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Nursing Home Stakeholder Views of Resident Involvement in Medical Care Decisions

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Abstract

Demand by nursing home residents for involvement in their medical care, or, patient-centered care, is expected to increase as baby boomers begin seeking long-term care for their chronic illnesses. To explore the needs in meeting this proposed demand, we used a qualitative descriptive method with content analysis to obtain the joint perspective of key stakeholders on the current state of person-centered medical care in the nursing home. We interviewed 31 nursing home stakeholders: 5 residents, 7 family members, 8 advanced practice registered nurses, 5 physicians, and 6 administrators. Our findings revealed constraints placed by the long-term care system limited medical involvement opportunities and created conflicting goals for patient-centered medical care. Resident participation in medical care was perceived as low, but important. The creation of supportive educational programs for all stakeholders to facilitate a common goal for nursing home admission and to provide assistance through the long-term care system was encouraged.

Keywords

decision making; health care, long-term; health care, users' experiences; holistic care; illness and disease, chronic; research, qualitative

Nursing home stakeholders have led the charge toward patient-centered care, by advocating for a move from protocol-driven medical models to homelike, individualized models of care, where residents can direct their care and quality of life outcomes, also known as nursing home “culture change” (Koren, 2010). In the context of culture change, descriptions of residents directing their care focus on giving residents more choices in daily living activities, for example, patients are given choices as to when to get up in the morning, what to wear, and where to eat (Colorado Foundation for Medical Care, 2006; Doty, Koren, & Sturla,

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2008; S. C. Miller et al., 2014). Rarely, however, have culture change innovations included providing residents with choices in their medical treatment regimens and self-care activities. Such choices might include choosing the type of medications or treatments received, the timing of medications or treatments, the type of exercises engaged in daily, or the type of diet maintained.

In this article, we add to the exploration of person-centered care within the nursing home by pushing the fledgling conversation on residents' preferences for care into a more complex discussion that also includes medical treatment. The Chronic Care Model (CCM) is presented as a means to guide the application of person-centered care to the nursing home residents' preferences for medical treatment. Finally, we present an analysis of the views of 31 nursing home stakeholders along with a discussion of the implications of this work.

Background

As mandated by the federal Nursing Home Reform Act of 1987, nursing home residents, to the extent they are capable and desire, have a fundamental right to be fully informed of their health status and medical condition and to fully participate in their medical care (Nursing Home Reform Act, 1989). The philosophy of patient-centered care reiterates these rights by empowering patients to be involved in their medical care through the offer of choices and negotiation in an atmosphere of mutual respect (Morgan & Yoder, 2012).

Studies focused on patient-centered care and patient–provider communication in nursing homes, have explored residents' and family members' involvement in medical care decisions, including critical care decisions (Funk, 2004; Kayser-Jones, 1995) and end of life care decisions (Berger & Majerovitz, 1998; Lawrence, 2009; McParland, Likourezos, Chichin, Castor, & Paris, 2003; Wetle, Levkoff, Cwikel, & Rosen, 1988). We found only two studies in nursing homes within the United States and two outside the United States conducted in the last 20 years addressing resident participation in medical care. Three of these studies, all qualitative in approach, suggested that residents often initially participated in their medical care, but participation waned over time as disease progressed or as provider/facility concerns for safety or control of outcomes interfered (High & Rowles, 1995; Hughes & Goldie, 2009; Shawler, Rowles, & High, 2001). A Canadian study surveyed 100 residents and found that 51% preferred to have some involvement when their medications were changed and that higher education levels, higher number of chronic illnesses, and residents' perceived worth of their input increased desire for involvement (Funk, 2004). Studies conducted in other health care settings have suggested that quality time spent with patients by medical providers affected patient involvement in medical care (Bastiaens, Van Royen, Pavlic, Raposo, & Baker, 2007; Belcher, Fried, Agostini, & Tinetti, 2006; Schulman-Green, Naik, Bradley, McCorkle, & Bogardus, 2006).

Infrequent focus on involvement of residents in their medical care in U.S. nursing homes may be due to several factors or perceptions. These factors include (a) the stereotypical perception that residents are incapable of or not interested in voicing their opinions in medical matters because of cognitive or physical frailty (Sherwin & Winsby, 2010) and/or because there is a reluctance among this generation of older adults to question authority or voice opinions (Thornton, 2009; University of Iowa School of Social Work–National Resource Center for Family Centered Practice, 2009); (b) the perception that providers lack adequate time to explain and discuss medical choices and preferences, often attributed to a U.S. long-term care payment system that monetarily rewards providers for number of patients seen and services provided and not for patient-centered outcomes (U.S. Department of Health and Human Services, 2011), and to a shortage of qualified geriatricians and advanced practice registered nurses (APRNs; American Nurses Association, 2011; National Gerontological Nurses Association, 2015); (c) medical provider perceptions that patient decisions may result in non-evidence-based and more costly medical care (Berwick, 2009; National Ageing Research Institute, 2006); and (d) the general lack of research evidence associating improved resident outcomes with patient-centered medical care in the long-term care setting (National Ageing Research Institute, 2006).

All these factors have the potential to change over the next 20 years. For instance, baby boomers will take over the older aged population in nursing homes, many quite used to questioning medical authority in their experiences caring for their older aged parents (Robine, Michel, & Herrmann, 2007). The long-term care Prospective Payment System is also undergoing change, as 10 states (and more expected to follow) are now operating under the Pay for Performance system, which focuses on outcomes of care (Werner, Konetzka, & Liang, 2010). In addition, the Affordable Care Act of 2010 includes several patient-centered medical care approaches such as Accountable Care Organizations and Medical Homes (Kietzman, 2012) that incentivize patient-centered outcomes. National initiatives toward legislation to increase the numbers of geriatricians and APRNs (Institute of Medicine [IOM], 2008) and to allow APRNs to practice to the fullest extent of their scope of practice (Vestal, 2013) are underway.

Although studies focused on outcomes of patient-centered medical care are lacking in long-term care, other settings, such as primary care and hospitals, have shown improved patient satisfaction when the provider–patient interaction relates information and empathy (Williams, Weinman, & Dale, 1998). Improvements in health status and more efficient use of health care services in physician office primary care settings have also been associated with patient-centered medical care (Kaplan, Greenfield, & Ware, 1989; Mauksch, Dugdale, Dodson, & Epstein, 2008; Stewart et al., 2000; Wagner et al., 2001). Efforts to increase the evidence base in support of patient-centered care have been recently fueled by funding agencies such as the Person-Centered Outcomes Research Institute (PCORI), established to generate patient-centered outcomes research (Selby & Lipstein, 2014).

