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Many Stakeholders, Many Perspectives: Person-Centered Care in Nursing Homes

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IRB Statement

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Abstract

Nursing home culture change moves facilities towards person-centered care. This study examined how people in different roles experienced choice and autonomy in four areas addressed by culture change: consistent assignment, food choice, waking/bedtime routines, and bathing. This descriptive qualitative study included 32 participants from one continuing care retirement community: 10 residents, eight family members, nine direct care workers, and five managers. Interviews were audiotaped, transcribed verbatim, and coded. Codes were grouped around the practice areas and cross-cutting themes. All groups reported choice in all areas. Challenges arose when patient choice and nursing home functions conflicted. Stakeholders disagreed when care needs should supersede choice. Findings suggest that it is difficult to balance resident choices 1) with the diverse needs/wants of other residents and 2) safety. Leaders, such as nurse managers, should provide ongoing education to residents, family, and staff to help them negotiate these challenges.

Keywords: person-centered, long-term care, organizational culture, resident safety

Introduction and Background

Organizational cultures are shared norms and attitudes that shape collective behaviors (Stone & Reinhard, 2007). In nursing homes "culture change" transforms culture from staff-centered to person-centered affording residents more autonomy and self-determination (Pioneer Network, 2017), where care includes home-like choices such as how to pass time, when and how often to bathe, and what and where to eat. (Jurkowski, 2013; Rahman & Schnelle, 2008; White et al., 2012; Zimmerman et al., 2014).

Nursing home workers sometimes have contradicting priorities (Simmons et al., 2014). Multiple stakeholders are needed to enact resident choice: management must empower direct care staff to honor resident preferences and family members need to understand choice principles. Bangerter et al., (2016) found, "residents identified preferences for interpersonal interactions, coping strategies, personal care, and healthcare discussions" (p.702). However, it is unclear how these preferences are actualized (Simmons et al., 2011). Palmer et al., (2018) found staff were particularly uncertain about facilitating choice when medical and safety needs conflicted with preferences.

Organizational culture shapes nursing home care. This study aimed to understand how people in different positions experience person-centered care by exploring how various stakeholders (residents, family members, direct care staff, managers) defined selected person-centered care practices (consistent assignment, meal choice, waking/bedtime, and bathing) and compared their perspectives. Residents, families, and direct care staff were chosen because they are the largest groups in nursing homes. Management staff were included because they shape expectations. The practice areas included are considered central to culture change by the Pioneer Network (2017), and the Centers for Medicare and Medicaid Services (CMS) (Jurkowski, 2013).

Methods

This descriptive qualitative study took place in the skilled nursing and assisted living of one continuing care retirement community. Prior to the study, management introduced culture change to staff and educated residents and families on resident choice. The nursing home self-defined culture change, but their practices reflected current research (Pioneer Network, 2017).

Purposive sampling was used to recruit representative samples of the target groups. Participation was voluntary and responses were confidential. Participants could withdraw at any time. Study procedures were approved by the Institutional Review Board at the University of Maryland Baltimore County.

Eligible nursing home residents who lived in the community for more than one month, spoke English, and had minimal cognitive impairment (BIMS $\geq$ 13) were identified by a manager who also notified families about the study. The first author confirmed the resident's interest and obtained consent. Family representatives consented for residents who were unable. Since many skilled nursing residents had advanced dementia, assisted living residents were added to the study during data collection. Assisted living residents were approached by the first author and provided consent when interviewed.

Family members were notified about the study by a manager and/or approached by the first author in the nursing home. Eligible family respondents had their resident in the nursing home for more than one month, were over age 18, and spoke English.

Managers notified workers about the study. Direct care workers on the long-term care household including nursing assistants, dining aides, and activity aides who worked at the community for more than one month, were over age 18, and spoke English were eligible. To reduce perceived coercion, the first author discussed participation, obtained consent and

reminded respondents participation was voluntary and responses were confidential. While staff on all shifts were technically eligible, the first author was only in the facility during first and second shift.

Five long-term care leaders were recruited. Since these individuals could be identifiable by their positions, this paper refers to them as management staff.

Participants completed one-time semi-structured individual interviews on four practice areas: consistent assignment, meal choice, waking/bedtime, and bathing. Interviews ranged from 14 to 56 minutes. All interviews were conducted face to face in person, with the exception of one family member who participated via video call. Family members received $20 for participating. Only family members received the gratuity due to concerns about perceived coercion for residents and staff. A one-time donation was made to the employee appreciation fund at the conclusion of the study. The semi-structured interview guide asked respondents to define the practices and describe their implementation. Interviews were audiotaped and transcribed verbatim. Both authors read each transcript and developed the coding scheme. The second author coded all transcripts line by line using NVivo 12 software (QSR International, 2018). The first author re-coded a subsample of transcripts (15%) to ensure that coding fit the scheme. Codes were grouped around the practice areas and cross-cutting themes.

Trustworthiness of the analysis was enhanced in two ways. The first author journalled during the study and discussed tentative conclusions with the second author. Member checking was also used to reduce bias and verify conclusions (Padgett, 2003). The authors discussed findings with two management participants.

