ICC COLUMN: The Voice of the Patient

Establishing a national culture of health and its values

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A New measure of health disparities

In early 21st century America there are several factors that have stimulated a growing momentum for creating a national "culture of health" in the United States. Among those precipitating factors are the following: the creation within the Department of Health and Human Services of the Healthy People Program, which publishes each year a report card of health, disease and mortality data broken down by gender, race, age and social/economic characteristics, which are compared annually with specific goals, including targets for reducing existing disparities for various groups of citizens at the end of each decade. In preparation of the second decade-long effort to collect such data in 1990, the Secretary of Health and Human Services asked the Institute of Medicine of the National Academy of Sciences to take the entire list of several hundred distinct and separate health and disease data sets and select ten, which taken together, could serve as an overall surrogate figure through which progress towards the elimination of significant health disparities could be followed. In 2000 and 2010, there was further evolution of the measurable data base, allowing the charting of progress towards or regression from specific measurement goals of the burden of disease on segments of our society and on the society as a whole.

Much of this collaborative, collective advance made in response to the collection and distribution of the data presented annually by the Department of Health and Human Services, came from a variety of non-governmental, not-for-profit and business groups. Thus, we have some new, but proven, evaluative tools to follow the success of the impact of the establishment of a new and innovative culture of health.

What is a culture of health?

In the mid-19th century, slavery was abolished in the USA, but Dr. Martin Luther King, late in the 20th century, was moved to proclaim that, of all the many injustices and inequalities still suffered by black and other minority Americans, the greatest of all had to do with health. In 2008, the first black President was elected, and he turned his initial agenda toward passing a health bill (the Affordable Care Act), driving the nation to reverse the greatest of racial injustices by extending health insurance coverage to millions more people, including many people of color. In that same law, the National Institute for Minority Health and Disparities (NIMHD) was created to spearhead the research and innovation needed to cure or prevent the major diseases causing the health disparities within our population. But now, well into the second decade of the 21st century, it is abundantly clear that 40 to 50 per cent of health disparities exist because of socio-economic reasons and that the poor health of non-white citizens and immigrants is largely a result of low social status and poverty. As a result, we as a nation are looking to the non-governmental sector to join forces to help reduce the social and human cost of correctable factors contributing to poor health to identifiable sub-populations of Americans.

Many insightful leaders have come to the conclusion that America, for the sake of all its people, must develop a culture of health, which would ameliorate the societal and cultural root causes obstructing the ability to prevent disease and promote healthy living among the entire US population. For example, the Robert Wood Johnson Foundation (RWJF), with the full support of its Board of Directors and sparked by its President, Risa Lavizzo-Mouri, has directed all of its division heads to realign their program plans for the next year and beyond, around the development of a new and improved, nation-wide culture of health. Thus, we can expect to see a full agenda of programs, centered on aspects of this evolving vision of a new culture of health, coming forth from this major health foundation.

Indeed, RWJF has already attracted more than eight thousand people to its internet discussions and explorations of this new health goal. Much of what is discussed about what such a culture comprises is in danger of dissolving into a recitation of individual items inherent in the effort to provide a fair, effective and comprehensive health program available to everyone, which can in turn, lead to widespread discouragement if we haven't first developed a coherent framework of values into which each health equity-promoting effort can logically fit. Health inequity problems will not be solved solely by throwing money and technology at individual problems without an overview of what is to be achieved.

The values inherent in a culture of health

Furthermore, it is not sufficient for us to declare a war on disparities and hope to bring the public and our political leaders along with us. I believe we have to go beyond the naming of our effort as "a culture of health" to describe the values that we as a society wish to express in our evolved or improved American health system, including the environmental, economic, and social forces impacting our effort.

I am not a professional ethicist, but as a physician deeply concerned about medical and health professional ethics in general, I was an early participant in the first years of the development of a not-for-profit organization, the Society for Health and Human Values, dedicated to bringing the liberal arts into the learning environments of medicine and the other health professions. Over the dozen years [1976-1988] during which I served as the Chancellor-Dean of the University of Massachusetts Medical Center and as the President of the University of Texas Health Science Center at Houston, the faculty and staff initiated and developed a series of innovative programs aimed at improving the humanistic care capacities of developing health organizations. Both of these institutions were among the cluster of new medical schools established in the decade around 1970, but the first medical school to create an academic department of medical ethics and human values in medicine was the Penn State University Medical School at Hershey, which promptly paved the way of curricular inclusion of the humanities and arts in the medical school curriculum from Day One for the new students.

In 1987, the University of Texas held a major national conference entitled "Integrity in Health Care Institutions". Many CEOs from major academic centers were in attendance in order to work on developing trust for their organizations on the part of their patients, their students, and their faculties (1). The impact of that meeting was felt at the Association of Academic Health Centers, where over the next decade and a half, academic health center faculty and hospital and university administrators developed a "values model" that could produce results that can be evaluated. It is this sort of model that is currently applied to clinical Quality Assessment in many hospitals and health care institutions. It could now be utilized in measuring results of attempts to create a well-structured "culture of health".

