PIONEER PERSPECTIVE

By Jonathan Evans, MD, MPH, CMD, Pioneer Network Board Member

Person-Centered Care and Culture Change

Person-centered care is a phrase that has emerged over the last quarter century in the United States. Despite the newness of the term, it represents values and a philosophy that are as old as humanity, even if not widely adhered to. Few practitioners reading this would question their own desire or ability to provide person-centered care. We generally pride ourselves on our desire to do right by others, and many of us hold selfless service to others to be among the most important aspects of our lives and our life's work.

To suggest that we do not provide person-centered care might therefore be taken as an indictment of our willingness or our ability to care at all. The phrase *person centeredness* was never intended to be a measure of how much we care, however. It refers more to power and control.

The Centers for Medicare & Medicaid Services — in listing person-centered care as among the six essential themes for nursing home care, regulation, and enforcement — defined person-centered care as the need "to focus on the resident as the locus of control and support the resident in making their own choices and having control over their daily lives" (42 CFR 483.5).

Person (or patient) centeredness stands in contrast to doctor, hospital, or facility centeredness. In that regard, it represents a shift of power and control from the health care provider or practitioner to the patient. The phrase "person-centered care" has come to be preferred over "patient-centered care" because people are much more than their diseases and diagnoses, and health care is only one aspect of the lives of people living in care settings.

Culture change represents an effort to shift the focus from task-oriented care to supporting person-centered care, and to change the physical environment to feel more like a home than an institution. The assisted living industry has created many beautiful and home-like physical spaces in which many people who might otherwise require nursing home placement choose to live (mostly, if they can afford it). However, many of the threats and challenges to person-centered care are as prevalent in these beautiful new assisted living communities and nursing homes as they are in the older ones — for instance, the overuse of psychotropic medications for people living with dementia. Obviously, a homelike physical environment by itself is not enough.

Ethics of Person-Centered Care

Throughout history, the fields of medicine and nursing have always been guided by an ethical framework that has aspired and strived to put the best interests of the patient first. This often has been accompanied by a paternalistic attitude that assumes patients cannot know or decide what is in their own best interests as they are not experts in medicine. But how do others really know what is in our best interest — especially if they don't really know us, our preferences, or our goals? Moreover, a grudgingly accepted part of health care delivery in the United States has been lengthy waits for care and attention (for emergency care, or for assistance to the toilet, or to be turned and repositioned, etc.), which often causes harm and is thus not in the patients' best interest.

For most of human existence, medical care and nursing care were provided to people in their own homes, the place where they had the most power and control over their lives. The development of modern health care and its various structures of health care delivery has, over the last century and a half, shifted more power from patient to provider. The physical structures of hospitals, clinics, and other health care settings and the processes of care delivery in those settings have always been built around the providers, particularly physicians, based in part on practical considerations such as provider efficiency and cost. Health care facilities themselves were never conceived of as people's homes, at least not from the perspective of the people living in them. Likewise, the concept, layout, and appearance of modern nursing homes in the United States was built around a hospital model, encouraged and funded by the federal Hill-Burton Act of 1954, and the culture of nursing homes has mirrored the culture of hospitals and medical care.

In recent decades, a societal shift has taken place with regards to health care, manifest in part by an ethical shift from paternalism to autonomy. Autonomy — the right to self-determination, to do what you want — has come to take precedence over all other guiding ethical principles, particularly "paternalism" and "best interest." This stands to reason, considering the importance Americans place on personal freedom. In fact, the fears that many Americans have about insurers or even the government dictating personal health care decisions speaks to the primacy of autonomy in American life and culture. You have the right to say and do things that others say you shouldn't, to make up your own mind and act accordingly. Having the right to something only goes so far, however, whenever you are dependent upon others to get it. Without power, autonomy may be worthless.

Health Care Culture

Health care culture is not built around autonomy. The culture of health care in America — while it may have noble and decent ethical underpinnings and millions of selfless and tireless people who strive to do good every day — is a culture of conformity that actively resists change.

Likewise, within health care is also a culture of fear and blame. The fear of lawsuits often results in defensive practices, which are perceived as such by patients and families and are often considered to be offensive (not person centered). This paradoxically increases the risk of lawsuits. Ceding power to patients and families only increases the fear and sense of loss of control among many practitioners and providers. Consequently, a wholesale culture change that embraces autonomy has yet to occur.

Pioneer Network and Culture Change

Pioneer Network is a nonprofit organization that was founded in 1997 by a small group of prominent professionals working in long-term care who set a goal of changing the culture of aging in the United States. They advocate change and have created, gathered, and disseminated the necessary resources. They have worked with CMS to set standards on aspects of person-centered care while partnering with AMDA — the Society for Post-Acute and Long-Term Care Medicine, with state culture-change coalitions, and with others to train care providers who are interested in learning and implementing person-centered care and culture change.

Changing the physical environment of care communities is important and necessary for creating a true home environment. There have been innovative and successful models that address this concept head on, such as the Eden Alternative, the Green House Project, and others. As the developers of these models are quick to point out, the building itself, while important, is insufficient for person-centered care. Without leadership, training, and tireless commitment at all levels of the organization, it will not happen.

Pioneer Network does not espouse one particular physical design or model for person-centered care and culture change; rather, it supports many current models, with the understanding that some settings may be constrained by current physical structures and thus are not in a position to renovate or rebuild. Even so, many nursing homes have started with modest changes — such as incorporating plants, pets, or gardens into their settings. Practice changes — such as providing people with choices about when and what they eat, or when they sleep or rise — are more difficult, and thus they have been less pervasive. Adoption of a whole new system and philosophy of care and support is even more rare.

Challenges and Barriers

Believing in person-centered care and making it happen consistently are two different things. In general, what is necessary is not just changing the physical environment, but changing systems and processes of care. It takes a lot of work for people to figure out how to operationalize and implement culture change because it requires changing how all the work gets done. This kind of fundamental change requires steady leadership, which may be lacking in high-turnover environments such as health and long-term care settings.

Medical directors, attending physicians, nurse practitioners, and physician assistants play a critical role, even when they are not in positions of power. They are often looked to as knowledgeable leaders who care.

Health care delivery continues to shift away from the most expensive sites of care — hospitals. Many nursing home operators have made a strategic decision to assume the post-acute care of the sicker, more complex patients who have ongoing acute illnesses or need intensive rehabilitation. With this shift, the enthusiasm for culture change has diminished among nursing homes that also provide long-term residential services. Culture change practices are being resisted on economic grounds — but these are not valid. The practice of person-centered patient input into goal setting can significantly impact outcomes; in the long run, it can reduce the number of dreaded rehospitalizations with their associated costs and burdens.

As practitioners, we have the ability to ensure that person-centered care is not relegated to only a small proportion of people receiving care or to a small proportion of settings where care is provided. It's the right thing to do for ourselves, our patients, and our families.

Dr. Evans is a long-term care physician in Charlottesville, VA. A past Society president, he serves on the *Caring for the Ages* Editorial Advisory Board as well as the Pioneer Network Board.