Dignity-Driven Decision Making: What is it and Why is it so Important?

By Anne H. Montgomery

This brief is based in part on a forum hosted by the Campaign to End Unwanted Medical Treatment on March 12, 2014, in Washington, D.C. The session featured remarks by Bruce Vladeck, senior adviser for Nexera, Inc., and head of the Health Care Financing Administration from 1993 to 1997. This paper is intended to provide a broad overview of the issue featuring a variety of sources and views.

Dignity-driven decision making (DDDM) is beginning to move into wider circulation in the U.S. health care system, driven by an accelerating push on two fronts: an imperative to substantially improve the quality of services for individuals with advanced illness by recognizing and incorporating their stated preferences into all aspects of care, and the goal of establishing a degree of consistency and control over costs late in life.[1] Achieving both will be difficult, Vladeck acknowledged at the forum, in part because in the policy and research arena, "we've locked ourselves into narrow boxes" with regard to building highly-tailored models of care, with the result that "nobody knows what components are essential."

To try to tackle these challenges together, DDDM is being formulated as a flexible model for deeply involving individuals with advanced illness, along with their family caregivers, in all aspects of treatment, in an ongoing relationship with care teams. In contrast with advance directives, Vladeck emphasized that "this is not a one-time decision…it is a continuing relationship over time…[with] sustained support." The DDDM approach can be incorporated into various service delivery models, he noted, and is best practiced not only by physicians, but also social workers and nurses who are part of an interdisciplinary team.

The core formal mechanisms needed for making DDDM possible include 24-7 access to a patient's medical ecord; formal care planning and structured care processes such as standardized protocols or checklists; case management; an emphasis on home and community-based service (HCBS) delivery in the patient's home outside of any medical setting;

and close communication between HCBS providers and other community providers. In the current fractured U.S. delivery system, these elements are far from universal, and existing gaps are exacerbated by the lack of a strong information technology infrastructure in many care systems to connect providers working in different settings. But the biggest barrier right now, according to Vladeck, is that "most practitioners don't know how to do this."

What is DDDM and Where Does it Fit in Service Delivery and Financing Reforms?

It starts simply, with a clinical team asking individuals with advanced illness and their family caregivers, "'What do you need today? How do you feel?'" Vladeck said. At its essence, the model requires that clinicians spend enough time with and understand their patients "well enough to help you where you are." This means knowing a patient's relationships, living situations, family caregiver(s), preferences for care, and personal goals. That information must then be made a central part of the medical record and the care plan, and revised and updated as circumstances change. DDDM also requires ongoing, sustained collaborative decision-making among clinicians, patients and family caregivers. All of this suggests that organizations that undertake DDDM must be "really committed to doing this and to investing in their patients."

Development of the DDDM model has taken off autonomously among several health care providers. One of the leaders to date in developing DDDM is Sutter Health, an integrated health system of 24 hospitals, physician groups and surgery centers based in California. The system was part of The SCAN Foundation-funded "Learning Collaborative" that also includes several types of integrated health systems, including selected Programs of All-Inclusive Care for the Elderly (PACE) and large multi-specialty group practices. The

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SCAN Foundation has also supported financial sustainability analyses for several different kinds of DDDM-based programs, and in 2012, the Center for Medicare and Medicaid Innovation (CMMI) awarded Sutter Health a three-year $13 million grant to expand its Advanced Illness Management (AIM) program throughout northern California.[2] Preliminary data on costs as reported by Sutter show a 75 percent reduction in Intensive Care Unit (ICU) days within three months of enrollment, a 60 percent reduction in hospitalization, high patient and family satisfaction scores, and overall reduced costs of about $5,000 per patient after three months, with the major cost savings going to Medicare and Medicaid.

According to Sharyl Kooyer, a Regional Administrator in Sacramento, Sutter Health has developed a four-day training program for nurses and social workers in the AIM model in which DDDM is embedded. The training consists of a half-day training on advance care planning, including use of the Physician Orders for Life Sustaining Treatment (POLST) paradigm; a half-day on techniques for having "deep conversations" with individuals who are declining; two days on the AIM model of care; and a day on pain and symptom management for those with advanced illness. Once trained, Kooyer said, nurses and social workers, working either independently or in teams, visit an individual's home, often several times, to assess and develop a relationship that is based on the premise of "How can we help make your goals happen? How can we manage your symptoms so you can meet your goals?" Information gathered during the home visits is then coordinated with treating physicians. As the relationship develops, subsequent conversations are held by phone.

Within the last several years, the American Hospital Association (AHA) has also begun urging its members to pay close attention to implementing AIM models. AHA defines comprehensive AIM programs as having several distinct and also occasionally overlapping phases. The first encompasses individuals who can recover and have reversible illnesses, and frequently includes preparation of an advance directive. The second is for individuals with chronic illness who can be managed, and whose treatment may be supplemented with palliative care to improve quality of life. The third phase is usually characterized by a need for assistance with activities of daily living, and a period when advance care planning is recommended. The fourth phase is for individuals who are deemed to be hospice-eligible. During this process, AHA notes, "the treatment plan will increasingly be driven by the personal goals and decisions of the patient and his or her family."