The incoming generation of nursing home residents may be more demanding of nursing homes for several reasons. First, baby boomers are growing older with more functional limitations, more obesity, less physical activity, more alcohol intake, and more chronic disease than the generation before them (Kaye, Harrington, & LaPlante, 2010; King, Matheson, Chirina, Shankar, & Broman-Fulks, 2013). Their need and use of nursing home facilities is expected to double by the year 2020, resulting in almost one in every two boomers needing nursing home care at some point in their lives (Spillman & Lubitz, 2002). Also, unlike the generation before them, boomers are growing older in an era of health care where patient-centeredness and self-management have become the gold standard for medical treatment of chronic disease (American Geriatrics Society Expert Panel on the Care of Older Adults With Multimorbidity, 2012; American Medical Directors Association, 2010; Berwick, 2009; Board of the International College of Person-Centered Medicine, 2012; IOM, 2001; Perez, Cummings, Schrag, Mead, & Jewers, 2013). Boomers tend to be educated, assertive, and engaged in their medical care, using Internet, various technological devices, and social media to inform themselves, their friends, and families (Cline & Haynes, 2001; Kickbusch & Payne, 2003; Samoocha, Bruinvels, Elbers, Anema, & van der Beek, 2010). Many have navigated and become very familiar with the health care system to care for the needs of their aging parents as well as their own chronic health care needs (Robine et al., 2007), making them well poised to face their older aged health care issues with open minds and open electronic tablets.

Primary research done in oncology (Collins et al., 2008) and a systematic review of 15 studies in cardiology (Schoenthaler, Kalet, Nicholson, & Lipkin, 2014) sampling boomer-aged patients found that a majority of patients preferred and reported positive outcomes from either making their own medical treatment decisions or making joint decisions with their health care providers. How much boomers will desire to stay actively involved in medical care choices once in the nursing home setting is unknown, but it can be expected that the demand for patient-centered medical care in the nursing home setting will be greater in the future than it is today (American Hospital Association and First Consulting Group, 2007; Kahana & Kahana, 2014). Our team posited that a first step in meeting this future demand of nursing homes was to explore the current state of patient-centered medical care in nursing homes and the perceptions of key stakeholders regarding resident involvement in medical care.

The specific aim of the study described here was to explore the current state of patient-centered medical care in Texas nursing homes to inform a patient-centered approach to improved medical care and outcomes in the long-term care setting. The research questions addressed within this aim included:

> **Research Question 1:** How do stakeholders perceive opportunities for residents to participate in their medical care?
>
> **Research Question 2:** How do stakeholders perceive the importance of resident participation in medical care?

Design

Because of the dearth of empirical evidence describing the involvement of nursing home residents in medical care decisions and self-care activities, we conducted a qualitative descriptive (Sandelowski, 2010) study to describe current resident involvement in medical care and the importance of that involvement to key stakeholders within the setting. The intent was to describe resident involvement in medical regimen decisions and activities, staying as close to the surface of the data and the words of the participants as possible (Sandelowski, 2000).

Sensitizing Framework

The CCM (Wagner et al., 2001) was chosen as a sensitizing framework for the study because of its emphasis on patient preferences (or patient-centeredness) in chronic illness management and its presentation as a team-based approach to patient-centered outcomes. It applies well to the nursing home setting because of the culture change focus on preferences of the resident, the increasing trend toward chronic illness in this setting, and the success of team-based interdisciplinary care for chronic illness in other health care settings (Bodenheimer, Wagner, & Grumbach, 2002; Jacelon, Furman, Rea, Macdonald, & Donoghue, 2011; McEvoy & Barnes, 2007). The framework was used to guide the design of the study and as a lens through which to view the findings. Concepts from the CCM (Improving Chronic Illness Care [ICIC], 2012) used in this study include health systems (administrator/facility), self-management support, decision support, the “activated” patient (resident/family), the “proactive” practice team (physician/APRN), and productive interactions (between practice team and resident/family; see Table 1).

A primary goal of the CCM is to have constant intercommunication among these elements. Ideally, the interested and capable patient is informed and active in decision making and self-management activities to the extent he or she desires, and the health care team is appropriately educated and organized to optimize patient outcomes. The CCM is not meant to be an explanatory, midrange theory, but rather, a flexible evidence-based framework that enhances the provision of person-centered chronic illness care, subject to change as new evidence emerges (Wagner et al., 2001). The CCM guided several aspects of the study including sampling, interview question formulation, and analysis.

According to the CCM, the ideal health care system promotes the empowerment of patients and families to the extent they desire, to increase their investment and satisfaction in the plan of care and its outcomes, very much in line with the goals of patient-centered care. The health care system element of the model, in the nursing home system, is led by the administrator under the authorization of the facility owners. Therefore, we sampled facility administrators as one of our key stakeholder groups. Administrators are the extension of owners and typically have their finger on the pulse of the facility. They are responsible for hiring and firing medical, nursing, and personal care providers and ultimately in deciding which patients will be admitted. In short, they determine the model of care implemented. They are greatly restricted by the mandates of private and corporate owners, as well as by a myriad of state and federal regulations. Their perceptions were integral to our research questions.

The “activated” or empowered patient and proactive practitioner elements influenced our decisions to include nursing home residents, family members of residents, and typical providers of medical care in the nursing home setting, physicians and APRNs, as stakeholders. Frontline caregivers, staff nurses and patient care assistants or certified nurse assistants, were not included because of our primary focus in describing a resident's ability to participate in the medical consultation and its outcomes. In future studies, we plan to include these vital members of the nursing home team as part of the proactive care team because of their close interaction with residents and families and their roles in facilitating communication between providers and residents/families.

