New Directions: Challenges and Opportunities to Engaging Technology

in Advanced Illness Management

Duke Institute on Care at the End of Life Roundtable Summary – October, 2010

Participants in the Duke Institute on Care at the End of Life's October 2010 Roundtable focused on the role of technology in advanced illness management. Presentations and discussions centered around three core questions:

- How does technological advancement impact care for people and families living with advanced and life-limiting illness?
- How might technologies help promote and fulfill the promise of patient-centered care?
- What organizational, regulatory, and ethical quandaries must we be prepared to navigate as the information explosion and technological innovation rapidly transform and disrupt the healthcare landscape?

Considering Impact: Real People, Real Stories

We value real stories that provoke thinking about the issues that public policy should address. Hearing the stories of patients and families puts the statistics and data that make up public policy decision into a human context. Our two storytellers started the meeting by giving their personal reflections on illness as it affected them and their families. We heard from Laurie Strongin about the power of love and how biotechnology provided hope in the pursuit to save her child's life. We also heard from Dave deBronkart ("e-patient Dave") that technology allows us to re-frame what we think might be possible for medicine to achieve, but only if patients take seriously the responsibility to fully engage with providers in true shared decision-making. DeBronkart opined that "patient is not a third person word," and urged active engagement of individuals in their health care decisions. He cited evidence that engaged patients who are involved with the care online do better--they're healthier and they ultimately consume fewer resources. This will drive financial incentives for behavior change.

Fulfilling the Promise of Patient-Centered Care

How we utilize technology to advance our aims of cost-efficient, patient-centered care, particularly for those experiencing advanced and terminal illness, will require us to enlarge our thinking. Although we commonly state that technology is neutral, we must acknowledge that technologies can also be more than a mere tool—they can actually shape the way we view the possibilities of medical advances and quality

improvements in care. For example, as one speaker noted, a fascinating and potentially revolutionary use of future technology is to "connect, contextualize and convey the world of the sick to the world of the well."   The use of multi-media technology in the hands of those who are sick can offer powerful means of communicating the illness journey that they are travelling with family and providers.

Navigating Quandaries

Even as we marveled at the power of technologies to prolong our lives, and to improve the quality of survival for persons with advanced and terminal illness, we also struck a few cautionary notes. One participant warned that the belief in technological "miracles" often places us in a "moral mud hole" concerning our choices and actions relating to care for persons with advanced and terminal illness, and implied that technology could be used as an easy prop to avoid the intimate contact and conversations--between the sick and the well, the patient and provider-- so critical to making truly informed and compassionate decisions. Picking up on this theme, another participant remarked that we must understand and "be responsible" to the complexity of the ethical issues that are associated with choices that we make. Still another warned that access to life saving biotechnologies requires a means to resources that are not equally available to all in our society. The socio-economic, class, race and gender disparities so evident in all aspects of health care are surely in play as we grapple with the wise and ethical use of health technologies.

There was consensus in the group that all of us—patients, family member, providers, institutions-- must keep our goals clearly in mind as we engage new technologies. Is the goal of a particular technological innovation to prolong life? Mitigate suffering? Reduce costs? Break through the isolation and fear of illness? These goals may not be compatible in every case. Technology is a major driver of the medical economy. This is a good thing if it promotes efficiencies improvements in life expectancy, and the quality of survival. It is not a good thing if it compromises the prime moral responsibility of health care providers to place the interests and well being of the patient ahead of other concerns.

Conclusions: Criteria for Evaluating Meaningful Use of Health Technologies

As we concluded, we highlighted criteria for evaluating the role of technology in the care of the sick. First is that its use be consistent with the goals of the patient and family experiencing illness. Additionally, the most cost-effective technology solutions should always be employed. We were all in agreement that whether we are applying state-of-the-art digital technological innovations such as computer-generated avatars to express subjective or existential experiences of suffering, or applying the latest genetic advance to better diagnose and treat disease, or engaging the power of digital communication to better coordinate care, the ultimate efficacy of technology to aid those with advanced or terminal illness is limited only by our imaginations and wisdom.

<u>Public Policy Considerations</u>

These considerations raise pressing policy-related questions. Some of the more important are:

- Since technology is a major driver of health care costs, and since "bending the cost curve" in health care is such an important need, how do we facilitate continued advances and wise use of technology, and yet contain access to all those who might benefit? A related question: should comparative effectiveness research, now funded through the Accountable Care Act, also consider *cost effectiveness* research (now currently forbidden)?
- How do we optimize the *information* available to patients, families and providers in Health Information Technologies so that we promote true patient-centered outcomes?
- What ethical principles and processes of decision-making should guide policy makers in defining appropriate and equitable access to new health technologies?

We will engage these questions and other important health policy considerations in the care of those with advanced illness at our next Roundtable, to be held in Washington D.C., in collaboration with Avalere Health, LLC. Stay tuned!