Published in final edited form as:

J Appl Gerontol. 2019 February ; 38(2): 183–206. doi:10.1177/0733464817732519.

Person-directed care planning in nursing homes: Resident, family, and staff perspectives

Kezia Scales, PhD,

Duke University Center for the Study of Aging and Human Development and School of Nursing,
kezia.scales@duke.edu

Michael Lepore, PhD,

RTI International, mlepore@rti.org

Ruth A. Anderson, PhD, RN,

University of North Carolina-Chapel Hill School of Nursing, rutha@email.unc.edu

Eleanor McConnell, PhD, RN,

Duke University School of Nursing and Department of Veterans Affairs Medical Center,
eleanor.mcconnell@duke.edu

Yuting Song, BSN,

Duke University School of Nursing, yuting.song@duke.edu

Bada Kang, MSN,

Duke University School of Nursing, bada.kang@duke.edu

Kristie Porter, MPH,

RTI International, kporter@rti.org

Trini Thach, BA, and

RTI International, tthach@rti.org

Kirsten Corazzini, PhD

Duke University School of Nursing, kirsten.corazzini@duke.edu

Abstract

Empowering individuals to direct their own care is central to person-centered care and health-care policy. However, there is limited knowledge of how “person-directed care planning” (PDCP) can be achieved in particular settings. This study identifies key structures and processes for operationalizing and implementing PDCP in nursing homes. Using participatory inquiry, we convened “stakeholder engagement sessions” with residents, families, nursing staff, and managers/administrators in two North Carolina nursing homes (N=24 sessions; N=67 unique participants). Stakeholders discussed current care-planning processes and provided feedback on an emergent conceptual framework of PDCP. Three themes emerged through directed-content analysis: *strategies* included providing formal and informal opportunities to engage in care planning and

Correspondence to: Kirsten Corazzini.

Declaration of Conflicting Interest: None.

ensuring effective follow-through; different *roles* were required among leadership, staff, residents and families to accomplish PDCP; and *limits* on achieving PDCP included competing priorities and perceived regulatory and resource constraints. Results are discussed in terms of the specific competencies required for accomplishing PDCP.

Keywords

long-term care; participatory inquiry; stakeholder engagement; qualitative research

Introduction

Across health systems and settings, person-centered care is emerging as an important approach to improve quality and equity and reduce costs (Harding, Wait, & Scrutton, 2015). Representing a paradigm shift from the traditional medical model, person-centered care is a holistic, biopsychosocial approach that takes into account each individual's values, preferences, goals, and abilities (Kogan, Wilber, & Mosqueda, 2016). Person-centered care has been promoted in nursing homes and other long-term care settings as a means to overcome institutionalization, dependency and depression by enhancing dignity, autonomy, and interconnection among residents (Hill, Kolanowski, Milone-Nuzzo, & Yevchak, 2011). In the United States, person-centered care is the linchpin of the culture change movement in long-term care, which for three decades has focused on improving quality in long-term care through operational and environmental changes to create a homelike environment in which residents are empowered for self-determination in all aspects of their daily lives (Koren, 2010).

An important element of person-centered care is "person-directed care planning" (PDCP), which entails empowering individuals and their chosen family members to become co-creators of their care plans (Chen, Mullins, Novak, & Thomas, 2016; Pioneer Network, 2011). PDCP is inscribed in long-term care policies and guidelines in a number of countries in Europe, North America, and the Pacific Rim (Edvardsson et al., 2016). In the United States, federal regulations for Medicare- and Medicaid-registered nursing homes have promoted PDCP since 1987, such as by supporting residents' rights to be informed about and to participate in developing their care plans. Recent revisions have explicitly identified residents as the "locus of control" and include residents, their families, and direct caregivers in the interdisciplinary team that decides the "goals and outcomes of care" (CMS, 2016). A person-directed approach to care planning has also been adopted in community-based services (CMS, 2014) and through other provisions of the Affordable Care Act that incentivize care coordination and person-centered outcomes (Kietzman, 2012).

In nursing homes, empowering residents and families to "direct" care planning is particularly important as care plans inform nearly all aspects of life, from daily routines and activities to clinical treatments, and underpin individualized and continuous care (Dellefield, 2006). However, evidence suggests that resident and family engagement in care planning remains limited (White, Newton-Curtis, & Lyons, 2008) compared with other culture-change initiatives, such as facility modifications, that may be easier to achieve or more

financially rewarding (Lepore et al., 2015). Where there has been progress toward resident engagement in care planning, the emphasis has been on decisions about discrete domains of daily life (such as mealtimes and activities) as captured by the Resident Assessment Instrument-Minimum Data Set (RAI-MDS 3.0), which drives interdisciplinary care planning in the United States and many other countries. In more complex decisions, the locus of control has largely remained with the provider and the institution (Garcia, Harrison, & Goodwin, 2016).

Barriers to accomplishing PDCP may include the inherent difficulty in changing established organizational practices (Barnes, Gartland, & Stack, 2004); limited time for care-planning activities, especially given workforce shortages (Stone & Harahan, 2010); and the heterogeneity, complexity, and acuity of nursing home residents (CDC, 2009). A further barrier is the lack of strong evidence linking engagement in care planning and decision-making to improved outcomes (Hamann, 2014), due to inconsistencies in the operationalization, implementation, and measurement of central elements such as engagement and empowerment (Shier, Khodyakov, Cohen, Zimmerman, & Saliba, 2014). However, evidence from other health-care settings suggests a positive link between engagement and improved patient outcomes (Olsson, Jakobsson Ung, Swedberg, & Ekman, 2013), consumer satisfaction (Wolf, Lehman, Quinlin, Zullo, & Hoffman, 2008), and reduced costs (Olsson, Hansson, Ekman, & Karlsson, 2009). Furthermore, it has been argued that empowerment should be measured as an important psychosocial outcome in itself, apart from other quantifiable health and financial benefits (McAllister, Dunn, Payne, Davies, & Todd, 2012).

