁶ Items assess preferences for a variety of every-day topics from food and dining to social interaction, to health and personal care preferences.

Procedures

Commentary from NH residents was elicited first spontaneously (e.g., voluntarily, without specific probes) and then systematically (e.g., through probing questions). First, when a respondent offered a spontaneous comment about any particular preference item, these comments were recorded by interviewers. Once the value of the spontaneous comments was recognized, a questionnaire was designed to offer participants the opportunity to systematically initiate discussion about changes they made in individual responses to the PELI questions. These questions also allowed residents to explore their perceptions of what caused their responses to change over time. Two probing questions were administered for a preference item if there was a discrepancy in scores between the two interviews: (1) what they thought made them change their mind about their answer, and (2) which answer better matches how they feel right now. These direct questions about the context of a different preference response initiated discussion and spontaneous comments which were transcribed verbatim.

Analysis

Spontaneous comments were read by the research team to better understand participants' interpretation of questions. Spontaneous comments were reviewed and analyzed using content analysis strategies to identify categories and themes that resulted in a qualitative coding scheme to classify barriers and situational dependencies around preference fulfillment.⁹

Results

Throughout the study, 7,893 comments were provided by residents. A major theme that emerged in these comments was the notion that even though a preference was important, there were often major barriers to fulfilling that preference. Thus, the content of these spontaneous comments indicated the need to delve further into the specificity of barriers associated with the fulfillment of certain preferences. As a result, it was decided that residents should have the option to respond that a preference item was “important, but can’t do”. These initial spontaneous comments indicated a need and important opportunity for the research team to probe for more specific information and brought light to the notion that preference fulfillment can be hindered by a range of barriers. Comments were categorized into five codes: 1. Functional impairment (e.g., “*My Parkinson’s curtailed it. How could I do those things? I can’t go outside alone. I am hindered. With reading my Parkinson’s only lets me read for 15 or 20 minutes and then I have to stop. It makes you lose your powers of concentration.*”); 2. Sensory impairment (e.g., “*Because of my hearing I can’t use a regular phone...but since my eyes have been bad, the screen is getting blurred*”); 3. Lack of choice/opportunity (“*I don’t think I have any choice of who to share a room with*”); 4. Lack of resources (e.g., “*But right now since I’ve been here, I would say I’ve lost all my friends. I don’t see them very often, I hope it gets better*”); and 5. Quality of Program (e.g., “*All depends on what the program is. I go to things two or three times and then I get bored and don’t go anymore.*”).

Spontaneous comments informed the modification of questions about the amount of choice residents’ felt they had in having their preference met. These questions were asked during interviews about the resident’s perceptions of choice, satisfaction and thoughts about why a resident may change his or her mind about an important preference.⁹ These interviews were also used to identify problems in wording, interpretation, reactions, and comprehension of items. Within the 85-item PELI used initially, 20 items were modified and then retained. There were 28 wording changes across the 20 items, there were 12 changed for problems related to item clarity, 10 for issues with response categories, 4 for sensitivity and bias, and 2 for assumptions. Spontaneous commentary from participants lead to deleting 23 items such as discussing personal things with your caregiver, talking about spiritual matters, using non-traditional health care treatments, taking supplements to boost health, getting rehab, using laxatives and suppositories, challenging activities, listening to the radio, spending time in your room, and watching activity around you. Eleven items were added based on participant responses including choosing what name to be called, personalized bathroom needs, choice of medical care provider and who is involved in care discussions.

Discussion

This case study approach demonstrates that spontaneous commentary of NH residents can greatly contribute to the measurement development process. Throughout this study, we found the spontaneous commentary of NH residents to be a critical source of data as participants’ explanations assisted to inform the measure in ways that were consistent with how the resident reacted to the survey questions. We found that using the voice of the resident provided critical details to understanding what was important to the resident.

Utilizing spontaneous commentary also provided a systematic way to develop a relationship with the resident as it touched what mattered to the resident throughout the course of day. Moreover, the benefit of this commentary is that it can assist clinicians with relevant information to better know how to care plan or set goals for that specific preference. Notably, spontaneous comments ensured that changes made to the PELI-NH items were heavily informed by NH residents. This approach capitalizes on NH residents' willingness to provide rich commentary,⁴ as well as the tendency for older cohorts to elicit more spontaneous commentary than younger cohorts.¹⁰

The NH culture change movement is an effort to transform NHs by redirecting and delivering person-centered care to all residents.¹¹ Thus, in order to truly deliver person-centered care, and fulfill the tenets of the NH culture change movement, it is critical that NH residents are seen as key stakeholders in the development of measures used in NHs. In this paper, we demonstrate how encouraging commentary can inform the development of such measures. Integrating the commentary of NH residents into this process holds particular efficacy for ensuring that measurement tools are informed by the needs, concerns, and priorities of residents.⁹ We argue that this approach, that is, allowing the voice of NH residents to guide key aspects of the measurement development process, lends itself to a resident-centered approach to conducting NH research.

Limitations and Conclusions

Our sample is limited in diversity such that most participants in our study were white and female living on the East Coast; future work should seek to understand comments of culturally diverse groups in different geographic areas. This limitation is largely due to the interviews being conducted in English; it was very challenging to recruit those populations that did not speak English. The ability to offer a comment is possible for those with moderate dementia; it is more difficult to uncover the nuance for individuals with severe dementia who do not have the cognitive ability to express their thoughts. Nonetheless, this article seeks to emphasize the potential benefits of both spontaneous commentary and open ended responses for NH research. It is our hope that demonstrating this utility will encourage researchers to consider recording and utilizing spontaneous commentary in future NH research, particularly in the development of resident-centered measurement tools. Ultimately, such efforts can advance our understanding of how to deliver high quality care that is truly based on the values and preferences of NH residents.

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Table 1

Descriptive Statistics for Sample

N	370
Age M	80.37(11.2)
Gender (female)	69.75%
Ethnicity (Not Hispanic or Latino)	100%
Days at facility M(SD)	828.17(799.72)
MMSE M(SD)	25.5(2.35)