

Culture Change in Nursing Homes: An Ethical Perspective

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Culture change is a philosophy and a process that seeks to transform nursing homes from restrictive institutions to vibrant communities of older adults and the people who care for them. A key principle of culture change is that residents and staff will become empowered, self-determining decision makers. This ethical thread is implicit in the principles and care plans constructed by and with residents and their caregivers. Substantive improvement in clinical indicators has been attributed to culture change. However, the link between clinical outcomes (eg, reduced anxiolytic and psychotropic medication use) and empowerment has not been demonstrated. Satisfaction measures indicate that residents are more satisfied, but it is unclear if this represents greater feelings of autonomy and self-determination than were felt prior to culture change initiatives.

Most health care professionals would agree that a nursing home can be the most restrictive long-term care setting. The “culture” in culture change is a community in which individuals value and respect each other and help each other, as would family members. Staff are members of the community, the family, not set apart from it. Hence, the focus of culture change is to reinvent the nursing home (NH) so that the depen-

dency and deterioration that seems almost inevitable after NH admission is replaced by resident growth, creativity, and “regenerativity”—a vastly improved quality of life. A survey of NH residents and nurse assistant staff, reported in 1997, indicated that both groups highly valued, but were currently dissatisfied with, their choice and control over awakening time in the morning, bedtime, food, personal care scheduling, roommates, telephone access, and activities outside the facility.¹ Culture change advocates hold that empowerment (ie, self-determination), a key ethical precept, is vital for an improved quality of life for residents as well as staff. A culture change environment is expected to support and enhance self-determination. This article will describe the culture change movement and what is known about its effect on resident and staff autonomous decision making and empowerment.

MODELS OF CULTURE CHANGE

Each model espouses, and to a greater or lesser degree, describes how *resident centeredness*, a cornerstone of culture change, will be accomplished. Some culture change advocates feel there is a substantive difference between *resident-centered care* and *resident-directed care*. They regard resident-centered care as “old-speak,” a

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shibboleth for politically correct marketing, but a philosophy of care that could be subverted as the resident becomes more dependent, particularly with regard to self-determination. Resident-directed care, in their view, can remain in force through the offices of a surrogate decision maker; hence, residents will always be in control of their care, and treatment decisions will reflect their wishes and preferences. The *resident-directed care model* first appeared in a nursing home in Seattle, WA, (Providence Mount St. Vincent) in 1991. The NH wanted to deliver care based on their vision of “a community directed by the residents,” in which functional dependency could be reduced (or at least slowed down). Changes included development of the “neighborhood model,” increased choices and control for the residents, and elimination of middle management.

The *regenerative care model* is based on the view that aging is another stage of life; a person can still develop. It is unclear if this model is based on Erik Erikson’s developmental stages theory. This model is resident-centered/directed; it seeks to increase resident autonomy and control.² The notion of continued personal growth that is inherent in the regenerative model is supported by a management philosophy of residents’ control over their lives, continued learning, and a community focus. *Learning circles* are seen as a way to place control of their lives in the residents’ hands. Rather like a community or neighborhood meeting, residents are asked to express their opinions, preferences, concerns, and interests in certain activities and events. By virtue of their decision making, residents own the decision; because they made a decision, they have control over it. Yet, the notion of control does not seem to extend to responsibility or accountability for the decision, nor is that aspect of personal decision making either alluded to or discussed.

A *neighborhood model* of culture change offers smaller units (8-20 residents), consistent staff assignments, separate dining and living room areas, and local (ie, community) decision making. Typically, a neighborhood or community “director” (or manager or coordinator), selected or appointed from among the staff, facilitates the discussion and solicits input from each resident. In some NHs, the neighborhood staff also attends these meetings. In a NH that had the opportu-

nity to adopt and implement the neighborhood model, residents could choose the following: when to retire; when to get out of bed; what, when, and where to eat; and the activities in which they wished to engage. Interestingly, the nurse assistant-to-resident ratio was one to five.

One of the early signs of a culture changing NH is a reconstructed “Table of Organization” (TO). Traditionally, a home’s TO depicted a top-down pyramid of management decision-making authority and communication distributed among departments and offices; the resident was nowhere in sight. A culture change TO is flatter and likely to depict the resident at the top/apex or in the center of a constellation of services that provide direct and supportive care. This type of TO is completely indeterminate with regard to accountability, but could suggest that the resident is the decision maker and accepts the risks associated with that power. This notion has never been expressed, however, by a culture change advocate. Some TOs depict assistance to the resident as being provided by a “universal care worker” who—as would be natural in a family or home setting—is an individual who does many things: cook, shop, assist, clean, etc. This kind of cross-training (eg, teaching a housekeeper how to transfer a resident and assist with toileting, or teaching a nurse assistant about portion control and food handling) likely creates a less restrictive environment for the resident, but the degree to which it empowers the worker is unknown.

