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# Diffusion of Palliative Care in Nursing Homes: Lessons from the Culture Change Movement

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# Abstract

**Context**—Studies have found that nursing homes (NHs) that rely heavily on Medicaid funding are less likely to implement innovative approaches to care, such as palliative care (PC) or resident-centered approaches commonly referred to as "culture change" (CC). However, a nationally representative survey we previously conducted found some high Medicaid facilities have implemented these innovative approaches.

**Objectives**—The purpose of this study was to identify the factors that enable some high Medicaid NHs to implement innovative approaches to care.

**Methods**—We conducted telephone interviews with 16 NH administrators in four categories of facilities: 1) low PC and low CC, 2) low PC and high CC, 3) high PC and low CC and 4) high PC and high CC. Interviews explored strategies used to overcome barriers to implementation and the resources needed for implementation.

**Results**—We had expected to find differences between low and high NHs, but instead found differences in NHs' experiences with CC and PC. Since the time of our national survey in 2009–2010, most previously low CC NHs had implemented at least some CC practices; however, we did not find similar changes around PC. Administrators reported numerous ways in which they had received information and assistance from outside entities for implementing CC. This was not the case for PC where administrators reported relying exclusively and heavily on hospices for both their residents' PC needs and for information related to PC.

**Conclusion**—PC advocates could learn much from the CC model in which advocates have used multipronged efforts to institute reform.

#### Disclosures

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## Keywords

nursing homes; NHs; long-term care; palliative care; patient-centered care; diffusion of innovation

# Introduction

Diffusion of palliative care and other innovative models of care in nursing homes (NHs) is a persistent challenge in the U.S. and many other countries (1–3). In the U.S., this is especially true in the case of facilities that rely heavily on Medicaid, the government program that funds health care for the poor and finances much NH care. For this study, NHs were considered high Medicaid if 80% or more of their residents' care was supported by Medicaid. Multiple studies have found that high Medicaid NHs often have lower quality care, worse outcomes for residents, lower staffing, and a host of other troubling issues (4–6). These facilities also have been found to be less likely to implement innovative approaches to care (7), such as palliative care or residentcentered approaches commonly referred to as "culture change" (8). However, a nationally representative survey we previously conducted with NH administrators and directors of nursing as part of another study found that some high Medicaid facilities have implemented these innovative approaches (9). To identify the factors that enable some high Medicaid NHs to implement innovative approaches to care, we examined two types of innovation in NHs, palliative care and culture change.

For this study, palliative care was defined as care provided to individuals with serious or life-threatening illnesses who may not qualify for or choose to enroll in hospice, which in the U.S. is care provided at the end of life as a benefit of the Medicare program (the U.S. health care program for those age 65 or older). Palliative care is provided for anyone with a chronic illness by an interdisciplinary team. The team supports patients and families in their psychosocial needs, and addresses patients' physical, intellectual, emotional, social, and spiritual needs while facilitating patient autonomy, access to information, and choice (10).

Culture change was defined, for this study, as practices aimed at making nursing facilities more homelike and less institutional by providing care that is more resident-centered and focused on the preferences and desires of care recipients (11). NH culture change has been operationalized through physical changes, such as removing nursing stations, and organizational changes, such as increasing the autonomy of direct-care workers (12). Specific practices include resident choice in dining, bathing and sleep times, consistent assignment of nurse aides, and provision of private rooms.

Research on the diffusion of innovation in health care organizations has focused primarily on two types of diffusion: diffusion of innovation among individuals within the same organization and diffusion of innovation among organizations (13). Both types of diffusion are necessary for the successful implementation of innovation; each relies on complementary sets of factors for their success that are both internal and external to the organization. Internal factors previously found to be related to implementation of innovation are the characteristics of the organization itself, such as size (14), and the characteristics of the leaders adopting the innovation, such as their communication styles and interpersonal skills (15). External factors include attributes of the environment, such as interpersonal

relationships among leaders in different organizations (16), mass media attention to the innovation, and the intentional spread of the innovation by formal networks and champions (17).