Given the importance of PDCP, there is a critical need to advance knowledge about its operationalization and implementation. The purpose of this study was to elicit input from a range of nursing home stakeholders about how to enhance resident and family engagement in care planning and delivery, with a view to developing an operational framework for PDCP.

Design and Methods

The study design was informed by the Adaptive Leadership Framework (Anderson et al., 2015; Corazzini et al., 2015), which posits that change, whether personal or organizational, creates both *technical* and *adaptive* challenges. Technical challenges, such as determining the decision-making capacity of a nursing home resident with dementia, can be addressed by extant technical solutions, such as implementing evidence-based tools to assess decision-making capacity. Adaptive challenges, such as how to incorporate the preferences of a resident with dementia as they evolve over time, require the development of new solutions that may involve changing norms, relationships or behaviors. Importantly, these new solutions must engage those who are facing the adaptive challenge(s). Reforming care-planning practices to enhance the role of residents and their families, which is the intent of PDCP, may necessitate development of new beliefs and behaviors among staff, residents and families; solutions will not come from external, technical solutions. To begin identifying these new beliefs and behaviors, we designed a study using participatory inquiry, which requires that the researchers partner with members of the target population to identify

research questions, develop the research design, and create new evidence-based knowledge (Heron & Reason, 1997). This approach aligns with the concept of adaptive challenges whereby those facing the challenges must be full partners in co-creating the solutions (Corazzini et al, 2015). Participatory inquiry has been used successfully in previous research on culture change in long-term care (Blair & Minkler, 2009; McKeown, Fortune, & Dupuis, 2016), to solicit input from a range of nursing home stakeholders, including residents, family members, direct-care staff, and management. The study was approved by the Institutional Review Board of the Duke University Health System (#Pro00067083).

This study was conducted alongside a separate scoping review of peer-reviewed and gray literature on engagement in care planning across care settings that was conducted by the same research team (Lepore et al., 2016).

Setting and participants

The study was conducted in two for-profit North Carolina nursing homes belonging to the same corporate care provider with whom the research team has a long-standing, productive relationship. One nursing home, pseudonym “Meadowview,” is located in an urban cluster and has approximately 90 beds. The second nursing home, “Brookside,” is located in an urban area and has more than 140 beds. Both nursing homes served populations who typically experience health disparities, including approximately 70% Medicaid-funded residents, and greater than 50% African-American residents (specific percentages omitted to preserve anonymity). Both homes had two out of five stars on the Nursing Home Compare quality rating system (CMS, n.d.), with average or below average ratings on health inspections, staffing, and quality measures. Without any claims to generalizability, the choice of research sites was guided by the intention to produce results to inform the development of an operational model that would be relevant and achievable for nursing homes with lower resources or ratings, which serve a higher proportion of health-disparity populations, and not just the better-resourced homes which tend to be culture-change adopters (Miller et al., 2014).

Participants were invited to engage in up to two focus group interviews to discuss challenges entailed in achieving PDCP (“round 1”) and consider potential solutions (“round 2”). Drawing from the literature on stakeholder engagement in deliberation about complex health care and policy issues (e.g. Watt et al., 2012), we called these “stakeholder engagement sessions” to reflect the participatory intent to co-produce knowledge about challenges and solutions rather than just elicit information. In each round, separate sessions were convened with residents; family members; nursing staff (including nursing assistants); and administrators (whose role is to supervise clinical and administrative affairs in the nursing home, including personnel, finances, medical care and supplies, and facilities) and managers (from departments including nursing, dietary, housekeeping, activities, therapy, social work, and the business office). The research team coordinated with our corporate partner and each home’s administrator to schedule the engagement sessions and recruit stakeholders. Flyers about the study were posted at each nursing home. Nursing home staff identified and invited residents and family members to participate, and stakeholders from nursing and other departments were invited by the administrator or other staff. All residents who expressed

interest in participating were asked four cognitive screening items to ascertain their capacity to provide informed consent, namely: What is your name? What date were you born? What year it is? Who is the current president? (Porter et al., 2015).

For this exploratory qualitative study, the participants represent a convenience sample of individuals who were present in the nursing home on the days when the engagement sessions were conducted, available and willing to participate, and capable of providing informed consent. Only one person chose not to participate after hearing the full study details, on the basis that she did not feel qualified to respond as she had just been hired at that nursing home.

Data collection and analysis

Stakeholder engagement sessions were conducted in November 2015 and January 2016. The first round of sessions solicited input about the care-planning process and identified the adaptive challenges involved in attempting to enhance resident and family involvement. These sessions began with a grand-tour question, e.g. (for residents) “Tell us how you go about telling staff when you have a particular preference or goal for your care.” The second sessions invited stakeholders to share feedback on emergent themes from the first sessions. If residents or family members joined the study in the second round (i.e., had not already participated in the first round), the facilitator initiated a general discussion of care planning before presenting the emergent findings.

The engagement sessions were conducted during paid hours for staff and at various intervals throughout the day for residents and families, avoiding overlap with scheduled activities and mealtimes. Participants were offered snacks and tokens of appreciation for their time, such as notebooks, coffee mugs, and stress balls. Table 1 provides demographic details for the participants (N=67 unique participants) in each round of engagement sessions at each site (N=24 sessions). Two residents participated in a session with their family member(s), as their families were present in the nursing home at the time and also interested in participating. Six residents participated in individual rather than group sessions, because they were not available to participate during the scheduled group sessions or because one-to-one communication was easier. Similar to other studies (Fetherstonhaugh, Tarzia, Bauer, Nay, & Beattie, 2014), we did not encounter substantial differences in the nature or quality of the data between these types of interviews, although participants had slightly more time and opportunity in individual sessions to provide in-depth details about their personal experiences. One member of administration was also interviewed separately due to her lack of availability during the scheduled group session. Sessions lasted 42 minutes on average (range: 18–102 minutes), and ranged in size from one to three residents, one to three family members, two to six nursing staff, and 12 to 17 managers/administrators. The sessions were recorded and transcribed verbatim, then imported into NVivo 10 (QSR International, 2012) for analysis by the full team.

