

Chapter 8

Thoughts on Sustainable Health Care...in a Patient-Centric Society

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The concept of “sustainability” immediately begs the question of “What are we sustaining?” As patients, the government defines us as “consumers,” of what always made me ask, “When did I ask for a pound of prostate cancer and go light on the impotence.” However, I suppose the argument can be made that we consume health entitlements through Medicaid, Medicare, Social Security, and programs through federally funded education, research, and treatment initiatives. But do these activities devolve from the patient needs analysis or from the establishment’s interpretation of, and provisions for, it? And, at what level should they be sustained?

The Institute of Medicine (IOM) defines patient-centered care as: “Providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions (Institute on Medicine).”

Given that nonconsumer stakeholders (medical centers, pharmaceutical manufacturers, public health agencies, and health-care professionals) often do not know what matters most to patients regarding their ability to get and stay well (Sepucha et al. 2008), care that is truly patient-centered cannot be achieved without active, and ongoing, patient engagement at every level of care design and implementation.

The concept of greater patient involvement in health-care delivery and design (Jo Anne et al.) is driving much of the conversation relative to how we understand and access the care that we need, from pharma company collaborative awareness campaigns, to Accountable Care medical practices, to multi-disease site public health initiatives. Many of the barriers to this objective stem from insufficiency in patient risk awareness and/or disease education coupled with systemic problems in delivering appropriate access to health care. A classic example can be seen in the disproportionate incidence and mortality of prostate cancer within African-American men in the USA.

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Many hypotheses have been put forward as to the causality of this situation; however, while scientific investigation has shown some factors of genesis, important progress has been made through increased access to information resulting in early detection and treatment. But this has not been an easily achieved objective due to socioeconomic factors relating to access to, and cost of, care, complicated by historic mistrust of the medical establishment tracing back to the Tuskegee experiments. Clearly, a nontraditional intervention was necessary.

In 2005, The Prostate Net launched its Barbershop Initiative, in partnership with MGM Studios and several regional medical centers and public health agencies, to utilize the release of the movie *Barbershop 2* to promote disease risk awareness and early access to care among the target populations. As a result, more than 30,000 men were screened for prostate cancer that had not been engaged with the medical system prior. The program continues today as an extension of various state comprehensive cancer control programs to drive ongoing education and detection services not only for prostate cancer but also for colorectal cancer and correlative men's health issues.

The core element of sustainability for this initiative has been the active engagement by community barbers, working with local medical centers, to provide critical information, access to centers of care, and motivation to participate in their clients' personal health responsibilities. Pharma partnerships were the key in the launch and advancement of this initiative in 2005 in part because of the uniqueness of the program and the potential media exposure to be generated. However, as the program matured, and negative perspectives arose as to the viability of prostate-specific antigen (PSA) screening, coupled with pharma prioritization of advanced-stage disease therapeutics, we have seen that the involvement goes to zero.

We see much of this new mandate for engagement in the inclusion of patient advocates as part of research advisory panels, institutional review boards (IRBs), industry-advocate collaborative groups, community oversight councils, and the like. It engenders much promise that the bad old days of patients without power are gone. But, are they? Have we really arrived to a point where patient centrality is a fact or is it still a wished-for illusion?

In the ideal world of patient-centered care and multidisciplinary engagement, the patient would have his/her clinical status reviewed collectively by physicians from each of the potential disciplines of therapeutic care and a collective decision taken, with the patient's input, as to the one with best outcomes therapeutically and quality of life. True centrality, but far from the reality of most patients when physicians' performance is evaluated by RBU production and revenue-oriented decision making. Is the issue of sustainability related to patient care and the quality of life or to that of the fiscal health of the institution?

While there have not been any RCT studies to compare systems and protocols, inferences can be drawn between the California University medical system wherein doctors are on fixed salaries versus those where compensation is determined by number of patients seen, number of diagnostics ordered up, and number of procedures performed. We can look at the National Health Service of the UK where a more relevant incentive system is in place based on quantitative improvement in the patient's health.

The Accountable Care Act in the USA seeks to address some of these issues by encouraging amalgamation of primary and some specialty care services into groups that should be able to deliver higher standards of care at lower costs. This hypothesis still needs to be proved because effectiveness and cost reductions are components of medical reimbursement either through private insurers or government agencies.

As advocates we sit in these sessions, advise on these panels, suggest new protocols, recommend new therapies; but are we really changing anything. We revel in our accomplishments as “partners” with pharma in meeting the needs of our patient constituencies. Yet, despite their outward manifestations of support and collaborative spirit, there continues to exist, to one degree or another, depending on the global space, that patients are something to be dealt with as revenue sources, markets to be exploited, and the like, hardly to be embraced as an equal partner in meeting corporate, community, and patient-centric needs.

True sustainable patient-centered care must begin before care is necessary. Consumers must engage with the legislative and health establishment to set priorities for government expenditures on preventive education and intervention, research funding priorities, restructuring of government payments for therapeutic care, prioritizing pharmaceutical drug development, and creating healthier environments.

We see today the approval and utilization of many new therapies for advanced-stage cancers, but with extremely high prices and limited patient effectiveness. As a nation, are we better serving our citizens by paying with our tax dollars for an agent that costs almost US\$100,000, is only effective in approximately 30% of the affected patient populations, and offers only a few months of survival. Would not our return-on-health investment be more effective in using those dollars to promote better health behaviors and early detection for a healthier society?

We need to analyze the cost of advanced-stage disease care versus that of proactive prevention and invest in initiatives that will stem the increase in chronic diseases of lifestyle, e.g., diabetes, obesity, etc., while concurrently increasing our support for research and information sharing towards heightened opportunities for cure and chronic care management.

And we need to break down the barriers to true universal access to care to insure that there will be true equitable sharing in the basic human right to good health and quality of life.

If we cannot become more educated and proactive consumers, if we do not embrace our responsibilities to ourselves and our communities relative to informed choice, and if we allow our “centricity” to be determined by special interests other than ours, if we do not define the real parameters of sustainable health care, we will see a continued erosion of those resources we value, and need, in profligate and unfocused consumption.

References

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