People living in nursing homes are usually there because of an inability to physically, cognitively, and/or emotionally manage the complications brought on by chronic illness (Gaugler, Duval, Anderson, & Kane, 2007). As suggested by Shawler et al. (2001), residents require help but often may find themselves becoming increasingly dependent not only physically but also mentally because decisions are being made for them with or without their knowledge or consent. They must grapple with trying to balance accepting necessary losses of independence while trying to maintain a semblance of normal life (Rodin, 1986). Within the CCM, residents are “activated” if informed of all treatment options and possible outcomes to their level of understanding and if assured their opinions are valued. An initial and ongoing assessment of whether or not, or the extent to which, each individual desires to participate is essential. Family members of nursing home residents are often faced with feelings of guilt and sadness while trying to help the resident or to independently handle complex financial and medical decisions, all the while dealing with family and career responsibilities (Ryan & Scullion, 2000). Within the CCM, they also should be “activated” by receiving information, education, and support, to the extent they desire.

Medical care providers in nursing homes have several competing obligations. They must meet high and specialized standards of medical care for older aged persons while ensuring that care is person centered, meets federal and state regulations for quality and payment, and allows for resident and family personal space and autonomy (Welford, Murphy, Wallace, & Casey, 2010). In addition, a shortage of physicians interested in nursing home care, increased patient acuity, increased regulatory responsibility, and decreased federal and state funding place added pressure on practitioners to provide high-quality, affordable care (Raphael, 2003). Within the CCM, providers are expected to be proactive in accessing evidence-based treatment plans, assessing resident/family interest or desire in shared decision making, and being compassionate and unbiased in their delivery of treatment information and options.

APRNs provide medical care in nursing homes, often collaboratively with physicians. Unlike physicians who have reported being able to spend only about 4% of their work time in nursing homes (Katz, Karuza, Kolassa, & Hutson, 1997), APRNs report spending the majority of their workday in the long-term care setting; extending resident, family, staff, and facility time spent with the medical provider; and improving quality of care and patient satisfaction (Bakerjian, 2008; Bakerjian & Harrington, 2012; Farley, Zellman, Ouslander, & Reuben, 1999). APRNs are certified as either nurse practitioners or clinical nurse specialists; all hold master's level degrees, and some hold doctorates. In 33 U.S. states however, APRNs are legally prohibited to practice as independent practitioners and must collaborate with a physician to provide medical care (Lowes, 2014). Texas APRNs practice within the strictest scope of practice regulations in the United States. They must practice and prescribe under the supervision of a physician via a prescriptive authority agreement (Texas Nurse Practitioners, 2013). This authority agreement represents new Texas legislation expanding the previous APRN scope of practice.

The self-management ideals of the CCM influenced the preparation of our interview questions. Interview questions for each set of stakeholders focused on four concerns central to the provision of team-based self-care success as described by Wagner, Austin, and Von

Korff (1996): team agreement on goals for care, continuous support by the care team to the patient/family, encouragement of self-management, and sustained follow-up. To explore stakeholder agreement on goals, we asked each stakeholder about their attendance at and purpose of the care plan meeting, an interdisciplinary meeting, required by state and federal regulations to discuss the residents' plan of care, goals, achievements, and problems. This meeting should include the input of residents, their families or advocates, their primary caregivers, medical providers, and facility administration (Carlson, 2010).

To explore support and encouragement given by providers and received by patients/families, we asked each stakeholder to describe the patient/family–provider interaction and encouraged them to relate stories or scenarios they could recall of memorable encounters. We asked administrators and providers about the barriers they perceived to providing patient-centered care to residents and families. We also asked for ideal characteristics of medical care providers and why these characteristics were important. To examine the concept of sustained follow-up to ensure outcomes reflected patient preferences, we asked stakeholders to describe their expectations of medical care in the nursing home. We asked them to describe whether or not they (the residents) or the other stakeholders thought residents wanted to be involved in medical care decisions and self-care activities and how important it was to each of them that residents were involved in these decisions and activities.

Analysis of the data was guided by the CCM in that the initial coding frame was structured based on the interview questions and the elements of the CCM. More information on the use of the CCM to analyze the data will be presented in the “Findings” section of the article.

Method

Sample, Setting, and Recruitment

After institutional review board approval of the study, we began purposive recruitment of participants. Residents were eligible for participation if they were aged 60 years or above, spoke and understood English, were able to provide independent informed consent for research and medical treatment per facility policies, and were considered long-term residents in a nursing home for more than 3 months. We included residents aged 60 years and above because the age of residents has been decreasing as a result of an increase in middle-aged (31–64 years) adult admissions related to chronic disease and psychiatric diagnoses (N. A. Miller, Pinet-Peralta, & Elder, 2012). Family members were eligible for participation if they were related to a nursing home resident, aged 60 years or older, who had lived in a nursing home for at least 3 months, were older than 18 years of age, and able to speak English. APRNs and physicians were eligible if they were current providers of medical care to people older than age 60 residing in a nursing home. Administrators were eligible if they had at least 1 year of experience. All participant stakeholders provided independent informed consent.

We recruited 31 stakeholders from the central and northern regions of Texas based on their affiliation with 11 independent and unrelated nursing homes. The participants were recruited as a single unit, for example, we defined stakeholders as a group of people with a common interest in the function and outcomes of the institution to gain a complete and balanced description of the phenomena (Milne & Oberle, 2005; Morse & Field, 1995). Stakeholders were not matched or recruited based on their relationship to one another but strictly on their relationship to the phenomenon of interest: medical care in the nursing home.

The recruitment process for administrators, physicians, and APRNs consisted of referrals and often introductions from colleagues in the clinical gerontology field to interested nursing home administrators and medical care providers. Additional administrator and provider participants were recruited through snowball sampling. Resident recruitment consisted of first obtaining permission from facility administrators and/or corporate owners to conduct the study within their facilities, then working with staff nurses and facility directors who approached residents they knew to be cognitively capable of providing independent informed consent. These residents were asked whether they were interested in participating in the research. If a resident expressed an interest, an appointment was set up with the researcher at the resident's convenience to explain the research and obtain his or her informed consent if he or she chose to participate. A follow-up appointment was made to conduct the interview. Family members were also recruited in this manner, as well as through snowball sampling. Recruitment continued until theme saturation was reached for care providers, administrators, and family members. Recruitment of residents proved difficult and time-consuming due to the logistics of often having to obtain corporate approval for research within the facility and then working with available facility staff who determined which residents were not only capable but would also be willing to participate.

