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Healthcare Preferences among Nursing Home Residents: Perceived Barriers and Situational Dependencies

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Abstract

While much research has examined end of life care preferences of nursing home (NH) residents, little work has examined resident preferences for everyday healthcare. The present study conducted interviews with 255 residents recruited from 35 NHs. Content analysis identified barriers (hindrances to the fulfillment of resident preferences) and situational dependencies (what would make residents change their mind about the importance of these preferences) associated with preferences for utilizing mental health services, choosing a medical care provider, and choosing individuals involved in care discussions. Barriers and situational dependencies were embedded within the person, facility environment, and social environment. Nearly half of residents identified barriers to their preferences of choosing others involved in care and choosing a medical care provider. In contrast, the importance of mental health services was situationally dependent on needs of residents. Results highlight opportunities for improvement in practice and facility policies that promote person-centered care.

Keywords

Nursing Homes; Medical Care; Mental Healthcare; Healthcare Preferences; Person-centered care

Introduction

A priority of long term care research is to understand how to provide quality, person-centered care to nursing home (NH) residents (Edvardsson, Varrailhon, & Edvardsson, 2014). A cornerstone of this effort is the assessment of NH resident everyday preferences for daily living, social engagement, and healthcare (Van Haitsma et al., 2014). Knowledge of

everyday preferences can inform the subsequent delivery of care that honors the person, influencing both physical and psychosocial well-being outcomes (Simmons & Schnelle, 2004). Within the complex medical needs of older adults, NH residents' healthcare preferences are of particular importance. Research in this area has largely focused on preferences for emergency and end of life care (Cohen-Mansfield, & Lipson, 2002; Marcella & Kelley, 2015). This work suggests many barriers to fulfilling end of life and emergency treatment preferences including a lack of awareness, confusion, cultural differences, limited opportunity, and avoidance (Boddy, Chenoweth, McLennan, & Daly, 2013; Center for Disease Control and Prevention, 2013). These barriers are more complex within the NH context (Tilden et al., 2011). Minimal work, however, has explored NH residents' everyday healthcare preferences. No inquiry has assessed factors that would change the importance of everyday healthcare preferences for NH residents. Within the medically focused environment of long-term care, knowledge of barriers regarding healthcare preferences can inform care efforts that may prove vital in advancing the delivery of quality care. The present study fills this void through qualitative assessments of barriers and dependencies that NH residents associate with preferences for three critical aspects of everyday healthcare: seeking mental health services, choosing a medical care provider, and choosing individuals involved in care discussions.

Methods

Participants and Procedures

Our sample consists of 255 NH residents drawn from the larger project entitled *Assessing Preferences for Everyday Living in the Nursing Home: Reliability and Concordance Issues* (Grant No: R21 NR011334-01 PI: Van Haitsma). This larger study sought to develop and validate the Preferences for Everyday Living Inventory for NH residents (PELI-NH), a comprehensive instrument that examines the content, meaning, and importance of psychosocial preferences among NH residents (Van Haitsma et al., 2012; Van Haitsma et al., 2014). Participants were recruited from 35 NHs in the greater Philadelphia area. NH staff referred residents who were English speaking, had been at their facility for at least one week, were expected to remain at the facility for at least one more week, and were cleared by his/her physician for cognitive capacity and medical stability. The director of nursing at each facility verified that residents had the capacity to consent and/or had a family member that could consent for the resident. Participants were further screened for cognitive impairment using the Mini-Mental State Examination (MMSE; Folstein, Folstein, & McHugh, 1975). The cutoff score of 13 for the MMSE was chosen based on work suggesting that individuals with mild to moderate dementia can reliably report on their values and preferences (Whitlatch, Piiparinen, & Feinberg, 2009). Informed consent for participation in the study was established in-person by iterative questioning according to institutional review board approved procedures and protocol. Participants were mostly female (67.8 %) with a mean age of 81 (see Table 1).

