DEAR DR. JEFF

By Jeffrey Nichols, MD, CMD

What is Person-Centered Care?

Dear Dr. Jeff:

Our mission statement asserts a commitment to “person-centered care,” as have those of every long-term care facility and chain for which I have worked. I have never really understood what this means, particularly in an era of computerized health records with automatic default orders, mandatory check boxes on templated practitioner notes, admission and periodic assessments all tailored to the Minimum Data Set, insurance-and-algorithm-generated lengths of stay, vendor-created menu cycles that repeat every two weeks, and standardized infection control practices that treat all residents as potential sources of contagion. Journal editorials and articles all emphasize that quality improvement is achieved through improved systems of care. Where does the care of the person fit into all this? Is there any prospect that we can bring unique and individual residents back to the center of all this?

Dr. Jeff responds

Many things have changed over the 12 years that I have written this column and the 40 years I spent as an attending physician and medical director in nursing homes. In this — my last — “Dear Dr. Jeff” column, I want to return to one of the core questions of long-term care. I believe that many of my prior columns have addressed aspects of this topic. I have no doubt that when Dr. Steven Levenson takes over responsibility for answering questions he will add more insights and perhaps correct a few of my errors and omissions. It was an honor to take over this responsibility from the beloved Dr. David Brechtlbauer when he assumed the presidency of AMDA—The Society for Post-Acute and Long-Term Care Medicine, as it will be to turn it over to a former Society president who literally wrote the book on medical direction.

The Corporate Process

I have never found a facility posting a mission statement that asserts the goal of maximizing the bottom line with increased return to investors and bonuses to senior management. Yet long-term care in the United States is a corporate industrial process whose product is billable patient days, and the quality of the lives experienced by those patients is a secondary consideration.

Even those who profess nonprofit status have typically adopted the slogan “No margin, no mission,” as first voiced by Sister Irene Kraus, the founding president of the Daughters of Charity Health System and former chairman of the Catholic Health Association and the American Hospital Association (Wall Street J. 1997;222:18; https://www.wsj.com/3bx3WPQ). Multimillion- and billion-dollar corporations and corporate health systems, regardless of ownership or sponsorship, cannot and will not center their activities on the persons under their care. Although recent news articles have reported pressure on facilities and chains by large shareholders and investment trusts to improve quality, their motivation is a concern that declining reputations and occupancy rates may imperil their investments.

Institutions may offer (read: sell) services, but individuals provide care. Nursing home care is delivered by teams of professionals and legions of employees. These professionals — including nurses, physicians, dietitians, social workers, and rehabilitation therapists — all come from occupations with codes of ethics that place primacy on respecting the autonomy and personhood of individuals. Errors and omissions. It was an honor to pass them on to all team members, especially the certified nursing assistants who provide the lion’s share of hands-on care.

The Change of Focus

Language matters. Although there is an understandable reluctance to insist on politically correct phrases, our choice of words does reflect our patterns of thought. The transition from “nursing homes” to “nursing facilities” reflects a change in organizational mindset. Our organization changed the name of the division from “long-term care” to “post-acute care,” recognizing a new concentration on the highly reimbursed short-stay residents rather than the 80% of beds used by long-stay patients who had not been “acute” for months or years.

Patients assigned to nursing units are not residents living on a floor of their home. Rather, they have been temporarily placed in a health care institution, often with all the institutional charm of psychiatric hospitals, school dormitories, and prisons. (One such charm that hospitals, prisons, and dormitories tend to share is the joy of their food.) Institutions expect the individual to adapt to the facility rather than the facility adapting to the special needs of the person.

Of course, many of the old nursing homes were never very homelike, but the words reflected an aspirational goal to someday be achieved. If nothing else, there is a vastly different power relationship between the status of a patient in a facility compared with the status of an individual living in his or her own home, even if Medicaid is paying the rent.

Physiological Needs

Maslow’s hierarchy of needs is a well-known construct useful to assess how a long-term care facility is meeting the individual needs of residents. Based on psychologist Abraham Maslow’s theories (Psychol Rev 1943;50:370–396), the hierarchy is often portrayed as a pyramid, with physiologic needs as its base — comprising basics such as air, food, water, sleep, shelter, and perhaps clothing. Health care institutions generally supply these biologic needs adequately and often better than the previous living arrangements for many functionally dependent residents.