Data Collection

We conducted one semistructured audiotaped interview per participant, lasting approximately 1 hour, including self-report of demographic characteristics. All administrators, two physicians, two APRNs, two family members, and all residents' interviews were conducted in a private room within a nursing home facility. The remaining interviews were conducted in private settings chosen by the participant. The interview questions were adapted to the roles of each group of stakeholders while maintaining consistency in the topics. Two researchers conducted the interviews. The first and second participants from each stakeholder group were interviewed by Harrison and the remaining interviews were conducted by Garcia. Garcia accompanied Harrison to at least the first interview within each group of stakeholders, listened to the audio and read the written transcripts of all the interviews, and discussed the interviews with Harrison for best methods of data collection. Self-reported demographic data were entered into SPSS Version 20 to obtain descriptive statistics. These two types of data were used for the analysis. Digital audio files and transcripts were stored on a password protected and encrypted computer. Consent forms were kept separately in a locked file cabinet. Hardcopies of transcripts were kept in a separate locked file and destroyed after analysis.

Data Analysis

We used qualitative content analysis (Schreier, 2012), integrating both deductive analysis, from the CCM framework, and inductive analysis, from the data, to provide a detailed description of the status of patient-centered medical care as seen through the lens of the CCM. Each interview was transcribed verbatim by a professional transcriptionist. Resulting de-identified interview transcripts were separately cross-checked for accuracy against the audio files. An initial coding frame consisting of several key categories was devised from the CCM elements and the interview questions. This initial coding frame was used to code two to three interviews from each participant type. The analysis process consisted of choosing meaningful words or phrases from the transcripts and placing them into the existing initial framework categories to explain or describe each category. New categories were added, and subcategories were created as dictated by the data. Categories were then renamed using participants' actual words in the interest of developing a final coding frame that stayed as close to the surface of the data as possible but allowed for the emergence of new ideas across categories (Sandelowski, 2000). We coded the rest of the transcripts using the final coding frame (Mayring, 2000; Saldana, 2009).

The initially coded transcripts were recoded to check for coding consistency and to ensure all transcripts were coded using the final coding frame (Schreier, 2012). A compare and contrast method was used to collapse sub-categories into larger categories and search for emerging themes. All transcripts were then reread, and categories were modified as needed, until underlying and overarching themes emerged and were identified. Analytic memos were kept on the coding worksheet to record reasons for coding and categorizing decisions, and a separate journal was used to record first impressions and later readings of each transcript. Exemplars of participant quotes for each category and subcategory were identified from the data to ensure the analysis stayed close to the words of the participants (Morse & Field, 1995). To add context to the narratives, we used participant demographics, adapted to gather relevant background data from each different type of participant. Study trustworthiness was achieved through the involvement of the researchers in the collection of the data, frequent discussion between authors to ensure coding consistency, and use of an audit trail via analytic memos and journals.

Findings

The sample of 31 nursing home stakeholders included 5 residents, 7 family members, 13 providers (5 physicians and 8 APRNs), and 6 administrators (see Supplemental Table 2, available at qhr.sagepub.com/supplemental) who, without exception, verbalized a vested interest in the outcomes of nursing home medical care.

Five nursing home residents, four women and one man, were included in the sample. Their mean age was 87.4 years, and they ranged in age from 80 to 97 years; four reported their ethnicity as White, one was Hispanic; four reported completing high school while one reported less than a high school education; all reported having three or more chronic illnesses and being cared for by both a physician and APRNs; and 60% reported “feeling closest” to the APRN. Mean age of family members was 66.3 years; five self-identified as daughters of a resident, one as a daughter-in-law, and one spouse. Within the 11 nursing homes associated with the study, medical care was provided by APRNs, half of whom reported a specialty in gerontology and half reported nursing homes as their sole practice; and physicians, of whom one reported a specialty in geriatrics and none reported nursing homes as their sole practice. The physicians worked in conjunction with both local hospitals and nursing home facilities. The APRNs were either independent nurse contractors who collaborated with a geriatrician, or physician corporation, or were nursing home employees who followed the direction of a nursing home medical director's protocol. Mean experience levels of physicians, nurses, and administrators were comparable, 19.6 years, 22.6 years, and 15.6 years, respectively.

Three central themes described the data: (a) limited interaction productivity—stifled by the system, (b) resident participation and empowerment rare but important, and (c) differing goals resulting in conflicting roles and uncertain outcomes. One theme was identified in response to each research question, and one additional overarching theme was identified from the data as a whole. Within each thematic finding, we will discuss the research question it informed and the major elements of the CCM and key stakeholders that helped to illuminate it.

Limited Interaction Productivity—Stifled by the System

In response to the first research question, "How do stakeholders perceive opportunities for residents to participate in their medical care in the nursing home?" the theme that emerged across stakeholders and through the CCM was that although multiple opportunities for resident involvement in medical decision making and self-care were available, they were laden with caveats and limitations (see Table 2).

As a whole, stakeholders viewed the health system as constraining. It seemed to dictate how "proactive" providers could be as well as how "activated" residents and family members could be. This feeling of being controlled seemed to stifle the efforts of all providers, which in turn seemed to decrease how productive their interactions were in effecting patient-centered outcomes. Several opportunities for resident involvement in their medical care were discussed by stakeholders, but often in limited terms, with qualifications and/or stipulations in place. For instance, residents had the ability to choose which hospital to be transferred to in the event of a crisis but only if the accepting facility allowed for that resident's admission based on acuity and insurance. Residents might also be able to choose which pharmacy to use, which physical therapist company to use, or when hospice care services were appropriate. All of these choices were contingent, however, on whether or not the facility could afford to provide these services through the specified contractors, or if the resident had the private resources to go out of the system for their services. As an administrator with more than a decade of experience stated, "They can opt either to pick one of the people [pharmacies] that we work with or go to their pharmacy and ask them to comply with this [these regulations]." Similarly, an APRN discussed physical therapy treatment options she wanted to provide for her patient but was quick to explain why her preferred plan of care was not possible, "There are times when I'd like physical therapy for my patients but they are not eligible because they've had too many days on a calendar year. So, you know, Medicare can get in the way …."

Administrators described a "problem" medical provider as one who might offer residents and their families medical alternatives that were not possible within the system. They stressed the need for providers to “understand the system” to be the most beneficial to the facility and the residents. As one administrator stated,

> When they [providers] come in from an acute care setting, the reimbursement levels are probably four to five times higher than what we get … It's a different environment here. And that's why a lot of times we get doctors from hospital settings that want to decide to do nursing home, and it's not always a good fit for them because it's so very different, learning to manage all of that, and the timelines, and how it all works.