Analysis of engagement-session data was conducted using directed-content analysis, by which current theory or research is used to focus the analytic process (Hsieh & Shannon, 2005). In this case, we developed an initial set of codes from the scoping review on patient and resident engagement in care planning across care settings that was previously conducted

by our team (Lepore et al., 2016). These initial codes included facilitators, barriers, and other elements of PDCP. Analysis was then undertaken in several well-documented stages to ensure dependability and confirmability (Miles, Huberman, & Saldana 2014). First, the three researchers who conducted the engagement sessions used the initial coding frame from the scoping review to conduct line-by-line coding of a subset of transcripts from the first round of engagement sessions, incorporating new codes as they were identified. Once the first set of transcripts was coded, the full research team reviewed all preliminary findings during a research retreat. The outcome of the retreat was to develop a heuristic diagram of PDCP (Figure 1) to share with stakeholders in the second round of engagement sessions. Transcripts from these sessions were coded using the same analytical approach, beginning with the code list developed from the first sessions. All transcripts were coded by at least two members of the research team, who met periodically to review the coded data, adjust the coding frame as needed, and discuss emerging interpretations. An audit trail of all coding decisions and interpretive developments was maintained through the code-definition and linked-memo functions in NVivo. The final set of themes presented here emerged from both rounds of analyses (see Box 1 for a list of codes informing each theme).

Results

Figure 1 summarizes the structures and processes of PDCP identified through the scoping review and confirmed/elaborated by stakeholders in this study. In this figure, PDCP (with a number of defining elements) is shown as a subsidiary element of person-centered care more broadly, which leads to enhanced wellbeing for all stakeholders. Challenges, constraints, and other contextual considerations are represented outside the main umbrella of person-centered care. In this paper, we develop three main themes from these findings related to: 1) *strategies* for supporting resident and family engagement in care planning, 2) the different *roles* that support resident and family engagement, and 3) the perceived *limits* on achieving PDCP.

Strategies for supporting resident and family engagement in care planning

Stakeholder comments suggested that engaging residents and families in PDCP requires two broad strategies, namely providing formal and informal opportunities for engagement in care planning and following-through effectively.

Formal and informal engagement—Stakeholders at both nursing homes discussed engagement in care planning in formal and informal terms. Formal opportunities included regularly-scheduled care conferences, while informal engagement occurred through unscheduled interaction between residents or family members and staff. The importance of this informal dimension of care planning was often emphasized. At Brookside in particular, the management group discussed its commitment to informal engagement in terms of an open-door policy:

Administrator: [T]he whole thing is having the open-door policy, allowing the resident to come to us if they have an issue and be able to discuss it, knowing that we'll take care of their concern...

Comments from some residents and families at Brookside confirmed that they were encouraged to raise concerns at any time and to expect prompt resolution:

[S]ince I've been here, my administrator told me not to be afraid to talk to anyone. So of course I go and talk to her if I have a problem. And we sit down and we discuss it, and she takes the action that needs to be taken.

A family member of this resident stated that “[we] *feel welcome at all times*” and confirmed that it was possible to “*go to the administration instead of ... [following] chain of command.*”

However, it was clear that other residents and families valued formal opportunities to engage in care planning. One resident suggested that the “open-door policy” at Brookside actually curtailed her right to participate in formal care-planning meetings:

I'm pushed straight out the door [of the meeting] because I live here and I can ask anything any time. And it really has made me so mad I haven't [been to a care-plan meeting] this year because of that.

At Meadowview, residents and family members also emphasized the importance of engaging through formal structures. One family member whose sister had dementia talked about keeping a list of issues for discussion in the care conference:

[I]f I have concerns, I like to just wait and bring it to the care meeting because then [we've] got the nurses and the other people, the staff members, where all of us can hear at one time.

Her comments suggested that raising issues in the care-planning meeting was preferable to addressing them individually and incrementally. When asked whether she would also approach nursing staff informally to raise concerns about her sister's care, this family member replied:

Sometimes, and then sometimes not. Because everybody have their own mood. I mean everybody's not the same every day. ... They not consistent in what they supposed to be doing. I put it like that.

This comment suggested that an important aspect of formal care-planning meetings is that they are less influenced by individual mood and personality than informal communication.

A resident from Meadowview also characterized care-planning meetings as an important avenue for engagement, saying “*you can get things done there.*” However, he had only recently learned about them and, similar to the Brookside resident quoted, he did not feel adequately acknowledged as someone who managed his own care:

I never went to [the meetings] because I didn't know they were having them even. [T]he thought here is “tell your family.” I don't have a family. I'm on my own. I can't get that through people's heads.

Taken together, these comments suggest that formal and informal structures serve complementary functions in supporting resident and family engagement in care planning.

Follow-through on engagement in care planning—Stakeholder responses suggested that a second element of meaningful engagement in care planning is effective follow-through, whereby resident and family engagement is met with an adequate institutional response.

At Brookside, requests gathered informally were addressed by formal follow-through, as the administrator indicated by saying, “*the care plan can be updated on a daily basis*” and “*we do a grievance for every concern, and we document every intervention we put in place.*” This was confirmed by the resident quoted above about speaking directly to the administrator: “*We sit down and we discuss it, and she takes the action that needs to be taken, if any, and then we just follow-through with it to make sure that I’m happy.*”

Generally, however, follow-through was described in negative terms by residents, as in the following example:

Brookside resident: I’ve got a lift chair in my room that ... I’ve slept in for the last four years ... [because] my bed is too short for me. And I have asked and asked and asked for a longer bed and I just can’t get one.

Facilitator: ... what’s the response?