The need to change institutional (nursing home) care was passionately and poetically expressed by Dr. Bill Thomas, a NH medical director, in the late 1980s. His concept of care, *The Eden Alternative*TM—a holistic “environment of diversity”—began as a small funded pilot project in an 80-bed NH in New York State.³ The program would eradicate the “afflictions” of NH life: “loneliness, helplessness, and boredom.” Helplessness is the pain one feels when one receives, but is unable to give, care. “Edenizing” includes bringing in animals, plants, and intergenerational connections, a varied and spontaneous environment, staff education, “wise leadership,” an opportunity to give care, medical treatments that support “genuine human caring,” and recognition that the process will never end. Residents

have to be involved in any architectural or space redesign decisions; this is their home, their “human habitat.” Staff make their own work schedules and assignments with the expectation that they will spend more time with residents. Nurse assistants have permanent assignments and are encouraged to develop real relationships with their residents. In comparison to a control NH, Dr. Thomas reported statistically significant reductions in illness, death rate, and psychotropic medication use.⁴

The *Pioneer Network* is an organization of culture change advocates (leaders, doers) who embrace a common core of principles and objectives first articulated in Rochester, NY, in August 1999.⁵ Significant change, a paradigm shift in their view, will occur *only* if there is commitment (and change) in government policy and regulations, changes in attitudes about aging within society, and changes in the attitudes and behaviors of caregivers. Common values and principles of this movement—originally called *Pioneers in Nursing Home Culture Change*—are returning decision making (“locus of control”) to the resident; team building; respecting, valuing, and empowering the caregiver at the bedside (ie, the aide), and enhancing his or her capacity to be responsive; promoting creativity in residents, staff, and families; creating a therapeutic home-like environment; recognizing that risk-taking is a normal part of adult life; and creating a pattern of life (routine) for the resident that is familiar and comfortable. Not dissimilar from the Eden Alternative, objectives of Pioneering for residents include helping them construct their own schedule, “restoring” eating choices, and providing a range of personal hygiene. Objectives for staff include self-managed work teams, cross-training, and (interestingly) developing productive relationships with surveyors. Positive outcomes attributed to culture change include reduced prescription use, especially with regard to anxiolytics and antidepressants, fewer falls, weight gain, greater resident satisfaction, fewer nosocomial infections, and decreased employee turnover.

In 2002, the Centers for Medicare and Medicaid Services (CMS) trained surveyors on indicators of culture change and how nursing home routines might begin to look different from standard practice. The

Medicare-funded Quality Improvement Organizations (QIO) have included culture change initiatives in their 2005-2008 work plan. At least nine states (Michigan, Colorado, Florida, Illinois, Kansas, New Jersey, North Carolina, South Carolina, and Pennsylvania) have formed culture change coalitions, either Eden- or Pioneer-linked. Despite a variety of obstacles (eg, financial support), the coalitions offer guidelines for culture change innovation, networking, communication, guest lectures, and surveyor education programs. Some are conducting or supporting program evaluation and workforce research. Several states (notably, Kansas, New Jersey, Michigan, Texas, and South Carolina) have allocated money to NHs to implement culture change. The NHs have used these funds to educate staff about culture change and better ways to communicate, to purchase plants, to redecorate interior and exterior space, and to build gazebos and walkways.

CULTURE CHANGE, EMPOWERMENT, AND DECISION MAKING

Virtually all NHs involved in culture change are conducting an evaluation of some kind. Is empowerment happening in culture change NHs? Did it increase or improve? Are the NHs teaching decision-making skills to staff? Although self-determination is a key value in the culture change movement, there is more information about the clinical outcomes that are purportedly a result of culture change than there is about resident and staff empowerment/autonomous decision making. Unfortunately, most of what is known to date about the impact of culture change on resident and staff lives is anecdotal and lacking in scientific research methods. The reports and presentations are not addressing the relationship, if any, between improved functionality, reduced morbidity, and empowerment. Are residents making more decisions? If so, what are they making decisions about? Do residents need decision-making skills as well, particularly if they have spent years in a dependent, passive role?

Another key tenet of culture change is a “homelike” environment in which lifestyle choices can be freely made. A qualitative examination of the experience of “being at home” for older adults found that, for some,

not being literally in their home eradicated any of the benefits of living in a protected and pleasant environment.⁶ *Being at home* meant “an existence that offers possibilities” (ie, choices), whereas *not feeling at home* was associated with inability to find meaning and connectedness. The relationship between a homelike environment and feeling empowered, making lifestyle choices, has yet to be demonstrated.

In a NH that purported to be actively engaged in culture change, staff did not feel that their decision-making power to modify the organization had changed appreciably from their old traditional model. In another NH where major structural changes created special dining areas and food service changes enlarged the mealtime window, few residents took advantage of sleeping late or requesting breakfast items other than what was available. In some states where funds have been given to NHs engaged in culture change, academic centers are being asked to evaluate effect. In one state, residents will be asked about their knowledge or awareness of a changed system or architectural feature, whether or not they use it or like it, and other changes they would recommend. The same questions will be asked of families and staff. While not construed as such, this kind of inquiry suggests that residents should now have an opportunity for a choice about something where none existed previously.