One difficulty in applying previous findings on the diffusion of innovation to high Medicaid NHs is that most previous research has focused on hospitals and, in particular, the experiences of above average organizations often characterized as "early adopters." Little research has focused specifically on the NH environment (18); even less attention concerns the special challenges faced by high Medicaid NHs. Therefore, the purpose of this study was to determine the factors that allow these types of facilities to implement innovative approaches to care, including palliative care and culture change.

# Methods

We conducted 16 qualitative telephone interviews with four administrators in each of four groups of high Medicaid facilities identified using data from a previously conducted national survey (9). Using Online Survey Certification and Reporting (OSCAR) data that is collected annually for most U.S. NHs, we identified the NHs that participated in our previous survey that had at least 80% of their residents' care paid by Medicaid. Using the culture change and palliative care scores derived from our survey data, we then categorized these facilities by he extent of their palliative care and culture change practice implementation. The four categories of facilities were: 1) low palliative care and low culture change, 2) low palliative care and high culture change. The interviews with four administrators from each category took place between September and November 2013. Interviews explored innovations implemented, strategies used to overcome barriers, how facilities began the process, the external and internal resources needed and utilized, and the role of outside networks/groups, among other factors.

Our survey included a set of items on culture change, including questions about physical environment, staff empowerment, and resident choice and decision making (i.e., resident-centered care). These survey questions were used in previous culture change surveys and had good measurement properties (19). The survey also asked a series of questions related to palliative care knowledge and practices. These questions derived from the validated NH "Palliative Care Survey" by Thompson and colleagues (20). To reduce measurement error and increase data validity, cognitive-based interviews of the draft survey items were conducted (21). Development of the culture change and palliative care scores are detailed elsewhere (22, 23).

We randomly selected NHs in each of the four categories and their administrators were mailed introductory letters explaining the purpose of the study and then called to schedule a convenient time for a telephone interview. Data collection was systemized by use of a standard interview protocol that was pilot tested with three NH administrators. Based on feedback from each pilot interview, the interview protocol was revised by the study team. This study was approved by our university's institutional review board.

We began each interview by briefly defining culture change and asking the administrator what practices came to mind when s/he thought of culture change. We next asked if their facility had implemented any culture change practices. For those that had not implemented any practices we asked why this was the case, what barriers to implementation existed and what resources would be needed to overcome these. For those who had implemented practices, we next asked a series of questions, including how long the practices had been in place, what steps the facility took to begin, who at the facility was responsible for starting or promoting the practices, the role of staff in the implementation, where they had received information about these approaches to care, whether any outside person or group assisted in the implementation, what challenges they faced and how these challenges were overcome.

Interviews were audio recorded and transcribed. Because the aims of our research were highly focused, we utilized a framework approach to data management and analysis (24). This allowed for a stepwise iterative and transparent process that included the use of a modified inductive, grounded theory-style technique (25) to identify and label ("code") portions of text. Whereas some coding labels emerged directly from the content of the data, others represented predetermined categories and domains reflecting our research questions and theoretical framework (26, 27). In this way, unexpected findings as well as anticipated areas of interest were captured.

To introduce the palliative care questions, we briefly defined palliative care and asked the

same questions now tailored to palliative care.

The first two authors each read all interviews multiple times and made initial notations to code the material. In subsequent and repeated meetings, we refined the code definitions and sought consensus about the coding of the material, with decisions recorded in a comprehensive audit trail. Codes were clustered into related categories to generate themes. Two researchers coded all interviews and final coding decisions were made during consensus meetings. In addition, we sought alternative interpretations for our themes to provide analytic rigor about the validity of the findings (26–28). Coded data were entered into the qualitative software package NVivo 10 (29) and subjected to comparative and relational analyses.

# Results

Thirty-five administrators were sent introductory letters and 19 were reached by telephone before data collection efforts ceased. Of the 19 administrators reached, 17 participated in the interviews, although one interview was truncated and then discarded because of the administrator's difficultly communicating in English. Only two administrators refused to participate. This resulted in interviews with four administrators in each of the four culture change/palliative care NH categories (see Table 1 for the characteristics of these NHs). Interview length ranged from 15 to 40 minutes, with most lasting 20 to 25 minutes.