The PELI-NH assesses everyday preferences for social contact, growth activities, leisure activities, self-dominion, and enlisting others in care. All participants completed the PELI-NH twice—during a baseline (T1) and follow-up interview three months later (T2)—rating

the importance of 72 preferences for everyday living on a Likert scale from 1 (*very important*) to 4 (*not important at all*). At T1 and T2, residents readily volunteered clarifications to explain and contextualize their quantitative rating of importance ascribed to each PELI-NH preference. The interviewer recorded these clarifications, resulting in 7,893 unique comments in response to 72 preference items. The present study draws on a portion of these open-ended comments and focuses on 323 responses provided in regards to three specific healthcare preferences: *How important is it to you to talk to a mental health professional if you are sad or worried? How important is it to you to choose your medical care professional? How important is it to you to choose who you would like involved in discussions about your care?*

Data Analysis

Responses were transcribed verbatim into Microsoft Excel for content analysis. Content analysis was conducted using a 27-item coding scheme developed by Heid and colleagues (2014) to classify barriers and situational dependencies associated with NH resident preferences. A barrier was defined as reference to something restricting fulfillment of the person's preference. A situational dependency was defined as reference to something that would change the person's level of importance (i.e., "*It depends on...*"). The coding scheme included 4 major domains: within person (e.g., functional ability, personal schedule), facility environment (e.g., facility schedule, facility policy), social environment (e.g., quality and type of interactions), and global environment (e.g., weather, current events, special occasions). Four research team members were assigned to code one fourth of the spontaneous comments in the total dataset (roughly 1,973 lines each). Discrepancies were settled through discussion. Each team member was then randomly assigned to double-code 25% of the data to ensure inter-rater reliability.

Results

One-hundred and twenty-five residents provided comments about utilizing mental healthcare, 58 provided comments regarding the involvement of others in discussions about their care, and 137 provided comments around choosing his/her medical care provider. For these three preferences, residents cited barriers and dependencies embedded within three domains: within-person, facility environment, and social environment (Table 2).

Mental Health: How important is it to you to talk to a mental health professional if you are sad or worried?

Among residents who identified barriers to accessing mental healthcare, the majority cited a lack of opportunity/choice: "*I don't get anybody that comes and talks and asks how you feel.*" Others expressed a lack of perceived choice due to limited knowledge of mental health services: "*I don't know if they have that here.*" Other comments provided additional key insight into factors that hinder fulfillment of mental health preferences. For example, a resident indicated perceived social acceptability as a barrier: "*Does that mean I'm crazy?*" while another suggested that his/her relationship to the mental health professional at the facility was a barrier: "*The one here doesn't know what he's talking about.*" Other

comments indicated that the quality of interaction was a barrier: “[I don’t] like to talk to psychiatrist, they come and check [my] memory and then move onto the next person.”

Residents also indicated a range of situational dependencies associated with preferences for utilizing mental healthcare. The majority of residents who identified a dependency cited a situational need as the reason for why the importance of their preference might change. One resident explained: “*My unhappiness doesn’t last for a long time. If it did then it would be important.*” Other dependencies had to do with the type of relationship with the mental health professional: “*If I can’t solve my problem, depends on the person too, if they are a good listener or someone that you can talk to*”, and “*It depends on the mental health professional and the quality of the professional.*” The comments of residents who did not identify a barrier or situational dependency in regard to mental health preferences yielded a rich contextualization for why they perceived no barriers to their preference fulfillment. Some residents explained that family and friends filled this need: “*I never had an occasion to do so. I have my daughter to talk to.*” Another stated: “*If needed for something serious it would be very important, but if not then talking to a friend or nurse is fine.*” Other residents explained that they use mental health services: “*I have had one I’ve been with for years*” and felt no barrier or dependency associated with use: “*[I] see a psychologist once a month. He’s a good listener and I enjoy talking to him.*”