Resident: [Impersonating the administration] “Well we know it’s short for you.” Well if you know it, damn it, excuse me, do something about it.

Similar examples came from Meadowview residents, as in the following example about a persistently insufficient supply of incontinence supplies:

Facilitator: Who have you talked to about this?

Resident: Everybody in the building. I be talking about it all the time. They know.

A specific dimension of follow-through was the documentation in care plans of residents’ expressed goals, preferences, and capabilities as well as their needs or deficits. This issue was highlighted by one Meadowview resident who told a story about negotiating to take showers without supervision.

Resident: They have a care plan that’s [posted] in the closets ... [but it’s] incomplete.

Facilitator: What would you say is missing?

Resident: Well, like I was telling you about the shower thing ... There’s nothing in there about a shower whatsoever. ... I would rather have them put it in writing, “Hey, the man takes his own showers” ... because that is a privilege, believe me.

These comments suggest that inclusion of positive language on the care plan is an important element of follow-through, by supporting the legitimacy and sustainability of care-planning decisions.

Roles required to enhance engagement in care planning

Stakeholders' comments underscored the importance of broad commitment across staff roles to the overarching principle of person-centered care, of which PDCP is a key element. For example, at Brookside all departmental managers attended "morning meetings" and walked through the halls daily to get to know the residents, as reported by one manager:

All of us have halls and we have to be on our hall every day so we can report what's going on. ... [T]hat is how I sell this building because that's what makes it great. We have to sit in here [in morning meetings]. We know. I don't have any medical [training] but I can tell you who can have water, who can't. I can tell you when Mr. So-and-So had his shoes off... I know that much about the [residents] and I don't have a CNA license or a nursing license, but I know that.

Although there may be a custodial element to activities such as walking the halls, the positive and enthusiastic tone of comments such as this – which aligned with many similar examples – indicated a clear commitment across the administrator/manager group at Brookside to knowing and supporting each individual, even when not directly involved in their care. Such commitment is important for facilitating the formal and informal engagement and follow-through that is important to PDCP.

A second key role identified by stakeholders was that played by the nursing team and other staff in "translating" or implementing the care plan in the spirit of PDCP. This role was expressed by certified nursing assistants (CNAs) as a commitment to encouraging residents' decision-making. A Brookside CNA gave this example:

[A shower] is an issue for the family in the care-plan meeting, but it still comes down to what [the resident] wants. When they say no, it means no... Don't take everything from them. Let them make some decisions for themselves.

Beyond their individual preferences for formal and informal communication with staff, residents varied on their preferred role in PDCP. In some cases, residents wanted to be fully engaged in care planning, as seen above, while others wanted to delegate some decisions to family members or staff. For example, one Meadowview resident spoke about deferring physical therapy decisions to the rehabilitation department:

I think the solution should be up to them because, I mean, they're the ones taking care of us. They're the ones getting paid for taking care of us. They're supposed to know what they're doing with us.

Many residents suggested that their expectations of engagement extended only so far as being informed, like this Brookside resident:

I'm okay with doing anything around here as long as I'm informed... I'll cooperate with you with anything in any way, as long as I know what your plan is for me.

Another Brookside resident shared a story that illustrates this point. Her breakfast tray began arriving with no meat: "*They [took away] the pork... I was wondering what had happened because I had been getting that ever since I been here.*" Upon inquiry, her family learned that the dietician had changed the breakfast order because the resident was gaining weight. The resident reported that she was satisfied with the decision after learning the rationale: "*I'm*

very happy because, when something happen to you, you want to know what cause it. ... I'm satisfied since now I know." A Meadowview resident wanted to return home, but agreed to extend her stay in the nursing home after discussing the decision with her physician:

My doctor still don't want me to go right now because of my heart. ... After she talked to me about it, I really don't want to go home, get sick, and have to come back. ... I was frustrated, but now I'm satisfied with what she's saying.

These scenarios underscore the importance of keeping residents informed as a step toward meaningful engagement in care planning. In each case, the resident apparently endorsed the decision after being informed of the risks and benefits; although being informed may be a necessary but not sufficient condition for PDCP, if decisions remain provider-led.

Finally, in addition to adopting various roles in relation to their own care, some residents spoke up on each other's behalf, such as this Meadowview resident:

[S]peaking about my roommate... She doesn't get changed [from bedtime] till the next morning. I mean [her bed pad is] just soaking wet. ... She can't say things for herself, and you really can't understand unless you get down close to her. And I told them. I said, "This is just ridiculous..."

In another example, a Brookside resident described coaching another resident to engage in his care:

[O]ne man... every time his CNA would come in there and make up his bed, he would tear the bed up because he didn't like the way she was making it up. I told him... "You go down there to your CNA and tell her, 'Listen, I want to show you how I want my bed made up'..." So he went down there the next day, he told her ... and she started fixing his bed like he wanted it.

In summary, residents' responses suggested that their role in care planning has both individual and social components that vary depending on personal preference and expectations, the nature of the care-planning decision, and other factors.

Perceived limits on PDCP

Stakeholders identified a number of factors that appeared to limit the potential for implementing PDCP. Competing clinical and organizational priorities comprised one set of limiting factors. The conflict between safety and autonomy, a primary example, was illustrated by one resident's story about losing the use of her electric wheelchair:

Brookside resident: [The physical therapist] took me in my room and says, "We're going to take your wheelchair away from you today."

Interviewer: Did you feel like you were able to discuss with the physical therapist?

Resident: No, no, no discussion. (crying) ... She went outside and got the administrator, she got one of the nurses, she got the lady that's in charge of physical therapy, and she got one of the social workers ... and they piled in my room, and said "We're going to take your chair

away today. As of right now it's going to be the last time you ride in it." ... [It was] just point blank.