We had expected to find differences between low and high category NHs, but instead found differences in NHs' experiences with culture change and palliative care. In fact, we found that since the time of our national survey in 2009–2010, most previously low culture change NHs (six of eight) had implemented at least some culture change practices. This was in

addition to increases reported at the eight high culture change facilities we had selected for interviews. Specific culture change practices reported and the reasons and methods for implementing these are not reported here because of space limitations and because they mirror our findings for culture change implementation in NHs in general (30). In contrast, no administrators in low palliative care facilities reported new implementation.

Tellingly, administrators reported numerous ways in which they had received information and assistance from outside entities for implementing culture change. However, this was not the case for palliative care. Facilities reporting some palliative care described relying exclusively and heavily on outside hospice agencies for palliative care information and assistance.

#### Special Populations as a Barrier to Culture Change

Six of the eight NHs that had low culture change scores on our survey reported implementing culture change practices during the three years since our survey. Several of the administrators we spoke to reported that their late adoption related to their "special populations." For example, when speaking of his facility's decision to not implement culture change related to dining practices, the administrator of a primarily Chinese population facility said:

But then I looked at our culture, looked at the... Chinese dining method is totally different from the dining method in here. The environment is not a romantic type or nice seating environment as the Western world. (#12)

Another administrator discussed why his facility had changed to restaurant-style dining at lunchtime, but not dinnertime:

Well I think partially because of the population. We are under the license of a skilled nursing home, but our average age here is 65 and predominantly male. And we have a higher percentage than normal of psych... With this population dinner's not so much a social event... (#14)

Several administrators cited their "special populations" as reasons for their late adoption of culture change practices. However, these administrators were able to discuss in detail what they had done, when they had done it and how. This was in stark contrast to how administrators discussed palliative care. None were able to speak in detail about what they were doing or how they were doing it. Instead, they spoke of palliative care only in terms of care provided by hospices.

#### **Reliance on Hospice**

A common theme we heard from administrators in both high and low palliative care facilities was that they tended to rely on hospices for both the palliative care needs of their residents and also for information about palliative care. Palliative care practices beyond comfort care and pain management were rarely cited and administrators reported little use of palliative care outside the auspices of hospice. For example, one said:

The way it kind of works here is that if we're receiving orders like, they come right from the hospital, just on palliative care, we kind of go based off what the doctor's

ordered. So I mean some people do. I mean we've had people come in on palliative care just kind of caring comfort, non-hospice. But, I mean, it's kind of rare. (#4)

When asked, many administrators described their facility's palliative care practices in very vague terms. For example, one said:

I would say like comfort measures only. Someone that is "do not resuscitate," they don't want to be sent out to the hospital and we give them care here. Make sure they are comfortable.... (#3)

#### "We Already Do That"

The few administrators who addressed specific approaches to palliative care mentioned only "pain management" or "comfort care." However, despite the fact that the definition we provided during the interview included several examples of practices, including interdisciplinary team assessment, psychological and spiritual care, advance directives and non-pharmacological therapies, they did not (or were unable to) cite specific practices. Instead, administrators reported long-standing provision of what they considered good or comparable care. We coded this as "we already do that." As one said:

Yeah, we do it. I mean I can't really think of anything specific to answer your question with. I mean we do that basically on a daily basis with some of our folks. (#3)

Another said:

I mean, you know, basically we already provide care, so I don't know what nonhospice palliative care would be. I don't know the kind of examples you're talking about because, you know, basically we take care of the needs of the patients. We give them pain medications if they're, you know, in severe pain, if they have cancer, if they're in end of life. (#7)

This apparent lack of understanding about palliative care and why its implementation is important seemed related, especially, to a general lack of available palliative care information or other external resources. This was in striking contrast to what we heard about culture change.