Residents also seemed to comprehend the limitations placed by the system on their ability to productively interact with their providers. They sensed ever present time limitations, evident in one resident's description of what he would like his medical provider to know about him,

> Just the basic problems I might have. I think some doctors want to go, “let me find out what's wrong with you” … you start telling them and then they get—I can see where some people would talk too much. Some do. But, you know, doctors, they want the facts. They want the one, two, three, what's your problem? Toe ache, headache, back ache, stomach ache, or what? They don't want your life story … I want to be a … informative both ways. Did I talk too much?

Family members also described system limitations as preventing productive interactions with providers resulting in unwanted outcomes. A daughter related being told she could choose her mother's medical provider, but he or she needed to be a physician who visited the home frequently and was familiar with facility operations. Given this restricted choice, she opted to use the facility's contracted provider and described the following outcome,

> Well he totally changed all of her medications and everything that she had been doing, that we had been doing with her doctor before she was in the facility. And he being the doctor, and we being the family, and her being so uncomfortable, we thought, well maybe it's worth a try. But our gut kind of told us, we know her, and we know how she responds to medication. So she was not doing well with the new program that he put her on. And quite honestly, he and I did not see eye to eye.

Ultimately, the participants discussed possible opportunities for residents to take part in their medical plans of care; however, all stakeholders mentioned one or more limitations to most of these opportunities that seemed to diminish the power of the resident or the importance of resident involvement. Administrators, medical providers, and residents not only expressed feeling stifled by the system but also seemed almost accepting of this universal theft of autonomy, that is, each stakeholder described areas where they would like to be autonomous in the provision of care or in managing their own care but knew and accepted they could not be because they understood the ultimate and overarching goal was profit motivated. The only stakeholders who did not seem accepting of this stifling effect of the system were the family members. Although family members expressed appreciation for the providers of care, they did not understand or accept the limitations placed on them or the residents.

Resident Participation and Empowerment Rare, but Important

In response to our second research question, “How do stakeholders perceive the importance of resident participation in medical care?” it was clear that stakeholders, as a whole, including residents, believed it was important for residents to be involved in their medical care, if they were capable of it and desired to do so. They agreed that the majority of residents, some providers estimated 75% to 85%, were not capable of participation, and they said that of those who were, some were very old and from a generation where participation was not expected or necessary. For example, a common administrator and medical provider response when asked if residents wanted to be involved was expressed by this APRN,

> There is a handful of people that do [want to be involved]. But a lot of them, if they're motivated enough, I mean, they do want to participate and they want to help themselves and get better … But I would say for the most part, the majority just will do what you [say], there's still that generation where the doctor knows the best and I'm just going to do it and not really question it too much.

Administrators and medical providers perceived that higher educated and quick-witted residents were more likely to participate in their health care than the average resident. This perception increased if residents were also healthier, more mobile, happier, more vocal, affluent, more confident, and had more involved family than the average resident. Providers and administrators described most family members as involved in health care decisions, although several spoke of decreasing family involvement, as expressed by this administrator,

> It's a little sad on that. I'm seeing more and more, as years go by, less and less family involvement. It's getting more where this is kind of a—just a drop them off and, you know, I might see you in a couple of months type thing.

When involved, though, family members were thought more likely to participate and support the participation of residents if they were educated, medically informed and aware of the residents' health issues, and visited frequently. Conflicting responsibilities between family members' jobs, home responsibilities, and other family members' needs that prevented frequent visiting were described as inhibiting factors to family involvement in a resident's plan of care.

Family members described instances of missing or inadequate support for their involvement in resident medical care, especially with regard to dealing with other overwhelming problems related to nursing home admission such as financial issues, insurance questions, social losses, and illness severity. This daughter described her experience of admitting her mother to a nursing home and dealing with the decision making as follows: “My main support would be myself and my sister. When you don't know anything about it, it's just overwhelming for someone that doesn't know or understand the system, just overwhelming, heartbreaking.” There was no mention of formal resident or family support groups within the facilities to help with the admission processes and changes and no platform to consistently provide late stage chronic illness care education to patients and family members.

All the residents we interviewed felt they were informed and involved in their medical regimens because they wanted to be. Some described caring and trusting relationships with APRNs and confidence in their physicians. One resident summed it up well: “If I'm literate in mind, body, and soul, I think I should be involved [in my medical care], yes.” Some residents also believed they were in the minority as far as being interested in their medical care. One elderly woman described feeling the need to advocate for other residents who chose not to ask questions about their medications. She said,

> And I have had to get some of the men in here and find out what their medicine is for and why they're taking it. They [staff or providers] wouldn't tell them. And I said, “They have to tell you.” And of course they think I can do miracles. But I said, “You could do the same thing if you will talk to them.”

The family members held a variety of opinions regarding the individual desire and ability of residents to be involved in their medical care. Those family members who were related to residents with cognitive impairment stated that their residents were not capable or interested in involvement. Those who were related to residents who were cognitively capable and interested were very outspoken about their family members' right and need to participate. The advocacy of family was largely tied to the capabilities and preferences of their individual family member.

Self-management support—As described earlier, self-management support within the CCM means providing ongoing education, encouragement to participate, and acceptance of that participation as important and vital to the medical decision. All stakeholders perceived that APRNs and physicians could facilitate resident involvement by being easily available to residents and staff, spending time with and knowing the residents as individuals, and having a friendly demeanor. Administrators and family members also perceived that providers needed to be willing to place resident preferences above protocol, age bias, and their desire for controlled outcomes to fully support resident self-management and involvement in their medical care plans. This opinion is evident in the following statement by an administrator,

> Sometimes we get so bogged down in the task and the institutionalization and the rules and all of this that we forget that we're dealing with people and that they have choices and that sometimes their choices don't mesh with what the medical community believes is in their best interest. And we need to ask them, “What do you all want?”

APRNs were described by physicians, administrators, family members, and residents as vital to resident participation in medical care. They were described as often spending the time necessary to explain conditions and treatment options to families and residents, providing compassionate care, and collaborating with staff, thereby providing empowerment, leadership, and high accessibility to medical expertise.