The same resident also talked about having her food choices superseded by clinical priorities:

Brookside resident: Last night, we had chicken nuggets, and it looked fine on the menu. ... They put it in the blender and chopped them up so badly it was like sawdust almost. I refused to eat it. ... They ended up making me a ham and cheese sandwich, which is what I told the girl to tell them I wanted. They took that ham and put it in that blender and crunched it all up. It was so nasty.

Similarly, a family member spoke about wanting to offer her sister, who had advanced dementia, a taste of ice cream. The staff refused, saying ice cream posed an aspiration risk. These examples imply an inherent limit on PDCP, in that resident direction may be encouraged, but only to the point that it conflicts with clinical care and risk management, when control reverts to the provider.

On a related note, stakeholders from the management group referred to regulatory factors perceived to limit the implementation of a more person-directed, flexible approach. Regulations were discussed as a reason to avoid specificity (or "follow-through") in care plans:

Meadowview manager 1: You don't want to be too specific. You can't say "I'll be there at 10:00" because if something happens and this person takes a little bit longer... [there would be] repercussions. ...

Meadowview manager 2: [That's] one reason you don't want to document ... what that [resident] really wants.

Finally, limited resources, particularly staffing, were commonly mentioned as a barrier to enacting PDCP. In the following example, a Brookside family member alludes to the effects of staffing limitations on her sister's music program:

She had a physical therapist working with her about sound, music. And he put earphones, let her listen through the earphones because she loved music and always have. ... But his time was up, so I don't know if they let her listen to the music now or what, you know. ... Sometimes they're short of aides and so I guess they just don't have time to deal with, to fool with her like that.

Residents also cited staffing shortages as a reason for lack of follow-through on their goals or preferences. One Brookside resident summarized how persistent understaffing curtails the CNAs' ability to provide personalized care:

Well, we just don't have the help around here that they need... So you [a CNA] got your residents that you normally look after, then you got to go over and look after some of [another CNA's] that you don't know anything about their wants and their needs. It makes it tough on you because you know while you're helping her residents, you got some residents that are being neglected.

Although sometimes blaming frontline staff directly for delayed or impersonal care, residents generally framed their concerns in the broader context of understaffing, and described their corresponding efforts to limit their requests and thereby lessen the staff's workload.

Discussion

Person-centered care has been described as a shift in approach from “what’s the matter *with* you?” to “what matters *to* you?” (HEE, 2016). Person-directed care planning (PDCP), defined as the process by which individuals and their families are meaningfully engaged in co-producing care plans, is a critical step toward ensuring that nursing homes address “what matters *to*” residents. To move from principles and policy mandate to operationalization, this study elicited stakeholders’ perspectives on care-planning practices and the potential for PDCP, discovering three key themes to inform the development of an operational framework for PDCP. The first theme is that of *strategies* that support PDCP, including formal and informal engagement mechanisms and consistent follow-through, which must be integrated into the policies and procedures throughout the organization. The second theme is that of *roles* required to support PDCP, including commitment from all staff and varied roles for residents, depending on the individual and type of decision. Developing and supporting these roles throughout the organization is therefore key to operationalizing PDCP. The third theme is the perceived *limits* on PDCP, including competing priorities, regulatory constraints, and resource limitations, which may inhibit operationalizing PDCP across the organization, thus meriting consistent, ongoing scrutiny to ensure appropriate application.

Underlying these findings is an implied shift from “problem-focused” to “strengths-based” care planning. Rooted in social work case management (Saleebey, 2000) and reflecting the holistic nature of nursing practice (Cederbaum & Klusaritz, 2009), the strengths-based approach emphasizes the individual’s role in defining his/her own strengths and developing goals accordingly. The resident who wished his care plan would affirm his ability to shower independently, rather than just reflecting an absence of language about dependence, provides one example of the strengths-based approach.

The strengths-based approach does not preclude the role of clinical expertise, but “does assert that [this expertise] must be seen as contextual and part of a larger process” that is driven by the resident (Graybeal, 2001, p. 236). In our research, we found that residents and families value the opinion and guidance of “the experts,” while also wanting to participate in shared decision-making in the care-planning process. As several residents in this study did not know about their right to attend care conferences or felt they were voiceless compared to residents with family advocates, however, it appears that shared decision making may remain aspirational in some nursing homes.

Balancing informal and formal engagement, honoring residents’ preferences for engagement in care planning, and ensuring appropriate follow-through are all strategies which require new ways of thinking and working. Accordingly, the findings in this study suggest a number of specific competencies required to operationalize PDCP. First, there is a need for leadership skills in modeling and championing PDCP. At Brookside, there appeared to be a

strong, formal endorsement of PDCP principles; whereas at Meadowview, there were fewer responses that indicated commitment to PDCP. It may be that there was less formal leadership about the importance of supporting resident and family engagement in care planning. Implementation science suggests that “champions” or “change agents” improve the likelihood of behavior change when new ideas or practices are introduced into the health sector (Thompson, Estabrooks, & Degner, 2006; Kouzes and Posner, 2012). Such leadership competencies have been emphasized by McGilton et al. (2012) in their person-centered framework for long-term care, with particular emphasis on RNs’ leadership in enabling others to provide person-centered care.

The Adaptive Leadership Framework guiding this study’s design requires us to look beyond formal leadership roles, however, to identify leadership as it emerges in various circumstances. In particular, the translational role played by CNAs, along with other non-clinical frontline staff, was highlighted in our findings as important for ensuring that care is responsive to the individual’s daily and changing preferences, mood, and health status. It is well-recognized that direct-care staff develop extensive, robust knowledge of residents through sustained daily contact (Scales, Bailey, Middleton, & Schneider, 2016); this includes, for many frontline staff, knowledge of residents’ individual values, wishes, and goals. These staff, therefore, play a key role in ensuring that the care plan is implemented according to those individual values and wishes on a daily basis, i.e. in the spirit of PDCP, rather than becoming a provider-driven artifact of a standardized care-planning process (Kontos, Miller, & Mitchell, 2010). They can also support opportunities for informal engagement.