A 2-year study of six NHs in Texas that had adopted the Eden model reported some reduction in polypharmacy and the use of as-needed anxiolytic and antidepressant medications.⁷ Yet, other NHs in the Eden sample reported increased antipsychotic medication use. Behavioral incidents decreased overall in all the NHs. In four of the six NHs, more residents became chairbound, but the incidence of contractures decreased significantly at some of these facilities—attributed to the fact that staff had become more attentive and had more time for resident-centered care. Some of these findings confirmed Eden-related outcomes reported in a different location; some did not.

Nursing homes invested in the culture change process report significant improvement in staff retention and reduced turnover (from 65-100% prior to culture change to 30%, annually). The presumption is that staff empowerment is reflected in

work satisfaction and, hence, remaining on the job. A 3-year study in a NH (Meadowlark Hills, Manhattan, KA; unpublished data) reported a 16% increase in satisfaction (ie, from 78% to 94%) when residents moved to a neighborhood model, and 100% overall satisfaction in markers that include autonomy and choice. Providence Mount St. Vincent (discussed earlier with regard to the resident-directed care model) reported an 11% reduction in routine anti-anxiety medications, an 87% reduction in as-needed administration of anxiolytic medications, a 100% reduction in use of antipsychotic and sedative medications; a 73% reduction in incident reports; a 7% increase in self-medication; a 50% increase in resident activity levels (not indicated how measured); and a 100% increase in social interactions (unknown how this was observed or measured). The culture change intervention or activity that was directly intended to reduce resident anxiety and the use of anxiolytic medications is not described. The increase in social interaction is heartening, but whether it represents residents' enhanced opportunity for the exercise of social preferences is unknown. It might be that because of cross-training in this NH, staff were more available to transport residents to socialization locations.

A variety of studies planned or in progress (eg, Illinois) are using satisfaction and depression scales as measures of the impact of culture change on resident (and staff) quality of life. If the purpose of a satisfaction survey is for “quality improvement” (as they generally are), rather than identification of individual satisfiers and dissatisfiers (or lack of satisfiers), then the instrument will not be able to delineate the relationship between a culture change intervention and a resident-specific perception, as for example, feeling of empowerment and truly being a self-determining person.

A multisite NH in New York City, The Jewish Home and Hospital Lifecare System, is studying culture change and comparable control units with particular interest in predictor and outcome variables. Each culture change unit was told it could implement its own culture change initiatives. Residents, staff, and families are being asked about the degree of choice they believe residents have over their everyday

activities. Staff are responding to a questionnaire that asks about their job characteristics, their degree of autonomous decision making, opportunity for job enrichment, job satisfaction and commitment, and burnout. Quality of life and satisfaction questions are being asked of residents and families. Nurse assistants are being asked to conduct periodic behavioral assessments, and the resident record is being scanned for data regarding pain assessment, pressure ulcer, falls, weight change, activities of daily living, advance directives, and medications. Other data collection includes turnover statistics and the nature of complaints on the culture change units.⁸

The Eden Alternative organization has three “Warmth Surveys” (for resident, staff, and family, respectively) to determine a NH’s readiness for change and the patterns and trends in optimism, trust, and generosity in the home. The 20-item resident version (Elder Questionnaire) has several items related to empowerment: participation in decision making, food choices, awakening and bedtime choices, personal space that looks homelike, and opportunity for privacy.⁹ The 46-item Employee Questionnaire, much of it having similarities to employee satisfaction measures, has several items concerning being respected and valued, phrased positively as well as negatively.⁹ Statements regarding empowerment and decision making are implicit in items, such as, “I can be creative in completing my tasks...”; “I feel free to ask questions”; “I am kept up to date on changes....” Interestingly, the survey seems to want to identify obstacles to employee empowerment and self-determination, such as “When I try to do my

work, I run into obstacles” and “I have to follow procedures that prevent me from doing my job well.”

Culture change is a change in philosophy, leadership, and management style that can reverse the assumption that decline and illness inexorably go with aging. It should not be assumed, however, that the medical goals of care for fragile elders with multiple chronic diseases and, for some, devastating dementing illness, become subservient to what appears to be a social model of care. Whether residents in culture change NHs are becoming more involved in decisions regarding their medical goals and treatments—as a direct result of culture change rather than a home’s commitment to ethical models of decision making—is unknown. Given its emphasis on choice, creativity, growth, and regenerativity, the principles and processes of culture change could be a new paradigm for caring, and for carers, in long-term care settings. The consistent ethical thread throughout culture change is resident self-direction and resident (and staff) empowerment. By looking at decision making, it might be possible to represent if culture change is (on its way to) fulfilling its promise to improve resident and staff quality of life through empowerment and self-determination. Culture change needs to make the case that the time, resources, money, and effort expended under its mantle are, in fact, empowering NH residents and staff. ✧

Please submit manuscripts on ethical issues in long-term care to Fred Feinsod, MD, MPH, CMD, Department Editor, at Feinsod@fnfjnd.com.

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