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Original Study

Delivering Person-Centered Care: Important Preferences for Recipients of Long-term Services and Supports

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ABSTRACT

Objectives: Although assessing individual consumer preferences are an important first step in providing person-centered care, the purpose of this study was to identify the top 10 shared preferences that are important to a majority of consumers receiving long-term services and supports.

Design: A cross-sectional survey design was used.

Setting and participants: Preference assessment interviews were conducted with 255 nursing home (NH) residents and 528 older adults receiving home and community-based services (HCBS).

Measurements: The Preferences for Everyday Living Inventory (PELI) was used to collect consumer preference information. Two versions of the PELI were used—the PELI-NH for NH residents and the PELI-HC for clients receiving HCBS and analysis focused on 41 shared items between the 2 versions. All respondents answered PELI questions independently and rated the importance of psychosocial preference items on a scale from not at all to a lot/very important.

Results: Ten preferences were shared as being important or very important by NH residents and older adults receiving HCBS. Most notably, more than 90% of respondents in each group rated "having regular contact with family" as an important priority. Having privacy, choices about what to eat, when to bathe, and activity options also were important preferences for a majority (77%-93%) in both settings.

Conclusion: Providers seeking to incorporate preference-based care can utilize study results as a foundation to incorporating important preferences into the care delivery process at the organizational level across care settings. For example, assessing all consumers on this core set of 10 shared preferences can assist with relationship building, transitions in care, and quality improvement. However, preferences with aggregate low-rated levels of importance in this study should not be discredited or eliminated. It is important for providers to understand the unique preference inventory of each older adult, which can then be targeted toward meeting goals for preference fulfillment. This can aid in bringing preferences into practice to improve the quality of care and quality of life to best meet the psychosocial needs of each person.

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The culture change movement in long-term care began in the early 1980s as a widespread effort led by consumer advocacy groups, policy makers, and health care providers to improve the quality of care and quality of life for individuals residing in nursing homes. The overarching goal of the culture change movement is to transform care delivery from a "medical model" to a more comprehensive, holistic model of care that recognizes all aspects of the person beyond his or her disease or disability. Following the Omnibus Budget Reconciliation Act of 1987, nursing home providers were required by law to provide "services sufficient to attain and maintain his or her highest practicable physical, mental, and psychosocial well-being" to their residents.[1] As a result, providers began incorporating more individualized approaches to care delivery and the concept of person-centered care emerged. Identifying and documenting residents' preferences is an important first step toward providing individualized, person-centered care. However, early efforts at meeting care preferences were often based on limited, standardized questionnaires due to a gap in literature surrounding psychosocial preferences.[2] Carpenter and colleagues conducted a conceptual mapping of psychosocial preferences, which provided an in-depth analysis of the organization and hierarchical structure of older adults' preferences.[2] This map created a foundation for the development of a standardized assessment of psychosocial preferences in multiple care settings known as the Preferences for Everyday Living Inventory (PELI).

The first version of the PELI was created using a home health sample of individuals receiving home care services—referred to as the PELI-HC.[3] The question of family proxy knowledge and congruency with older adult preferences was also examined for the PELI-HC.[4] The second iteration of the PELI was its modification for use in a nursing home population (PELI-NH) based on results from cognitive interviewing techniques.[5] Cognitive interviews resulted in the 72-item PELI-NH, which assesses nursing home (NH) resident preferences grouped into the 5 originally derived concept mapping domains.[2] Since its development, the PELI-NH has been studied extensively looking at its validity,[3] consistency of self-reported preferences among nursing home residents over 1 week,[6] reasons that nursing home residents give when changing their ratings about the importance of specific preferences,[7] family proxy's knowledge of and congruency with resident preferences,[8] qualitative analyses of contextual factors influencing specific resident preferences,[9–11] and staff perspectives on their ability to fulfill specific resident preferences.[12] In addition, the PELI-NH has been used in evidence-based approaches that integrate preferences into care delivery,[13] as well as the development of quality improvement tools to help providers measure their success in integrating resident preferences into care delivery.[14,15] Several items from the PELI instrument informed the development of the Centers for Medicare and Medicaid Services' Minimum Data Set (MDS) 3.0 Section F "Preferences for Customary and Routine Activities"—a required assessment of all residents in certified nursing facilities. In addition, results from a controlled trial and a translational study found significant, but small, increases in morning care choices and mealtime feeding quality.[16,17] However, several studies have identified barriers to translating NH residents' basic preferences into practice. For example, an observational study of morning care found that 70% of the time staff offered no choices to residents.[18]