Medical Care Provider

When asked about choosing a medical care provider, 137 residents indicated either a barrier or dependency associated with their preference; 48.5% of these comments included at least one barrier to choosing a medical care professional. The most common barrier was a facility policy that inhibited their ability to choose: “*I don’t have any control over that, they downgraded to a non-skilled facility, I had my own doctor, but now I can’t.*” Another resident stated: “*I don’t get to do that. I had my own doctor and they wouldn’t allow it.*” Other residents perceived a more general lack of opportunity to choose their medical care provider although they would like such an opportunity: “*I have no choice. I wish I had another doctor. I never can see him. I wish he would talk to me.*” While another suggested this lack of choice was a source of conflict: “*Can’t do that, many fights over that.*” Few residents identified situational dependencies that would change the importance of being able to choose their medical care professional. Yet, those cited included perceived personal health and their perceived level of choice/opportunity. One resident explained: “*It depends on how sick I was. I’d want to see a specialist based on the ailment. If really sick it would be very important.*” Another comment mirrored this same notion: “*Never think about it. I guess it’s important if there’s something wrong.*”

Care Discussions

Fifty-eight residents provided comments regarding the involvement of others in discussions about their care; 42.4% of these comments identified a barrier to fulfilling this preference. The most frequent barriers were residents’ level of choice/opportunity. One resident addressed this lack of choice by having family take over such decisions: “*Because my son is the power of attorney,*” while another stated: “*Tough to answer. I’m tied up here away from everything.*” Another common barrier associated with the preference of choosing who is

involved in care was the residents' level of personal resources. Residents explained that they did not have family available to have them involved in their care: *"My family they are younger than me and they have too many problems to worry about me. They never worried about me."* Or, they stated that they were unable to contact family who they wanted involved: *"We haven't been able to get in touch with her."* Other residents cited the facility schedule and their relationships with staff as barriers to involving staff in care discussions: *"Annoying because I have a different aid every day. And I have to explain myself every day to the new person what they need to do."* A smaller proportion of residents identified dependencies for choosing who to involve in discussions about their care. One resident explained it is *"Sometimes very important. Depending on what it is. Some I could decide on my own, others I want [a family member] there."*

Discussion

Understanding the everyday healthcare preferences of NH residents is an understudied, yet critical component of providing person-centered care within the long-term care setting. Findings suggest that residents' perceived need for mental health services is predominantly driven by situational needs. The situationally dependent nature of mental health preferences suggests that counseling consultation may be a suitable approach to mental healthcare in NHs (Kennedy, Covington, Evans, & Williams, 2000). Further, residents indicated the importance of favorably evaluating their relationship with mental health staff. As such, an evaluation of resident satisfaction with mental health services may help to better meet the preferences of residents. Another finding revealed that residents often chose to talk with family, friends, and NH staff instead of mental health professionals. Thus, NH administrators may seek to increase family integration and involvement in the lives of NH residents. A similar effort could be made in training NH staff to offer social support to residents when needed. In contrast, residents who do not have close family or social ties may be a logical target for mental health intervention efforts.

An important finding with vast implications for NH staff and administrators is that preferences of choosing a medical professional and choosing others involved in care were predominantly restricted by barriers in the care system. Comments indicate that residents' interpret facility policies as restrictive suggesting that policies that allow residents' to have a choice (e.g., choice of physician) may be beneficial to residents. NH administrators may consider adapting facility policies to facilitate resident autonomy where possible (i.e., encouraging residents to choose from a list of approved medical providers as opposed to assigning a medical provider). Residents primarily indicated a lack of choice as a barrier to choosing others involved in care suggesting the need to create opportunities for involvement of preferred family members or staff in decision-making processes. While research on end of life decisions has explicated various pathways for this involvement (Dreyer, Førde, & Nortvedt, 2010), additional efforts are needed to integrate multiple stakeholders in discussions about NH residents' everyday healthcare when desired by the resident.