Future expectations—We asked administrators and medical providers if they had seen any change in the involvement of residents in medical care over the past 3 to 5 years. A physician who was both a medical director in several nursing facilities and a hospitalist stated,

> It's going to be a problem. Baby boomers, I hate to generalize, they're very unrealistic about life in general. They want everything to be absolutely perfect. They think they're going to live forever and that as Americans they deserve to live

> to be 105 without any joint pain or any sort of consequences of age. They're starting to trickle into the nursing facilities and it really is a problem because you have to kind of re-wire somebody who's been around for the last 65 years ….

The consensus of stakeholders, even residents, was that many residents, especially those of older age and generation, chose not to participate in medical matters, but there were some who were capable, very interested, and seemed to enjoy or benefit from participation. Administrators, family members, and residents believed providers were instrumental in encouraging and supporting resident involvement by increasing the amount and quality of time spent with residents and by making resident and family preferences their priority.

Decision support—According to the CCM, decisional support provides the resident, family, and providers with chronic illness education needed to make informed and evidence-based decisions. There were several opportunities for productive interactions described by all stakeholders where medical care information and choices could be explained and explored with residents and families, empowering both to feel more comfortable and confident with medical care decision making and involvement. These opportunities included care plan meetings, initial admission meetings, in-room provider visits, problem-prompted meetings requested by providers or family members, social worker visits, and resident council meetings. The care plan meeting, mandated by federal and state regulations, and the initial admission meeting were the only "team" type meetings discussed.

Initial admission meetings were generally described as meetings that took place within 72 hours of admission where the resident and family members were informed of facility routines, their preferences were requested, and goals were discussed. None of the resident or family member participants mentioned this meeting during the interviews. Administrators and providers varied in their descriptions of the purpose of these meetings. Administrators mainly described the admission meeting as a discussion of resident goals and preferences, whereas providers described a discussion of reasonable goals based on realistic expectations. A physician stated,

> We meet very often with patients and their families to try and make sure that we've answered questions and addressed the expectations of their goals. And then try to revise the goals so that those goals are reasonable and obtainable within the resources, both time wise and medically, that are available.

All stakeholders, in no particular pattern, had widely varying perceptions of the purpose of and need to attend care plan meetings. For example, some described the care plan meeting as a forum to discuss the resident's condition and plan of care, others felt it was for voicing administrative concerns, and still others thought it was primarily for residents to voice their facility-related complaints. Very few mentioned this meeting as a place to discuss residents' goals or to empower residents and increase participation when desired.

Differing Goals Resulting in Conflicting Roles and Uncertain Outcomes

The overarching theme derived from the data was related to the discrepancy between the different stakeholders' goals for the resident during and after the nursing home admission. The CCM theorizes that the result of bringing together proactive providers and activated residents is productive interaction, which ultimately leads to resident-centered goals and, eventually, resident-centered outcomes. Based on our conceptual interpretation using the CCM as a guide, it was evident that a lack of agreement existed among the different stakeholders regarding the goal of provider–patient interactions and the overall goals of and for the resident. These discrepancies were most noticeable when discussing the nursing home admission because all providers were asked to state the purpose of the admission into nursing home care. For instance, residents communicated that their medical goal was to improve their health. Most also implied or directly stated that their long-term goal was to return home. One resident stated, “But if they offered me a million dollars to stay here for the rest of my life, I would say, ‘no; say, keep your million dollars. Let me go home.’” No other group of stakeholders, aside from residents, discussed returning home as a major goal of long-term nursing home medical care.

Providers and administrators, although generally describing most families as interested and appropriately involved in residents' care, consistently described a small portion of family members as being either underinvolved or overinvolved in care. They perceived this unhealthy involvement of family as being related to unrealistic expectations or goals for the residents' condition to remain stable. According to providers and administrators, the actual natural trajectory for nursing home residents was not stability but more of a gradual downward trend. Thus, stakeholders' goals or expectations for nursing home admission ranged from getting well and going home, as expressed by residents, to remaining stable and happy as described by family members, to staying as safe and healthy as possible while gradually declining, as described by administrators and providers.

Stakeholders, each in their own way, were dedicated to their roles in a manner consistent with their views of the goals of the nursing home system. The pursuit of these individual goals was incorporated into their interactions and influenced the degree to which outcomes might be patient-centered. The roles that demarcated different stakeholders sometimes conflicted, resulting in disagreement on purpose, expectations, and goals for the nursing home admission. Ultimately, stakeholders provided a seemingly unlikely environment for the provision of patient-centered or resident-directed care and outcomes.

Discussion

To our knowledge, this study is the first to use the CCM as a lens through which to view patient-centered care focused on medical treatment choices in the nursing home setting. We suggest that although there were several opportunities for residents to be involved in their medical care, they were limited by the perceived economic and profit-motivated constraints of the nursing home system. These perceived limitations stifled the efforts of all stakeholders to strive toward patient-centered medical care. The data revealed that the involvement of residents in their medical care was important to all stakeholders; however, few current residents actually were involved, and few support systems to empower residents to be involved were described. Overall, our data revealed that different stakeholder groups had dramatically conflicting perceptions of the purpose of the nursing home stay, which made the delivery of patient-centered medical care difficult, if not impossible, to apprehend, much less deliver.

Stakeholders described several opportunities for residents and family to participate in medical care and its related decisions and activities. One successful example of resident medical care involvement was related by a resident who communicated her goal to stand and walk a few steps to her APRN who advocated for her to receive prolonged physical therapy, overcoming financial barriers, with a good and satisfying outcome for the resident. Overall, however, there were stipulations to almost every available resident choice. The limitations implied a degree of duplicity on the part of the long-term care system. Opportunities were presented for choice, when very little choice existed. For example, residents were told they could freely choose a meal or select a medical care provider when, in reality, they were given only one alternative meal or the choice of only two preselected providers. The realization by the residents of their limited choices in one domain threatened the credibility of choices offered as a whole by the nursing home system. Several instances of these types of limited options may have led to resident disillusionment and disinterest in making choices. Considered “dangling carrot” scenarios in the long-term care literature, these problems are often present in culture change studies where residents have been told they are to be allowed to direct their care, knowing it is their legal right to do so; yet findings reveal that after 20 years of patient-centered care initiatives and culture change efforts, these choices are still not routinely provided to residents (Christensen, Buchanan, & Houlihan, 2011; Schnelle et al., 2009, 2013; Simmons et al., 2011).