Evidence for AIM is summarized in a 2012 report from the AHA's Committee on Performance Improvement.[3] The Association's report cites research and analytic findings, a few

of which are highlighted below, to support hospital use of AIM. It asserts that:

- Evidence is accumulating that hospitals and integrated health systems using AIM may provide patients with improved quality of life, reduced major depression and increased length of survival:

  - *Median survival among early palliative care patients is longer (11.6 months versus 8.9 months).*[4]

  - *Patients with cancer who died in an intensive care unit or hospital experienced more physical and emotional distress and worse quality of life at the end of life compared with patients who died at home with hospice.*[5]

- Overall, patients enrolled in AIM experience a lower utilization of clinical treatments and hospital admissions at the end of life, due to improved coordination and honoring the patient and family's wishes:

  - *Medicare patients with AIM use 13.5 days of hospital care in the last 2 years of life compared to 23.5 as the national average.*[6]

  - *Fewer ICU admissions[7] and as much as an 85 percent reduction in ICU days.*[8]

- AIM programs lead to improved satisfaction scores reported by patients, family caregivers and multi-disciplinary AIM-trained staff for these indicators:

  - *Knowledge and respect of patient's preferences.*[9]

  - *Increased time devoted to family meetings and counseling.*[10]

  - *Reduced family and caregiver depression, distress, and documented anxiety.*[11]

- Due to improved care coordination and associated prevention of crises, a secondary impact of AIM programs is a reduction in aggregate spending:

  - *On average, patients who received palliative care incurred $6,900 less in hospital costs during a given admission than a matched group of patients who received usual care.*[12]

In a subsequent report focusing on AIM and the health care workforce's readiness to implement these programs, AHA concludes that "the success of AIM programs is contingent upon the education and training of health care providers as the demand grows for managing multiple chronic conditions, as well as for palliative and end-of-life care."[13] But it further notes that at present, "there are not enough health care professionals who are ready, willing and able to manage

advanced illness with patients and their families, and there is a constant need to engage in conversations and provide guidance to more expert resources."[14]

This point is in agreement with earlier points from a June 2012 *Health Affairs* article written by Vladeck with The SCAN Foundation's Erin Westphal, who argue that "for interdisciplinary teams to function effectively… appropriate training is required, and organizational practices must be in place to support necessary information sharing and decision making. Formal care planning is also a necessity, and in some organizations the care plan itself serves as the focus for interdisciplinary collaboration and information sharing."[15]

Vladeck and Westphal view development of replicable DDDM training programs for "dedicated clinicians and committed organizations…struggling to improve care for those with advanced illness" as a worthy goal. The *Health Affairs* article argues for the importance of patient and family satisfaction as a primary goal and performance measurement for DDDM-based programs, stating: "This kind of care requires skills and experience that are teachable, but that are rarely part of physicians' and nurses' training and that require regular reinforcement and updating…informal, continuous monitoring of patient and family perceptions of the care delivery process is at the core of dignity-driven decision making."[16] In addition, the article asserts that "robust measures of patient and family control of decision making and satisfaction" are needed. Current quality measurement tools that try to assess patient satisfaction "do not even come close to capturing patients with advanced illness and their relationship with the care system," according to Vladeck.

Having appropriately targeted populations for further development of DDDM is important. Patients with congestive heart failure and chronic obstructive pulmonary disease are among the most appropriate, according to Vladeck. The lack of explicit payment for the time-intensive work required by DDDM may make it a difficult fit for the Medicare fee-for-service system, he noted, but suitable for capitation arrangements with adequate risk adjustment, and potentially a good fit for shared savings models such as Accountable Care Organizations (ACOs). At Sutter Health, DDDM in the context of the AIM program is being tested in both a home health-based model and in the hospital environment. Kooyer also noted that work is ongoing to try to make the resulting longitudinal care plan an integral part of Sutter Health's electronic health record system, with information gathered available across all settings of care.

International "Dignity in Care" Models

Interest in developing "dignity in care" protocols is not confined only to the U.S. In the U.K., the Social Care Institute for Excellence (SCE) issued a document in June 2010 on "choice and control" that is designed to empower people to "make choices about the way they live and the care they receive." SCE urges providers to take a range of specific actions to achieve dignity in care for their patients, including:

- Taking time to understand and know the person, their previous lives and past achievements, and support people to develop 'life story books';
- Empowering people by making sure they have access to jargon-free information about services when they want or need it;
- Ensuring that people are fully involved in any decision that affects their care, including personal decisions (such as what to eat, what to wear and what time to go to bed), and wider decisions about the service or establishment (such as menu planning or recruiting new staff);
- Giving staff sufficient training to include people with cognitive or communication difficulties in decision-making;
- Working to develop local advocacy services and raise awareness of them; and
- Involving people who use services in staff training."[17]