Two sets of competencies are therefore indicated in an operationalized framework of PDCP. First, CNAs must recognize and respond to residents’ expressed preferences, rather than rigidly implementing the care plan. Second, they must engage “upwards” in the formal care-planning process, i.e. share their knowledge about the resident to the broader interdisciplinary team. CNAs’ engagement in care planning is now mandated in the revised nursing home regulations (CMS, 2016). Historically, however, CNAs have not been systematically involved in care planning (Caspar & O’Rourke, 2008) and are often excluded from communications that would help them engage more effectively (Kolanowski, Van Haitsma, Penrod, Hill, & Yevchak, 2015). Therefore, specific training to support CNAs’ translational role is required. Neither set of competencies can be exercised without appropriate resources, however. As stakeholders in this study described, fulfillment of PDCP is inevitably compromised when CNAs do not have sufficient time, necessary competencies, or support to care for residents.

The second set of required competencies is that of residents and their families to engage effectively in care planning. A key finding from this study is that preferences for engagement must be disentangled from the competency to engage, and this warrants further study. Individuals bring different preferences for engagement in the care-planning process, but they also bring different levels of experience and ability to engage with health-care professionals. These skill differences may coincide with broader health disparities related to health-care engagement and communication between different populations (Williams & Jackson, 2005). Therefore, it is important not to assume that less confident or experienced

individuals prefer more passive roles, when their reticence may relate instead to inexperience. Conducting this study in nursing homes serving a high proportion of residents from low-resource and/or minority backgrounds brought attention to this important issue.

Given the small size and limited geographic scope of this study, the findings represent only a starting point for understanding how to conceptualize, operationalize and implement PDCP. Our sample included a diversity of voices from the administrators/managers group but, by contrast, the number of family participants was very small, as we were only able to include those who saw the study poster and chose/were able to come to the nursing home for a scheduled engagement session or who happened to be at the nursing home at that time. Further research is required to explore what PDCP means for a broader range of family caregivers and residents, including those residents who cannot, due to memory or communication problems, participate in the care-planning process in the same ways as those who are cognitively intact. Given that nursing homes vary substantially—and that “survey cultures” regarding the interpretation of nursing home regulations also vary from state to state (Harrington, Mullan, & Carrillo, 2004)—further observational research must also be conducted in different jurisdictions. Finally, as the concepts explored in this study are still emergent, opportunities should be taken to further solicit stakeholders’ input as ideas about and interventions to promote PDCP are developed.

Conclusion

This paper has explored nursing home stakeholders’ views on care planning, identifying potential strategies to operationalize and implement PDCP, the roles and competencies required, and the limits or barriers that must be overcome. It was clear from the analysis that PDCP, although focused on the individual, is not an individualistic undertaking; it is a shared undertaking that requires a commitment to work together to navigate the care-planning process, taking into account clinical, psychosocial, and social-environmental factors.

Acknowledgments

The authors wish to thank our nursing home partners for their collaboration and the residents, family members, and staff who contributed their valuable insight.

Funding

The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work was supported by the Duke University-RTI International collaboration initiative “Funds Launching Alliances for Research Exploration” (FLARE; to K.C. and M.L.); the National Institute of Nursing Research (NIH P30NR014139; MPIs: Docherty & Bailey; to K.C.); the Duke University School of Nursing Postdoctoral Fellowship Program (to K.S.); and the National Institutes of Health T32 Postdoctoral Fellowship through the Duke University Center for the Study of Aging and Human Development (5T32AG000029–40; PI: Cohen; to K.S.).

References

- Anderson RA, Bailey DE, Jr, Wu B, Corazzini K, McConnell ES, Thygeson NM, & Docherty SL (2015). Adaptive Leadership framework for chronic illness: framing a research agenda for transforming care delivery. *Advances in Nursing Science*, 38(2), 83–95. doi: 10.1097/ANS.000000000000063 [PubMed: 25647829]