#### **External Resources**

Common among those high Medicaid NHs that reported having implemented culture change practices was the plethora of external resources they described accessing. Administrators reported receiving support and information from culture change coalitions in their states, trade organizations, state agencies and their corporate offices. They reported learning about culture change at conferences and seminars, through trade magazines, other print materials and online, and by visiting other NHs that had implemented culture change practices. Table 2 presents quotations related to the external resources administrators reported accessing for culture change implementation. In contrast, most administrators could not report having received information or other resources about palliative care from any organization besides hospices. When asked about where they had received information about palliative care

practices, most administrators reported receiving training or information from hospices only. As one administrator said:

Because we have a very close relationship with the hospice companies that we have contracts with we know how their process works. (#16)

When asked where he'd recommend other NHs get information and training another administrator said:

I would advise them to coordinate with the hospice agencies they're already using and then you can always in-service some palliative care from [them]. (#13)

As evidenced by the quotations above, most administrators reported relying exclusively on hospices for information about palliative care. They also did not report any other external resources. The vague understanding about the meaning of palliative care coupled with the general reliance on hospices was in striking contrast to what administrators reported regarding the information and resources available to them with regard to culture change. Differences in the resources and information available to NH administrators about palliative care and culture change appear to be related to the differences in the diffusion of these two approaches to care in NHs.

# Discussion

Since the time of our national survey conducted in 2009–2010, most administrators in the facilities we identified as low culture change had implemented at least some culture change practices. The administrators reported that their later implementation of culture change practices was related to their "special populations," including both ethnic minority populations and high proportions of residents with psychiatric diagnoses or behavioral issues. Administrators in the high culture change facilities reported implementing new practices in addition to those they had previously reported. In striking contrast to this, few administrators described introducing any palliative care practices beyond "comfort care" or "pain management." Further, the term "comfort care" appeared to represent the withholding of resuscitation or hospitalization, but not the addition of services integral to palliative care, such as spiritual or psychosocial support or the management of symptoms beyond pain. Similarly, although "pain management" was noted as something that these NHs do, little mention was made of pain management teams or staff expertise in pain management, reflecting a general ignorance about the meaning of palliative care. Despite having been provided with a definition of palliative care that included examples of practices, such as interdisciplinary teams, spiritual care and advance directives, those administrators who claimed that "we already do that" were unable to name specific practices or provide any details about what they do or how they do it.

Differences in implementation of palliative care and culture change in high Medicaid NHs, even within the same facilities, appeared to be related to differences in the external resources available to these facilities. Most administrators named multiple organizations and other types of resources they were able to access for information, support, and training related to culture change, whereas no administrators mentioned any external resources beyond the hospices they contracted with when it came to palliative care.

Our research suggests that palliative care advocates could learn much from the multipronged efforts used by culture change advocates to institute reform. As a result of these efforts, resources for culture change are available from multiple sources, including state coalitions, trade organizations, advocacy groups and even other NHs. Indeed, culture change seems to have permeated the industry and this may be causing a kind of peer pressure even among high Medicaid facilities. In addition, there are real structural supports for culture change in terms of policy changes and Medicaid payment incentives. For example, culture change champions have been able to persuade policy makers at both the U.S. state and federal levels to institute a number of policy changes that promote culture change (31, 32). Our previous research found NHs had greater implementation of culture change practices when they resided in states with pay-for-performance (P4P) programs incentivizing culture change (33). These programs reward NHs through higher Medicaid payments for implementing certain practices. Also successful in increasing implementation have been efforts that bring together stakeholders from numerous organizations and governing bodies (34). In addition, in the U.S., culture change advocates pushed for the Centers for Medicare and Medicaid Services (CMS) to better enforce regulations that promote culture change. The CMS also could do this for palliative care by advising state survey agencies to ensure annual NH inspection surveys focus on the recently available palliative care and advance directive interpretive guidelines (35).

The "feel good" aspects of the benefits of culture change practices seem to have relied on high face validity instead of rigorous evidence (36). Palliative care may lack this "feel good" aspect because of the discomfort many feel in relation to the topic of death and dying, but it does not lack the evidence base. A reframing of palliative care may be needed. A report by the Coalition for Compassionate Care of California and the California Culture Change Coalition suggests that palliative care be incorporated into culture change efforts (37); this suggestion is especially appealing because, when done right, palliative care is supremely resident-centered and includes improved choice and autonomy.