The level above the base in the hierarchy is often labeled “safety.” Health care needs are typically placed somewhere between the basic needs required for life and the need to be free from pain and other major discomforts or threats. Recent efforts to address past trauma (trauma-informed care is the phrase used in federal requirements) work to prevent potential threats to the resident’s sense of safety in their environment. Typically, resident safety has been a major concern for most facilities, if only as protection against liability and lawsuits. Families also frequently mention safety as a major justification for nursing home placement, particularly for residents with dementia. Of course, nothing can provide absolute safety, particularly for those at risk for falls, but a safe environment — including safety from abuse and neglect — should be the right of every resident and every human being.

These basic needs can and should be addressed through effective systems. On the simplest level, then, all nursing home care has a person-centered element. Medications should be prescribed based on individual diagnoses and known individual responses including allergies. Nurses direct their care to problem areas (no one puts a dry sterile dressing on everyone resident’s hips regardless of wound locations), and they initiate nursing preventive measures to minimize identified risks.

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Psychological Needs

The higher levels of Maslow’s hierarchy comprise the psychological needs. These are the areas where person-centered care differs from routine care, recognizing the unique human characteristics and needs of each resident.

Of course, 21st-century medicine pays lip service to the notion that the mind and body are connected. Numerous studies and endless observations have confirmed the complex interactions between emotional well-being and health. The potential for emotional distress to worsen bronchospasm, gastric acid production and motility, blood pressure and multiple aspects of cardiac function, wound healing, muscle recovery in rehabilitation, immune function, and many other “physical functions” has been well-documented. But beyond these basic health factors, our emotional health is a central aspect of our being.

The third level of needs in Maslow’s pyramid is the need for belonging and love. Included in this category are friendship, family, physical contact, and sexual intimacy. Even though a nursing home cannot routinely provide family and love, cultivating a sense of belonging — of being where you belong and treated as a valued member of the community for who you are — should be a goal in every resident’s care plan. A sense of belonging requires that you be “seen” and accepted as a unique person.

Among the best aspects of the new struggles for diversity, equity, and inclusion has been to focus attention on the systemic discrimination against so many groups within our society — women, persons of color, immigrants, the LGBTQ communities. Our residents already face denigration based on age, functional, and often cognitive limitations. When we can recognize the value and individual worth of our residents and make them believe that they belong, we will be on our way to the fourth level of Maslow’s hierarchy: the need for respect, esteem, and recognition.

The Whole Person

Completion of the Minimum Data Set (MDS) is a federal requirement with near universal compliance. It includes some basic demographic data, limited information regarding typical habits and preferences — and virtually nothing about goals of care or formative life experiences. Unfortunately, all too often this minimum is regarded as complete. For example, despite the important role that work plays in most people’s lives and basic identity, this is almost never available information on residents’ charts. In the rare facility where “Occupation” is an item on the demographics page, it’s usually filled with the word “Retired.”

The last several decades also have revealed to everyone (except for a few politicians) that checking the box for either Male or Female does not describe the complexity of sexual activity and gender identity. Similarly, checking boxes for the standard religions or “None” does not begin to describe the diversity of religious belief, experience, and practice within those categories or the growing group who describe themselves as “spiritual but not religious.”

Therapeutic recreation interviews that record that a resident enjoys “listening to the radio” do not differentiate among the lover of talk radio still mourning Rush Limbaugh, the devotee of FM classical music stations, and all the variations between the two. Nor does it address those who sometimes listen to one and at other times another. I currently provide care for a nonagenarian who cannot speak at all but happily sings along with gospel music all day.

Typically, information about who a resident really is will be gathered only when disruptive behaviors and cognitive impairment provoke further investigation, in hopes of identifying mitigating maneuvers. Person-centered care requires that we do this for every resident.

As professionals we have been told that we deserve respect. In fact, the respect that we treat as our right is not a right at all — it is a function of the respect that we give others. The business model that pays our salaries uses “person-centered care” as a marketing slogan. For us to make it a reality requires changes in systems and behaviors throughout the facility. Begin the change with the “history” we take becoming a true life story.

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