- Barnes W, Gartland M, & Stack M (2004). Old habits die hard: path dependency and behavioral lock-in. *Journal of Economic Issues*, 38(2), 371–377. doi: 10.1080/00213624.2004.11506696
- Blair T, & Minkler M (2009). Participatory action research with older adults: key principles in practice. *The Gerontologist*, 49(5), 651–662. doi:10.1093/geront/gnp049 [PubMed: 19491353]
- Caspar S, & O'Rourke N (2008). The influence of care provider access to structural empowerment on individualized care in long-term-care facilities. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 63(4), S255–S265.
- Cederbaum J, & Klusaritz HA (2009). Clinical instruction: Using the strengths-based approach with nursing students. *Journal of Nursing Education*, 48(8), 423–424. doi: 10.3928/01484834-20090518-01
- Centers for Disease Control and Prevention (CDC). (2009). National NH Survey. Atlanta, GA: CDC.
- Centers for Medicare and Medicaid Services (CMS). (2016). Medicare and Medicaid Programs; Reform of Requirements for Long-Term Care Facilities, 81 FR 68688 C.F.R.
- Centers for Medicare and Medicaid Services (CMS). (n.d.) NH Compare. Retrieved from: <https://www.medicare.gov/nursinghomecompare/search.html?>(accessed 12/13/16).
- Chen J, Mullins CD, Novak P, & Thomas SB (2016). Personalized strategies to activate and empower patients in health care and reduce health disparities. *Health Education and Behavior*, 43(1), 25–34. doi:10.1177/1090198115579415 [PubMed: 25845376]
- Corazzini KN, Twersky J, White HK, Buhr GT, McConnell ES, Weiner M, & Colón-Emeric CS (2015). Implementing culture change in NHs: An Adaptive Leadership framework. *The Gerontologist*, 55(4), 616–627. [PubMed: 24451896]
- Dellefield ME (2006). Interdisciplinary care planning and the written care plan in NHs: a critical review. *The Gerontologist*, 46(1), 128–133. [PubMed: 16452293]
- Edvardsson D, Backman A, Berglund Å, Björk S, Bölenius K, Kirkevold M, . . . Winblad B (2016). The Umeå ageing and health research programme (U-Age): Exploring person-centred care and health-promoting living conditions for an ageing population. *Nordic Journal of Nursing Research*. doi:10.1177/2057158516645705
- Fetherstonhaugh D, Tarzia L, Bauer M, Nay R, & Beattie E (2014). “The red dress or the blue?”: How do staff perceive that they support decision making for people with dementia living in residential aged care facilities? *Journal of Applied Gerontology*. doi:10.1177/0733464814531089.
- Garcia TJ, Harrison TC, & Goodwin JS (2016). NH stakeholder views of resident involvement in medical care decisions. *Qualitative Health Research*, 26(5), 712–728. [PubMed: 25721717]
- Graybeal C (2001). Strengths-based social work assessment: Transforming the dominant paradigm. *Families in Society: The Journal of Contemporary Social Services*, 82(3), 233–242. doi: 10.1606/1044-3894.236
- Hamann DJ (2014). Does empowering resident families or NH employees in decision making improve service quality? *Journal of Applied Gerontology*, 33(5), 603–623. doi:10.1177/0733464813508650 [PubMed: 24652909]
- Harding E, Wait S, & Scrutton J (2015). The state of play in person-centred care: a pragmatic review of how person-centred care is defined, applied and measured, featuring selected key contributors and case studies across the field. London: The Health Policy Partnership.
- Harrington C, Mullan JT, & Carrillo H (2004). State NH enforcement systems. *Journal of Health Politics, Policy and Law*, 29(1), 43–74.
- Health Education England (HEE). (2016). Person centred care. Retrieved from: <https://www.hee.nhs.uk/printpdf/our-work/person-centred-care> (accessed 12/13/16).
- Heron J, & Reason P (1997). A participatory inquiry paradigm. *Qualitative Inquiry*, 3(3), 274–294.
- Hill NL, Kolanowski AM, Milone-Nuzzo P, & Yevchak A (2011). Culture change models and resident health outcomes in long-term care. *Journal of Nursing Scholarship*, 43(1), 30–40. doi: 10.1111/j.1547-5069.2010.01379.x [PubMed: 21342422]
- Hsieh H-F, & Shannon SE (2005). Three approaches to qualitative content analysis. *Qualitative Health Research*, 15(9), 1277–1288. [PubMed: 16204405]
- Kietzman KG (2012). Using a “person-centered” approach to improve care coordination: Opportunities emerging from the Affordable Care Act. *Journal of Geriatric Care Management*, 22(2), 1–14.

- Kogan AC, Wilber K, & Mosqueda L (2016). Person-centered care for older adults with chronic conditions and functional impairment: a systematic literature review. *Journal of the American Geriatrics Society*, 64(1), e1–e7. doi:10.1111/jgs.13873 [PubMed: 26626408]
- Kolanowski A, Van Haitsma K, Penrod J, Hill N, & Yevchak A (2015). “Wish we would have known that!” Communication breakdown impedes person-centered care. *The Gerontologist*, 55(Suppl 1), S50–S60. doi: 10.1093/geront/gnv014 [PubMed: 26055781]
- Kontos PC, Miller KL, & Mitchell GJ (2010). Neglecting the importance of the decision making and care regimes of personal support workers: a critique of standardization of care planning through the RAI/MDS. *The Gerontologist*, 50(3), 352–362. doi: 10.1093/geront/gnp165 [PubMed: 20026525]
- Koren MJ (2010). Person-centered care for nursing home residents: the culture-change movement. *Health Affairs*, 29(2), 312–317. Doi: 10.1377/hlthaff.2009.0966 [PubMed: 20056692]
- Kouzes J, & Posner B (2012). *The Leadership Challenge: How to Make Extraordinary Things Happen in Organizations*, 5e. Hoboken, NJ: Wiley.
- Lepore M, Scales K, Thach T, Porter K, Anderson R, McConnell E, . . . Corazzini K (2016). PDCP: Foundations, elements, barriers, facilitators, and outcomes. *Gerontologist*, 56, 128.
- Lepore M, Shield RR, Looze J, Tyler D, Mor V, & Miller SC (2015). Medicare and Medicaid reimbursement rates for NHs motivate select culture change practices but not comprehensive culture change. *Journal of Aging & Social Policy*, 3, 215–231.
- McAllister M, Dunn G, Payne K, Davies L, & Todd C (2012). Patient empowerment: The need to consider it as a measurable patient-reported outcome for chronic conditions. *BMC Health Services Research*, 12(1), 157. doi:10.1186/1472-6963-12-157 [PubMed: 22694747]
- McGilton KS, Heath H, Chu CH, Boström AM, Mueller C, M Boscart V, . . . Bowers B (2012). Moving the agenda forward: a person-centred framework in long-term care. *International Journal of Older People Nursing*, 7(4), 303–309. doi: 10.1111/opn.12010 [PubMed: 23164252]
- McKeown JK, Fortune D, & Dupuis SL (2016). “It is like stepping into another world”: Exploring the possibilities of using appreciative participatory action research to guide culture change work in community and long-term care. *Action Research*, 14(3), 318–344. doi: 10.1177/1476750315618763
- Miller SC, Looze J, Shield R, Clark MA, Lepore M, Tyler D, . . . Mor V (2014). Culture change practice in US NHs: Prevalence and variation by state Medicaid reimbursement policies. *The Gerontologist*, 54(3), 434–445. doi: 10.1093/geront/gnt020 [PubMed: 23514674]
- Olsson LE, Hansson E, Ekman I, & Karlsson J (2009). A cost-effectiveness study of a patient-centred integrated care pathway. *Journal of Advanced Nursing*, 65(8), 1626–1635. doi: 10.1111/j.1365-2648.2009.05017.x [PubMed: 19493145]
- Olsson LE, Jakobsson Ung E, Swedberg K, & Ekman I (2013). Efficacy of person-centred care as an intervention in controlled trials—a systematic review. *Journal of Clinical Nursing*, 22(3–4), 456–465. doi: 10.1111/jocn.12039 [PubMed: 23231540]
- Pioneer Network. (2011). Continuum of Person-Directed Culture. Retrieved from: <https://www.pioneernetwork.net/Providers/Continuum/> (accessed 12/13/2016).
- Porter J, Ntouva A, Read A, Murdoch M, Ola D, & Tsakos G (2015). The impact of oral health on the quality of life of NH residents. *Health and Quality of Life Outcomes*, 13(1), 102. doi: 10.1186/s12955-015-0300-y [PubMed: 26169066]
- Salabee D (2000). Power in the people: Strengths and hope. *Advances in Social Work*, 1(2), 127–136.
- Scales K, Bailey S, Middleton J, & Schneider J (2016). Power, empowerment, and person-centred care: Using ethnography to examine the everyday practice of unregistered dementia care staff. *Sociology of Health & Illness*, 39(2), 227–243.
- Shier V, Khodyakov D, Cohen LW, Zimmerman S, & Saliba D (2014). What does the evidence really say about culture change in NHs? *The Gerontologist*, 54(Suppl 1), S6–S16. doi: 10.1093/geront/gnt147 [PubMed: 24443607]
- Stone R, & Harahan MF (2010). Improving the long-term care workforce serving older adults. *Health Affairs*, 29(1), 109–115. doi:10.1377/hlthaff.2009.0554 [PubMed: 20048368]