Opportunities to provide decisional and self-management support to the residents were clearly available in the form of care plan meetings, admission meetings, and provider visits but, again, there were limitations. The greatest limitations seemed to be the inconsistent format of the care plan meeting and the absence of residents and inconsistent presence of medical providers at these meetings. Although this type of gathering seemed the perfect venue for promotion of involvement, empowerment, and productive interactions between residents and providers and is required by federal nursing home regulations, attendance by many stakeholders, especially residents, was perceived as rare or, at most, very inconsistent. The National Senior Citizens Law Center listed care planning as the second most common problem in nursing homes today in that residents and family do not understand their right to a care plan centered on the resident's needs and preferences (Carlson, 2010).

Only a small percentage of residents were perceived by providers and administrators as involved or interested in their medical care decisions and self-care activities because of cognition, illness, depression, lower education, or generational background. All residents sampled here and most other stakeholders expressed that at least some residents had definite interest in medical care decision making and self-care activities. Our sample of residents was limited by two factors: (a) we had to obtain approval from facility administration/ownership before we could sample residents, which proved to be overly time-consuming for the logistics of the study, and (b) recruitment methods involved facility staff choosing residents whom they thought were cognitively capable and interested in participating in research, which could have biased this sample against the recruitment of residents who were not interested in medical care involvement. Thus, the voice of those residents is missing from these data. We do feel that the richness of the data from the residents in our sample and the consensus of the stakeholders as a whole as to the current lack of involvement and the importance of resident involvement in their medical care supports the notion that medical care choices should become a bigger focus of nursing home culture change.

Most family members were perceived by administrators and providers as involved to some extent, with a trend toward underinvolvement in medical care decision-making. When viewed through the CCM lens, a need for family support mechanisms was revealed, evidenced by family members' descriptions of the nursing home admission experience as “overwhelming, heartbreaking.” There was no mention in this data of decision support or self-management support in the form of formal meetings or support groups for residents and families to empower them to participate in their medical care with education and confidence. Support for transition into the system and medical care participation should be provided by the facility or by medical providers, perhaps in conjunction with the local community to assist with changes associated with nursing home admission, long-term stay stress-ors, or chronic illness course and treatment options. Some residents did mention the existence of a Resident Council to voice their opinions of items or practices they did not like or wanted changed within the facility, but they did not perceive these councils addressed medical care, and these meetings were not mentioned by medical care providers.

The use of support groups for nursing home residents and their families has been encouraged to help them understand role changes and cope with new stressors (Bern-Klug, 2008; Campbell & Linc, 1996). Maas et al. (2004) found that educational sessions with families of dementia patients helped improve families' experiences and staff attitudes toward family members. Hospitals have instituted Patient and Family Councils to serve as a means of communication between patients, families, staff, and administration (Institute for Patient and Family-Centered Care, 2010). These councils often partner with medical care providers to meet the needs of the patient. Extending the present purpose of or establishing Resident and Family Councils in nursing facilities and/or partnering with medical care providers to create a forum to discuss medical care concerns may facilitate positive changes to improve patient-centered medical care.

Resident involvement may also be hampered by the shortage of medical care providers in this setting. The need to increase the number of medical providers in long-term care has been reiterated by many (American Geriatrics Society, 2014; Eldercare Workforce Alliance, 2015; IOM, 2008), and although APRNs are providing badly needed coverage, their numbers are also low and obstacles such as limited scope of practice in many states across the country contribute to the problem (Bakerjian & Harrington, 2012; IOM, 2010).

These data also provided insight into stakeholders' perceptions of the purpose and goals of the nursing home admission. Most residents described an underlying desire to get better and go home, a goal seldom realized in this setting. Similarly, family members had goals for resident health status to improve or remain static, which with end-stage chronic illness is rarely the case. These unrealistic goals are further indication for facilities and providers to team with the larger community to provide resident and family support groups and education on the course of chronic illness, goal setting, and the purpose of a nursing home admission. Perhaps if this support and information were offered prior to admission, in the general public arena, fewer residents and family members would enter into the long-term care system with unrealistic goals that only lead to disappointment and disillusionment.

Health care providers and administrators described goals of providing high-quality, efficient medical care in a safe environment to promote resident comfort and quality of life. Providers perceived their roles as preserving the integrity of the system by seeing as many patients as they could in as little time as possible to maximize care and profit, while administrators focused on satisfying governmental regulations and minimizing costs, again, to maximize profit. There appears to be a clear need for stakeholders to come to some agreement as to the purpose and focus of care provided in the nursing home setting and to set attainable goals to fulfill this purpose. Educational support for medical care providers is indicated to heighten their awareness of the constraints placed by the structure and limited resources of this health care system and to help them be proactive in their efforts to empower residents and families to work together toward patient-centered outcomes.

Use of the CCM as a lens through which to view these data revealed a deficiency in the basic elements necessary for patient-centered care. These elements have been described in the literature as holism, personhood, autonomy, service, and therapeutic relationships (Love & Kelly, 2011; Morgan & Yoder, 2012; Pelzang, 2010). Translated into the characteristics of team-based medical care we found necessary and supportive of resident medical care decision making, these elements became: education, empowerment, collaboration, encouragement, and compassionate interactions. In addition, because stakeholders expressed low expectations for successful resident self-management to occur, it was not surprising that the elements necessary for self-care success as described in the CCM were also missing from these data, namely, stakeholder agreement on goals for care, continuous support, encouragement of self-management, and sustained follow-up. Low expectations for resident involvement were also described by Funk (2004) who questioned this assumption among long-term care stakeholders that autonomy somehow is of less importance or relevance in this setting. Given the descriptions from all stakeholders of the constraints of the system limiting them from either providing or participating in patient-centered care, it appears they did have some awareness that patient-centered care was not occurring, or at least not consistently occurring in this setting.

Limitations

This study was limited to a sample of nursing home stakeholders in the central and northern regions of Texas and is not intended to be generalized. Instead, the data provides the opportunity to broaden the conversation on patient-centered care to include medical treatment choices within the activities of daily living choices advocated for in the nursing home. Another limitation of our study was the inclusion of stakeholders primarily responsible for medical treatment and organizational structure without the voice of nursing home staff nurses, pharmacists, therapists, and attendants. Future studies in other regions of the country might include the expanded health care team to obtain a deeper understanding of resident involvement in their medical care. As mentioned earlier, a larger sample of resident participants may have provided richer data; however, we were limited by the number of nursing homes who approved research in their facilities within the time frame of the study.