Although a large body of research examines the use of the PELI and the psychosocial preferences of older adults, little research explores which preferences are identified as important to the majority of older adults receiving long-term services and supports (LTSS). Although it is crucial that providers focus on the unique preferences of each resident, looking at aggregate data of important preferences across settings of care can serve as a starting point for providers beginning the process of enhancing their organization's capacity to deliver person-centered care, regardless of the specific setting of care. The important preferences identified by a majority of respondents in each care setting can serve as a guide for goals geared toward delivering person-centered care at the organizational level, whereas responses of individual older adults can serve as a vehicle to further customize care plans for each person based on his or her individual preferences, values, and needs. The purpose of this study was to identify shared preferences that are important to a majority (75%) of nursing home residents and older adults receiving home- and community-based services.

Methods

Procedures

This study used secondary data analysis of PELI responses collected from 2 separate samples—NH and HCBS. The HCBS sample respondents (n=528) were selected using a stratified random sampling method from the Visiting Nurse Service of New York's (VNS-NY's) client database to ensure that at least a third of the respondents were new to receiving HCBS. Respondents were deemed cognitively capable to participate by passing the Orientation-Memory-Concentration Test (OMCT).[19] The OMCT was administered by telephone by the research assistants.[3] Based on cutoffs reported in the OMCT validation study, weighted scores of 0–6 were presumed to indicate no cognitive impairment. Interviewers were instructed to use clinical judgment in deciding whether respondents could complete the interview for those who scored 7 to 9. Scores of 10 or higher signified cognitive impairment, and respondents scoring in this range were excluded from the study. After passing the cognitive screening, participants were interviewed in their homes by trained research staff. The mean OMCT score for our sample was 3.56 (SD 2.7, range 0-8). The PELI-HC measures 55 items of psychosocial preferences through a 5-point Likert-scale format where respondents rate preferences using the following scale: 0 = not at all; 1 = no preference; 2 = a little; 3 = somewhat; and 4 = a lot.

The NH respondent sample (n=255) was collected through a convenience sample of 28 nursing facilities in the greater Philadelphia, Pennsylvania, region. Social workers identified older adults in selected NHs that were eligible to participate in the study. To be eligible, participants needed to be English speaking, have a Mini-Mental State Exam (MMSE) score greater than 13, have long-stay status, and residing in the facility more than 1 week at the time of the study. Research assistants administered the MMSE after participant or family consent as part of the eligibility screening. A total of 581 residents were referred by organizations to participate in the study, and 207 declined participation in the study. Of the 123 individuals deemed incapable of self-consent, family consent was obtained from 70. There were 321 participants enrolled at baseline, and 255 completed both the baseline and 3-month follow-up interviews. This indicates a consent rate of 43.8% and an estimated 5.5% of the total resident population that the sample represented. Research assistants conducted face-to-face interviews using the 72-item PELI-NH specifically for this study, asking respondents to rate preferences on a 4-point rating scale: 1 = very important; 2 = somewhat important; 3 = a little important; and 4 = not at all important. The response option of important but can't do/no choice used in the MDS 3.0 was not offered as an answer category for this research study. Institutional internal review board approval was obtained for both studies from a federally assured review board.

Data Analysis

This study analyzed PELI responses of both samples to determine a hierarchy of preference importance within each sample. Sample groups were analyzed separately rather than in the aggregate to provide comparisons between these unique care settings. Because of