Our research is limited by the fact that we spoke to a small number of administrators and not to residents, their families or to other NH staff. Also, our study was exploratory in nature; therefore, our findings cannot be generalized to all NHs or even to all high Medicaid NHs. It is possible that the administrators willing to be interviewed are different in important ways from other administrators. It is also possible that the information and resources now available about culture change has increased administrators' knowledge about culture change resulting simply in an improved ability to speak about its practices. It may not be surprising that NH administrators were unable to discuss palliative care in any kind of detail. Confusion in the health care literature about the meaning of palliative care and its appropriate recipients reflects a lack of clarity about the subject more generally. In addition, respondents' may feel that available information is insufficient to mounting any attempt to implement palliative care. Thus, a dearth of resources on how, why and when to incorporate palliative care in NHs and its associated lack of "buzz" may combine to inhibit NHs from trying these approaches.

In summary, our research suggests multipronged approaches palliative care advocates can take to promote the diffusion of palliative care practices in NHs. It also suggests several

avenues of new research that should be pursued as part of the continued efforts to improve diffusion of palliative care in NHs, both in the U.S. and internationally.

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Table 1

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Characteristics of Participating Nursing Homes

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Quadrant	Bed Size	Profit Status	Chain Member	kegion	Special Population <sup>a</sup>
High CC/high PC	41	For-profit	No	Northwest	No
High CC/high PC	82	Non-profit	Yes	South	No
High CC/high PC	130	For-profit	No	Northeast	No
High CC/high PC	225	For-profit	No	South	No
High CC/low PC	40	Non-profit	No	Northeast	Yes
High CC/low PC	80	For-profit	Yes	Southwest	Yes
High CC/low PC	89	For-profit	No	South	No
High CC/low PC	141	For-profit	No	Northeast	Yes
Low CC/high PC	31	For-profit	No	Northeast	oN
Low CC/high PC	100	For-Profit	Yes	South	oN
Low CC/high PC	100	For-Profit	No	Northwest	Yes
Low CC/high PC	118	For-profit	No	Southwest	oN
Low CC/low PC	44	For-profit	No	South	No
Low CC/low PC	50	For-profit	Yes	Midwest	Yes
Low CC/low PC	60	Non-profit	Yes	Midwest	No
Low CC/low PC	159	For-profit	Yes	Northeast	Yes

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CC = culture change; PC = palliative care.

<sup>a</sup>During the interview, the administrator indicated that the facility had a special population of some sort, such as primarily residents with mental health or behavioral issues, residents with HIV/AIDs, or an all ethnic minority population.

# Table 2

# Quotes Related to External Resources for Culture Change

Type of Resource	Quote
State Culture Change Coalitions	Well there's the Qualidigm [Quality Improvement Organization] here in the state of Connecticut. They have a movement now for culture change and person-centered care and they have a quarterly meeting They also are the agency here which is trying to build up a coalition more or less with the nursing homes and moving forward with culture change (#14)
Conferences, Trade Organizations	It's been a big focus on resident-centered care in conferences, especially over the last five or six years. The ones I attended were generally conducted by the Texas Healthcare Association. I've also attended national conferences, a few national conferences sponsored by the American Healthcare Association. (#15)
State Inspection Surveyors	It was just a fight as all nursing homes go through with surveyors all the time, you know, it's something new and they didn't like it. And you know in five or six years later they're all advocating it. (#7)
Advancing Excellence Campaign, State Ombudsman	I have a very good working relationship with our Ombudsman who's with the Ohio Area Agency group. And I got some input from her when we joined the Ohio Advancing Excellence program (#16)
Other Nursing Homes	We visited several nursing homes nearby and gathered some good feedback from those nursing homes. And they tell us what they like and what they don't like. So that's how we started with the design of our [new] building. (#1)