Finally, the sampling technique used to recruit residents to minimize any pressure to participate, may have introduced bias as facility staff, despite our request to include all cognitively capable residents, may have tended to refer residents they knew were interested in their medical care and in research participation, removing the perspective of the uninterested resident.

Implications

When considering the implications of this work, we suggest that stakeholders in nursing homes should have a shared understanding and agreed on purpose for medical care in a nursing home. Support groups for potential and current residents and families both inside and outside the nursing home facility could focus on this understanding and prepare families and residents for the many changes associated with a nursing home admission. A large-scale media push, perhaps headed by organizations such as the American Association for Retired Persons (AARP) or The National Consumer Voice for Quality Long-Term Care, to educate the general public on the purpose, benefits, and goals of nursing homes would be beneficial in reducing the misunderstandings that occur when expectations are not met.

According to the CCM, medical care providers need to be proactive or prepared to impart evidence-based and up-to-date information to patients. This education should include information pertaining to the nursing home system and how best to achieve the resident's goals within the constraints of the system. Providers should receive ongoing education on the financial structure and current changes in the system aimed at ensuring that all stakeholders have congruent and realistic goals and are working together to achieve the resident's preferred outcomes within the limitations of the system. In addition, nursing homes and providers should ensure there is a well-defined, well-attended care plan meeting as it seems the best existing opportunity to maximize empowerment, collaboration, and productive interactions.

The role of nurses in the “nursing” home system is critical, but their role in culture change has often been perceived as resistant (Mueller, 2008). Is it possible this perceived resistance is due to a lack of clinical emphasis in general culture change efforts? Nurses are educationally and philosophically prepared and ideally situated to advocate for patient-centered medical care in nursing homes and to bring it to the forefront of nursing home culture change efforts. This study included the perceptions of APRNs in this setting because of their vital medical provider role, but the perceptions and actions of directors of nurses, staff nurses, patient care assistants, and other health care providers are just as vital to the delivery of team-based care that supports and promotes the preferences of the resident, including preferences for medical care that can affect the daily activities of a resident's life. Nurses within this system should recognize, bring attention to, educate, encourage, and advocate for patients who are capable and want to be involved in their medical care. Future research efforts might consider a more in-depth ethnographic approach to describing the state of patient-centered medical care in nursing homes and its effects on resident quality of life including the perceptions of nurses and other vital members of the nursing home team.

The support necessary for patient-centered care in nursing homes is not likely to materialize or be sustained without changes in health care policy. Changes suggested by this study include continued efforts to reform the long-term care system's payment structure to incentivize and philosophically support patient-centered outcomes, mandating and financing the education of all stakeholders and the general public on the purpose and goals of nursing home admission and the importance of teamwork and effective communication, passing legislation to alleviate the geriatric medical care provider shortage, and allowing APRNs to practice to the full extent of their educational preparation in all states.

Conclusion

This qualitative study added to the literature by describing the current state of patient-centered medical care choices for residents in nursing homes and the importance of providing these choices from the perspectives of key medical care stakeholders. Our findings suggested that some residents actively seek participation in their medical care and that this participation is perceived as important to all stakeholders. Nursing homes offered opportunities for residents and their families to participate in medical care, but they included limitations imposed by the system. These limitations created to conserve limited resources instead created conflicting stakeholder goals, making resident self-management and patient-centered outcomes extremely difficult to achieve. A predicted future increase in the number of chronically ill nursing home residents with greater interest in their medical care suggests the need for the long-term care system and providers to offer more credible options and formal support to residents, families, and providers to actively encourage and sustain patient-centered outcomes.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1

Concepts of the Chronic Care Model Adapted for Nursing Homes.

Chronic Care Model Concept	Concept Description Adapted for Nursing Homes
Health systems	Administrator philosophy, facility culture, and facility regulatory environment determine the degree of priority placed on and the quality of *productive interactions* between the *practice team* (physicians and APRNs) and the *patient* (resident and family)
Decision support	Sharing of expert information, including evidence-based guidelines and exceptions to those guidelines, providing a venue for *productive interactions*, improving the residents' comfort level and willingness to participate in self-management
Self-management support	Acceptance of the resident as director of his or her own health care management, provision of ongoing education, support, and encouragement to participate
Patient	Nursing home resident/family member informed of illness treatment options and “activated” or aware of the importance of his or her role in chronic illness care
Practice team	Physicians and APRNs focused on placing the resident at the center of chronic illness care and providing proactive rather than problem-oriented care
Productive interactions	Quality, frequency, and mode of communication and resulting understanding and motivation between providers and resident/family

Note. APRNs = advanced practice registered nurses.

Table 2

Medical Care Decision-Making Opportunities and Limitations.

Decision-Making Opportunities	Limitations
Available options for health care provision: Which pharmacy to use Which hospital to be transferred to Which medications to take	Only facility-contracted entities can be chosen; generally, there are only 1 or 2 available
	Contracted entities must meet and follow certain criteria and policies, which few will do for individuals
	Extra personal expense is incurred if noncontracted entities are used
Residents can often choose: Whether to move to hospice services Whether to be moved to DNR status Whether to be hospitalized	Although these opportunities were named as resident choices, they were discussed as choices primarily faced and decided by family members or care providers
Residents can always choose: To see a medical care provider	Timeliness, date of visit, and time of visit are at the convenience of the medical care provider
Choices to participate in health care activities: Exercise (physical therapy) Diet (daily menu, type or consistency) Medications (type, frequency, compliance) Diagnostic testing (time, timing) Hospital admission/transfer Environment (room decor, music, entertainment)	Most therapies (PT, meds, testing) are limited by contracts held by the NH with insurance companies, therapy groups, pharmacies, provider time restrictions, facility protocols, federal and state regulations, etc.
	If there is a dietary choice, it is usually small, such as one meal alternative
	Residents may be unaware they have choices in these areas
	Choices by residents may be ignored unless family member becomes involved
	Choices are limited by resident cognitive ability and ability to communicate

Note. DNR = do not resuscitate; PT = physical therapy; NH = nursing home.