Results

Responses are presented for each group and practice area. Overarching challenges included tension between choice and safety, resident/family preference disagreement, and between-group differences in experiences. Quotes are identified by group (DCW=direct care worker, R=resident, FM=family member, MG=management). Some quotes edited for clarity.

Participants

Thirty-two individuals participated across all four groups. Some participants were in more than one group, i.e. assisted living resident who was a long-term care resident's husband, and manager whose family member was in assisted living. They are counted in the group through which they were recruited (Insert Table 1 here).

Consistent Assignment

All groups defined consistent assignment similarly. Staff regularly saw the same residents. While residents saw different staff on different shifts, they and their families knew familiar staff. All groups reported consistent assignment contributed to staff/resident collaboration. Direct care staff said they formed "bonds" and "connections," and knew resident preferences. Family members described staff as "caring and accessible." One direct care worker (DCW2) said, "They know me, we know them… we know what they like. You know what they want to do." Another direct care worker (DCW 5) said with consistent assignment, residents with "Alzheimer's dementia …still have an inkling of who you are." Consistent assignment allowed staff to recognize changes. "If this day the resident is eating good and the next day not…You know you have to talk to the nurse (DCW3)."

Family members felt consistent assignment made staff familiar with residents. One family member (FM01) said, "They get to know them and the staff gets to know their routines…

what they like and what they don't like…My dad…hated to be pushed along….The staff members who understood that… [were] very patient with him."

Scheduling made consistent assignment challenging. One resident (R03), said: "I've gotten to like and admire one person. I almost demand that she come every night though she's not here every night, so I can't."

Meal Choices

All groups said food was available 24/7 and there were several options for where people could eat including bedrooms, particularly for breakfast. "[Staff] bend over backwards to give people what they want (MG03)." Staff and family members felt showing food to residents with dementia fostered choice. DCW1 said "The kitchen [staff], they put plates, food sample[s] of what we have today…even if they are not talking. If they…point, we can give it to them."

Available options were different than at home. A direct care worker (DCW2) said, "We have cold food around the clock….we have tuna sandwich, egg, chicken...snacks… crackers, apple sauce…fresh fruit, and we have cookies, chips." The structure was different too. R07 said, "At home you make plans for, I don't know, maybe a week. And shop and serve whatever it is you decided on." FM04 agreed, saying "It's hard when you don't have a choice. When you're going out for dinner every night and the restaurant is going to serve you what they're going to serve you." Additionally, her mother eats in her room because other "…residents are in pretty bad shape … I think if I was around those kinds of people, I would want to eat by myself as well." This was only an option because she "[doesn't] have a swallowing issue that it's unsafe for [her] to be unattended while [she] eat[s] (MG03)."

Residents with specific needs or preferences had fewer choices. According to R08, "Sometimes the menu items either don't fit my personal likes and dislikes [or] they violate [the]

restricted diet that I'm on… it's less than perfect." Vegetarian options were also limited. FM07 describes: "[My sister] noticed [resident] wasn't eating his food, and she said don't you like it? He said that I don't eat meat. She said, do they know that? He said I think so. So, she kind of made a stink and got something vegetarian for him." R03 summarized choices and challenges. He could eat in his room or get an alternative entrée. But prior to moving in, R03 had, "eaten at a lot of three-star restaurants." When asked about ideal foods he said, "My menu… probably would include too many expensive things, like Peking Duck or certain French foods which I particularly like… [but] I have a champagne desire and a beer budget."

Waking

> Direct care staff noted culture change changed waking practices:
>
> Person-centered care, in my words, is definitely what the residents want and need. So, it's not about the employees…. Let's say, we want to get the resident up at 7 AM, but that resident is still asleep…Leave her be. (DCW5)

They were less clear how preferences intersected with care, like meals. DCW4 said, "Everybody get(s) up for breakfast," while DCW 5 said, "They don't have to get up for breakfast. They don't even have to eat breakfast if they don't want to. They could get up at 12…"

Other care was seen as essential. "They need a breathing treatment, or they need some medication at this time so they do need to be woken up, but if it's none of the above then let them sleep... You might have to wake them up to go to the bathroom (DCW5)." But getting residents up on their own time could threaten safety: "You tell them, I'm with somebody else right now, but I'll be right back… to make sure they are in a safe position… you start with the one that will jump out of the bed (DCW1)."

Facility factors limited resident choice. R07 said staff woke her at seven which was, "a little earlier than I would like. I could do with at least another half an hour," because, "it suits their schedule." R08 said he had to "coordinate" when he gets up with breakfast; "Get up too early, you can't get food."

Families were unsure of morning routines, but said staff would not "bother" their family member. "I think they come and get her, get her dressed for breakfast, but if she doesn't want to go, I'm sure they wouldn't force her (FM01)." FM06 said she was told, "We don't get everybody up at one time because not everybody wants to get up at the same time."

MG03 said, "We give them the choice. They can go to bed, get up, whenever they want…Especially in our memory [household]…let them wake up naturally." MG04 said staff knowledge of resident preferences shaped routines. "They're using their judgement...if they['re] in a deep sleep they shouldn't be waking them." If several residents wake up at the same time, "We have to prioritize. Because it depends [on] the safety of each resident…they may have to share with their colleagues. (MG04)."

