Dignity as the Cornerstone to Better Care: The Dignity-Driven Decision-Making Initiative

The cornerstone of a more effective and efficient system of care is to engage people in making decisions about their life and health in a way that upholds their dignity, independence, and right to self determination. Unfortunately, when it comes to serving older Americans who face advanced illness, this concept is contrary to the way most health care is actually delivered.

Currently, the locus of control in the American health system tilts away from patients and their families, with decision-making generally resting in the hands of providers and payers. Even in a strong doctor-patient relationship, technical information about the risks and benefits of medical treatment overwhelmingly resides with the physician. In an acute care-driven model, the goal is curative and the intent is to provide care that is evaluated against the best available evidence of what may or may not work. While at times imperfect and frustrating, this model has improved the overall quality, effectiveness, and efficiency of medical care in the United States for people who spend the vast majority of their time as healthy and not ill. The desired outcomes for these individuals are reasonably easy to define and categorize in purely medical terms.

However, this acute care-oriented paradigm is insufficient for those experiencing functional decline as part of serious and chronic illnesses, a situation where medical evidence becomes thin and the outcomes do not fit into simple medical categories. For most of us, being a
“patient” is tolerable when confined to a short time frame and when clear cures are available. When a cure is not available, however, none of us want to be a permanent patient, destined to live out our days defined by the cure-at-all-costs lens of the health care system even as we actively use it.

Knowing where a person stands in the face of advanced illness is too often unclear, and the compartmentalized way in which the American health care system operates makes any hope of understanding it even dimmer. For an older person with a cancer that cannot be cured or arthritis so severe that she cannot dress or bathe without some help, the challenge is to manage as opposed to cure these problems while still enjoying life to the fullest extent possible. People in these situations often do not wish to chase health outcomes that may not be attainable, yet they will fight hard for quality of life outcomes of their own design. Ultimately, so much of what people with advanced illness want from the health care system is support for their efforts to maintain dignity, choice, and autonomy on their terms. Structured, preference-based planning is the key to helping people and their families make truly informed decisions to achieve these person-centered outcomes. For some individuals and families, continuing to do everything possible will be their path of choice for personal or religious reasons; these desires need to be respected and embraced, not just accepted by the medical delivery system. For the majority of those with advanced illness, however, the goal is not more care but better care that is more closely linked to one’s personal goals and preferences. This is the key to improving outcomes while reducing health care costs.

Beyond implementing delivery system models that coordinate care among providers, models most likely to meaningfully improve quality of life and the efficiency of health care delivery must actively engage people in planning and decision-making based on their needs, values, and preferences. This connection between models of care coordination and the primacy of person-centered decision-making is summed up by the phrase, “Dignity-Driven Decision-Making.” The specific focus of Dignity-Driven Decision-Making is to transform health care decision-making to explicitly include quality of life, dignity, and self determination as key outcomes for all and particularly for those with advanced illness. This approach will not only improve quality of life while supporting person-centric health outcomes, but will likely achieve savings, in terms of dollars and time for seniors, families, providers, and payers.

The recently enacted health reform law has created opportunities to test key models and practices for improving health care delivery, especially for older adults, in a way that allows successful models to be rapidly diffused into widespread clinical practice and public policy. These include evaluating, refining, and scaling new practices in Medicare and Medicaid through managed care models such as Special Need Plans, other risk-bearing models (such as the Program of All-inclusive Care for the Elderly or PACE, accountable care organizations, medical homes, or primary care case management), systems components (hospital systems, medical groups), and publicly funded “closed models” such as the Veterans Administration.
Through The SCAN Foundation’s Dignity-Driven Decision-Making initiative, we seek to explore the full range of delivery models and structured approaches that build rigorous person and family involvement into decision-making centered on quality of life, not simply quality of health. An effective delivery model should have the following characteristics:

- Identify and serve a target population, specifically persons with advanced illness who have experienced a triggering event;
- Implement a structured approach to providing care;
- Charge providers to collaboratively develop and implement a care plan with the person/family, which is driven by the person’s needs, values, and preferences;
- Create and/or facilitate active connections between medical and supportive service systems;
- Focus on community service delivery and not be solely dependent upon inpatient admissions or activities; and
- Generate better person-level outcomes and systems savings.

Fortunately, there are a range of current programs that demonstrate many of these characteristics, such as comprehensive geriatric assessment, shared decision-making, palliative care, and advance care planning. But even with enlightened providers who seek to subvert an acute-care focused medical model interested only in curative measures, the center of gravity for many of these efforts is still the provider rather than the person needing the service. While some people with advanced illness will be fortunate enough to encounter one of these programs with enlightened providers, most will not. This must change. Dignity-Driven Decision-Making has the opportunity to improve a person’s quality of life outcomes while reducing costly services that may be unnecessary or even harmful. Dignity-Driven Decision-Making begins and ends with the seriously ill person’s quality of life as the basis for a better, more cost-effective delivery system.