The findings must be interpreted in light of several limitations. Participants had no more than mild to moderate dementia; findings do not generalize to residents with greater limitations in their cognitive ability. Furthermore, because comments were made at different

frequencies for each preference, a comparison of barriers and dependencies between these preferences is not suitable. Despite such limitations, findings reinforce the merit of utilizing the voice of NH residents to understand stakeholder perspectives in the long term care system. Residents' perceptions are essential to identifying modifiable aspects of care that may build autonomy of residents and ultimately advance person centered care efforts. It is important to consider, however, that autonomy is not always the superlative ethical value and that beneficence and impartiality may at times take precedent in healthcare decisions. Allowing residents to articulate dependencies provides critical information about the circumstances that affect residents' preferences, providing NH staff with information to anticipate changes in and meet care preferences. A critical next step is to identify how barriers and dependencies are associated with person-centered outcomes, such as satisfaction with care, health, and quality of life.

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Table 1Demographic characteristics overall sample ($N = 255$)

Characteristic	<i>n/% or M(sd)</i>
Age	81.0(11.2)
Gender (Female)	67.8%(173)
Race	
African American	22.7%(58)
Asian	0.4%(1)
Caucasian	76.9%(196)
Ethnicity (Not Hispanic or Latino)	100.0%(255)
Length of Stay (days)	923.6(.900.9)
Veteran Status (yes)	9.8%(25)
MMSE Score (0–30)	24.6(3.9)
Marital Status	
Never married	24.3%(62)
Married	17.3%(44)
Widowed	44.3%(113)
Separated	1.6%(4)
Divorced	11.4%(29)
Education Status	
8th grade or less	2.4%(6)
9th to 11th grade	11.4%(29)
High School	48.2%(123)
Technical School	4.3%(11)
Some College	9.0%(23)
Bachelor's Degree	9.0%(23)
Graduate Degree	4.7%(12)
Religion	
Protestant	34.5%(88)
Catholic	32.2%(82)
Jewish	22.0%(56)
Other	0.4%(1)
None	1.2%(3)

Table 2

Barriers and dependencies associated with Nursing Home residents' preference for mental healthcare, choosing who is involved in their care discussions, and for who their provider of medical care

Domain/Theme	Definition	Mental Healthcare (N = 125)		Care Discussions (N = 58)		Medical Care (N = 137)	
		Barrier n(%)	Dependency n(%)	Barrier n(%)	Dependency n(%)	Barrier n(%)	Dependency n(%)
<i>Within Person</i>							
Perceived Personal Health	Physical and mental health; experiencing pain, not feeling well, not sleeping well	-	1(0.8)	-	-	1(0.7)	5(3.6)
Situational Need	Situationally driven, adjustment issue	-	26(21)	-	3(5.1)	-	2(1.4)
Cognitive Ability	Cognitive functioning	-	-	-	1(1.7)	-	-
Level of Interest	Cognitive words like interested; level of interest in how preference is met or what preference is	2(1.6)	-	-	-	-	-
Perceived Level of Choice/ Opportunity	Feeling of lack of choice or opportunity	14(11)	-	7 (12)	-	20 (14)	5 (3.6)
Level of Personal Resources	A person's financial, social, or other resources	-	-	6(10)	-	2 (1.4)	-
Life Stage or History	Stage of life or past history of person	-	1(.80)	-	-	1(0.7)	-
Perceived Social Acceptability	The perceived social acceptability of the preference; social conformity	2(1.6)	-	-	-	-	-
<i>Facility Environment</i>							
Facility Schedule	Timing and frequency of facility events	1(0.8)	-	4(6.8)	-	1(0.7)	-
Facility Policy	Based on rules/policies of the facility	-	-	4(6.8)	-	43(31)	-
Staff Proficiency	Abilities of the staff	-	-	1(1.7)	-	-	2 (1.4)
<i>Social Environment</i>							
Quality of Interaction	Behavior of others	2(1.6)	-	1(1.7)	-	-	2 (1.4)
Type of Staff Relationship	Quality of relationship with staff.	3(2.4)	4 (3.2)	2(3.4)	1(1.7)	-	2 (1.4)
Type of Non-staff Relationship	Quality of relationship with others besides staff	-	-	-	1(1.7)	-	-
Total		24(19)	32(25.8)	25(42.4)	6(10.2)	68(48.5)	18(12.8)
N/A	No Barrier/Dependency identified	101(80)	93(74)	36 (28)	52(89)	72 (52)	122 (89)