- Thompson GN, Estabrooks CA, & Degner LF (2006). Clarifying the concepts in knowledge transfer: A literature review. *Journal of Advanced Nursing*, 53(6), 691–701. doi: 10.1111/j.1365-2648.2006.03775.x [PubMed: 16553677]
- Watt AM, Hiller JE, Braunack-Mayer AJ, Moss JR, Buchan H, Wale J, ... & Elshaug AG (2012). The ASTUTE Health study protocol: Deliberative stakeholder engagements to inform implementation approaches to healthcare disinvestment. *Implementation Science*, 7(1), 101. [PubMed: 23088222]
- White DL, Newton-Curtis L, & Lyons KS (2008). Development and initial testing of a measure of person-directed care. *The Gerontologist*, 48(suppl 1), 114–123. doi: 10.1093/geront/48.Supplement_1.114 [PubMed: 18694992]
- Williams DR, & Jackson PB (2005). Social sources of racial disparities in health. *Health Affairs*, 24(2), 325–334. doi: 10.1377/hlthaff.24.2.325 [PubMed: 15757915]
- Wolf DM, Lehman L, Quinlin R, Zullo T, & Hoffman L (2008). Effect of patient-centered care on patient satisfaction and quality of care. *Journal of Nursing Care Quality*, 23(4), 316–321. doi: 10.1097/01.NCQ.0000336672.02725.a5 [PubMed: 18806645]

Box 1.**Themes and Codes****Theme 1: Strategies**

- Care plan meeting
- Communication
- Engagement
- Follow-through
- Implementation – facilitators
- Implementation – strategies
- Needs and preferences (of residents)

Theme 2: Roles

- Adaptive leadership
- Advocating for residents
- Collaborative work
- Implementation – leadership
- Individual activation, leadership
- Relationships
- Resident trajectory

Theme 3: Limits

- Adaptive challenges
- Technical challenges
- Implementation – barriers
- Institutional factors – human resources
- Institutional factors – physical resources
- Institutional factors – time
- Policy, regulatory issues

Figure 1.
Person-Directed Care Planning

Table 1.**Demographic Data**

	Brookside		Meadowview	
	Round 1	Round 2	Round 1	Round 2
Residents	n=5; 4 sessions	n=3 (0 new); 1 session	n=6; 4 sessions	n=5 (2 new); 2 sessions
Gender – female	4	2	5	5
Age – mean (range)	63 (53-87)	59 (53-67)	72 (55-88)	76 (61-92)
Length of time at facility – mean (range)	3y (1y-4y11m)	4y2m (3y6m-4y11m)	3y (3m-10y)	5m (1m-1y)
Race				
White	2	2	3	3
African-American	3	1	3	2
Family members	n=3; 1 session ^b	n=0	n=2; 1 session	n=1; 1 session ^b
Gender – female	2	N/A	2	0
Age	66 (50-77)	N/A	68; 79 ^a	59
Race				
White	0	N/A	0	1
African-American	3	N/A	2	0
Nursing staff	n=2; 1 session	n=5 (3 new); 1 session	n=4; 2 sessions	n=2 (2 new); 1 session
Gender – female	2	4	4	2
Age	34; 44	40 (29-48)	45 (27-53)	46; 61
Race				
White	1	1	2	0
African-American	1	4	2	2
Job title	LPN; CNA	Activity asst; CNA; LPN	CNA	CNA
Length of employment at this NH	1y3m; 13y ^a	5y2m (9m-13y)	4y (8m-7y8m)	6y; 29y10m ^a
Managers/administrators	n=17; 2 sessions	n=12 (2 new); 1 session	n=17; 1 session	n=13 (1 new); 1 session
Gender – female	16	12	15	12
Age	48 (27-63)	48 (28-61)	42 (25-69)	42 (29-65)
Race				
White	8	7	16	12
African-American	9	5	0	1
Length of employment at this NH	7y10m (4m-16y11m)	9y (5m-16y11m)	6y6m (3m-25y7m)	10y4m (2y3m-25y-7m)

Notes: CNA=Certified Nursing Assistant; LPN=Licensed Practical Nurse; m=months; y=years; N/A=not applicable

^a A semi-colon is used to describe data for each participant when n=2.

^b Indicates that one resident was included in the session; that resident's demographic information is included in the Residents' data.