Bedtime

All groups reported residents chose bedtime but staff encouraged residents to go to bed if they seemed sleepy: "Most of the time they choose but…when we see them sleeping in the chair…you go ahead and put them in bed (DCW2)." One family member said (FM05), "I've been there late. He can do whatever he wants…they don't micromanage that way." According to MG04, "They don't have to go to bed early…As long as it [doesn't] affect others." MG04 also noted, "The hardest part … I have staff who work other places and they forget."

Bathing

Direct care staff and residents reported flexibility in time and frequency of resident showers. A direct care worker (DCW1) described practice changes, "We used to have twice a week. But now … if they want to get a shower any time, they can get it, if they don't want to get a shower, they don't have to get a shower." Another worker (DCW8) confirmed, "Sometimes like, it's not their shower day and they still ask for a shower so we give it to them." Family members echoed this, but were unsure of details. According to FM06:

> [T]he staff member said that if they want to take three showers a day, they can do it. If they want to take, one shower, like every other day, they can do it…whatever it is, they'll work with the resident on that. I'm not sure what my mother's schedule is, but she's mostly clean when I'm there.

Yet residents did not always realize they could ask for something different. One resident (R04) said her shower schedule was "their choice. I was never asked. I was given the two days. Which, the days were all right with me, and that's it."

FM01 disagrees with her resident about bathing. "I've got to put notes in the room, make sure my mother showers and please wash her hair. Cause she'll say no, or just say not interested, so I just sort of like have to encourage that she can't say no." However, using culture change principles of choice and autonomy, according to MG03, if a family member wants a resident to be bathed more often a change is made only, "If it's what the resident wants." MG03 continued:

> We just kind of have to, go with what the resident wants. We try, as diplomatic as possible…as you know, to say, you know, I understand you want what's best for your father, but you know we, we have to respect his wishes.

Approaches to Logistical Challenges

Many people seek "home-like" settings when they need care (Oswald & Wahl, 2005; Wada et al., 2019). Choice and relationships (Pioneer Network, 2017) are essential parts of a home-like atmosphere. This research suggests it is difficult for facilities to balance resident choices with meeting diverse needs and wants of multiple residents. As one family member said,

> You build a system to take care of a set of the population. And you try and get the averages of what everybody needs together and you try and satisfy them. And … you can't quite cover all those bases (FM08).

Managers explained how staff negotiates the challenges of resident choice, particularly when family preferences and resident preferences diverge. MG03 said:

> [W]e get that all the time, where, oh no, mom needs to be woken up at this time. Well if mom's not waking up until an hour later, let her sleep that extra hour. And then we'll get her breakfast when she gets up. It not, she's not going to miss anything.

MG03 also described educating families about the culture change approach:

> We talk about it. You know, we say we're going to speak to your loved one…We're going to take in all this information from you and from them [resident]. And then we're going to assess when we go in, we'll see if this is what they want to do, but you know, it's their preference.

Regarding the challenge of several residents waking up at the same and requiring assistance, MG05 commented:

> Well the challenge is that, depending on staffing level, I mean you can't get everybody cared for all at the same time. You have to be very aware of knowing your resident, knowing a time that works well for them as well as knowing a time that works well for the congregate environment. So, and that comes with a skilled worker.

Regular culture change meetings are also a part of educating staff on culture change principles, “Where we introduce these different ideas about getting people up and putting people to bed, what’s the difference between that and having natural rhythms of life…(MG05).”

Discussion

In this community all groups said consistent staff cared for residents and residents had choice in meals, waking/bedtime, and bathing. Direct care staff knew about culture change, and management reported commitment to culture change. Resident choice was incorporated into day-to-day practice. While this community facilitated choice and autonomy in the four practice areas, and empowered staff to accommodate resident choice, limiting factors included ensuring care needs were met, safety, and differing opinions about care.

Our findings are limited by the one community, but we were able to provide an in-depth look at the diversity of perspectives long-term care. Future research should consider choice in standalone nursing homes, and with more diverse populations.

Implications and Conclusions

These findings raise the question of how much choice is realistic in a setting balancing the needs of multiple frail adults. Safety and competing needs are compelling reasons for not increasing resident choice. Some staff were reluctant to provide specific answers when resident choice and care imperatives conflicted which may be due to social desirability or because they have difficulty negotiating between resident choice and their responsibilities.

Past research has identified “staff and resident education, staff reinforcement, staff deliberation, stakeholder collaboration, and supportive leadership” (Palmer et al., 2018, p 5) as strategies for helping staff. Direct care workers need ongoing mentoring to negotiate nuances between choice and care, such as the regular culture change meetings our community noted, and

an environment where they feel safe enough to address their challenges. We recommend that leaders facilitate ongoing conversations between stakeholders, and that nursing staff include all perspectives in these conversations. Leaders can see the extensive resources on the Pioneer Network website for more information. The growing body of trauma-informed care literature that talks about safety is also a useful resource for changing an organization's culture in a way that includes all perspectives (SAMHSA, 2014).

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