The Institute warns that choice and control are "particularly at risk where a person needs support to meet their most basic and private needs… [and] is more easily lost where people have impairments that affect their ability to communicate, including dementia." It also notes that older Europeans found dignity to be an essential manifestation of autonomy, suggesting that care providers must "understand the importance of a person's identity by ensuring time is taken to understand and know the person, their previous lives and past achievements."[18]

Empowering patients and focusing on ways to ensure that their dignity remains intact as they approach the end of life is also the aim of research conducted in Canada by Harvey Max Chochinov. A leader in palliative care, a psychiatrist and author of *Dignity Therapy: Final Words for Final Days*, Chochinov's "dignity therapy" model engages individuals with advanced illness in structured interviews that produce a "generativity" legacy document – a record of key moments in an individual's life that can then be given to heirs.[19] Based on a framework of questions (a sample of which are below) that guide participants, dignity therapy allows individuals to "share their thoughts, reminiscences, advice, hopes and dreams with those they are about to leave behind."[20]

- Are there particular things that you feel need to be said to your loved ones, or things that you would want to take the time to say once again?

- What are your hopes and dreams for your loved ones?

- What have you learned about life that you would want to pass along to others? What advice or words of guidance would you wish to pass along to your [son, daughter, husband, wife, parents, others(s)]?

- Are there important words or perhaps even instructions that you would like to offer your family?

In an August 2011 "Healthy Blog" written for the Altarum Institute's Center for Elder Care and Advanced Illness, The SCAN Foundation President Bruce Chernof succinctly summarizes the challenge ahead: "The specific focus of [DDDM] 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….Dignity-driven decision making offers 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."[21]

The challenge is how to push DDDM beyond the boundaries of initial development. After SCAN examines DDDM sustainability as part of its analysis in Sutter's AIM program and various community-based health and aging services in California, the Foundation plans to continue to invest in this work through building the business case for person-centered care models that value dignity, choice, and independence. Some of this work could potentially be adopted for the next phase of development of ACOs and other types of shared savings models, which the Centers for Medicare and Medicaid Services has already signaled its intent to pursue. Meanwhile, Sutter Health is expanding its AIM program steadily across its health care system in California, with the goal of having the program active at all sites. With proper planning, the CMMI grant, which ends in June 2015, may further the goal of widespread sharing of DDDM techniques and the AIM program during the evaluation and dissemination phase.

Endnotes

1   Advanced illness may be defined as "occurring when one or more conditions become serious enough that general health and functioning decline, and treatments begin to lose their impact. This is a process that continues to the end of life." See Coalition to Transform Advanced Care. *What is Advanced Illness.* Retrieved from http://advancedcarecoalition.org/what-is-advanced-illness/.

2   Advanced Illness Management encompasses four phases as a patient's health declines, from basic good health and chronic care management through palliative care and hospice care.

3   Diegel, J. A., American Hospital Association, Committee on Performance Improvement, *Advanced Illness Management Strategies: Engaging the Community and a Ready, Willing and Able Workforce.* Chicago, December 2012.

4   Temel, J.S., Greer, J.A., Muzikansky, A., Gallagher, E.R., Admame, S., Jackson, V.A., Dahlin, C.M., Blinderman, C.D., Jacobsen, J., Pirl, W.F., Billings, J.A., Lynch, T.J. (2010). "Early palliative care for patients with metastatic non-small-cell lung cancer", *New England Journal of Medicine*, 363(8), 733-742.

5   Wright, A.A, Keating, N.L., Balboni, T.A., Matulonis, U.A., Block, S.D., Prigerson, H.G. (2010). "Place of death: Correlations with quality of life of patients with cancer and predictors of bereaved caregivers' mental health", *Journal of Clinical Oncology*, 28(29), 4457-4464.

6   Gundersen Lutheran Health System presentation to AHA Committee on Performance Improvement. April 2, 2012.

7   Id.

8   Diegel, *supra*.

9   Gundersen, *supra*.

10 Id.

11 Id.

12 Morrison, R.S., Penrod, J.D., Cassel, J.B., Caust-Ellenboegen, M., Litke, A., Spragens, L., Meier, D.E. (2008). "Cost savings associated with US hospital palliative care consultation programs", *Archives of Internal Medicine*, 168(16), 1783-1790.

13 Diegel, *supra*.

14 Id.

15 Vladeck, B.C. and Westphal, E. (2012). "Dignity-Driven Decision Making: A Compelling Strategy for Improving care for People with Advanced Illness", *Health Affairs*, 31(6), 1269-1276.

16 Id.

17 Social Care Institute for Excellence. (June 2010). *Dignity in Care – The Dignity Factors: Choice and Control.* Retrieved from http://www.scie.org.uk/publications/guides/guide15/factors/choice.

18 Id.

19 Chochinov, H. M. (2012). *Dignity Therapy: Final Words for Final Days.* New York, NY: Oxford University Press.

20 Id.

21 Chernof, B. (August 4, 2011). *Dignity as the Cornerstone to Better Care.* Altarum Institute. Received from http://altarum.org/health-policy-blog/dignity-as-the-cornerstone-to-better-care.