Many people have contributed to the movement to minimize errors within hospitals and clinical practice, but none more successfully than Dr. Donald Berwick and his colleagues at the Institute for Health Improvement. However, the leaders of major health universities and the major schools for each of the major professions realized that they needed to find a way to ensure that all health care institutions operated from a "values model" that would bring about a "culture of health". They established, in 1990, the first of four consecutive annual national conferences of all faculties from the major health professions. They examined innovations in developing curricula within individual professions and across several of them interested in educating for multi-professional teams. In recent years [2012-2014], many of these same leaders and the Josiah Macy Foundation, spearheaded a series of working conferences at the Institute of Medicine of the National Academy of Sciences, driving the educational culture change even further into the main educational and health policy mainstreams, and they placed the patient on the health care team, even though resisting their formal recognition as Chief of his/her own health care team.

Many of the same people from across the country and a collaboration among several NGOs and non-profit groups, worked with the Association of Academic Health Centers to develop The Organizational Therapeutic Index, a tool that organizations could use to measure how "therapeutic" they might become, especially in their patients' eyes.

To reach a credible example of what The Organizational Therapeutic Index (2) would look like, in 2010, it was necessary to settle first upon the core values of American Health Care, which would also be the core values of an American Culture of Health. Eventually, the core values selected were justice, hope, mercy, and autonomy for individual patients and providers. The next step was a project to answer the question of how to measure and test for these basic values; the answers led to queries of the patients, family, providers of care and external perceptions of care that was delivered. Ultimately, the movement to the inclusion of the patient in the access loop for the medical record will be a great boon to improving the human values

dimension of the caring enterprise.

Social contract between patients and health care professionals

The net result should be a tool that can allow patients and providers as well to measure how they are doing as regards those basic human values in addition to the competency and outcomes of the care rendered. But before moving further with this model, we should explore a little more of the background work that went on over the past few decades largely with the involvement of several outstanding NGOs. There is now widespread agreement among providers and patients that the social contract for the health care sector includes competence (including safety), compassion, hope for successful treatment (including merciful assistance in a dignified death if cure or remission is not possible), justice and equity, and full respect and dignity for all patients, while including them and their close family in the decision-making as much as possible.

Every major health profession has its own oath-taking ceremony upon graduation and the official entry into its profession. However, increasingly, in the last decade, more and more ceremonies have added a paragraph that pledges a commitment to collaborating with other health professionals on the therapeutic teams upon which most patients will need to rely. An important kind of inter-professional health culture change for the better has, slowly but surely, been taking place (3).

Associations in America

It may be informative at this point for us to take note of what the recognized experts say about America and its use of associations and organizations to structure public life. In the middle of the nineteenth century, Alexis de Tocqueville travelled through the United States and wondered in his subsequent writings and analyses, at the nature of the first frontiersman, who ventured forth from the relative safety and comfort of their initial colonies and with his family at his side in search of a home in relative seclusion or, where possible, in the company of some other families to begin a new community. Such small settlements were by necessity looked to by its members to support collective functions, safety, security and community life in general. This independence aside, de Tocqueville made a prescient observation upon which Fukuyama was to build into the core of his recent book (4). Fukuyama introduces his sweeping view of the importance of the art of associations around the world by quoting de Tocqueville (5):

"Americans of all ages, all conditions, and all dispositions constantly form associations. They have not only commercial and manufacturing companies, in which all take part, but associations of a thousand other kinds, religious, moral, serious, futile, general or restricted, enormous or diminutive. The Americans make associations to give entertainments, to found seminaries, to build inns, to construct churches, to diffuse books, to send missionaries to the antipodes; in this manner they found hospitals, prisons, and schools. If it is proposed to inculcate some truth or to foster some feeling by the encouragement of a great example, they form a society. Wherever at the head of a great undertaking you see the government in France, or a man of rank in England, in the United States you will be sure to find an association".

In this book Fukuyama presents the power and importance of trust in social and economic life. Dr. David Mechanic wrote the first paper on the obligation of health groups, clinics, hospitals to build trust in them on the part of their patients. He was the first to suggest that an entity had first to instill and earn trust before it could become a genuine therapeutic institution. Thus, I believe that the Organizational Therapeutic Index (OTI) has to add trust as one of the cardinal virtues or elements to be assessed*.

Founding of a new organization to promote health equity

To bring this discussion to a close, there are more than twenty different "associations" in de Tocqueville's terms that we hope to link together to further the Culture of Health in America and to find ways in which they might focus on America's greatest health problem: inequity.

These organizations, have been or will be formally invited to join together as the first and founding organizations to establish a new proposed "association" to be called the American Council on Health Equity and Disparities (ACHED). The organizing committee for the creation of ACHED intends to invite the following to help initiate the launch of the new not for profit organization:

- ADEA (American Dental Education Association)
- AACN (American Association of Colleges of Nursing)
- ASPH (Association of Schools of Public Health)
- AAMC (Association of American Medical Colleges)
- AACP (American Association of Colleges of Pharmacy)
- ACOM (Association of Colleges of Osteopathic

Medicine)
- IOM (Institute of Medicine)
- APHA (American Public Health Association)
- AMGA (American Medical Groups Association)
- GERF (GER Foundation)
- RWJF (Robert Wood Johnson Foundation)
- RESEARCH AMERICA
- ACADEMY of HEALTH (formerly the Association for Health Services Research)
- NCHC (National Coalition for Health Care)
- Healthcarevlogs.com
- Health Affairs Journal (Project Hope)
- AIHA (American International Health Alliance)
- SPLC (Southern Poverty Law Center)

The global importance of health care

Now, with globalization of health concerns rising to the top of our national and the international agendas of other nations and cultures, we might ask what is or is not applicable outside of the US. For example, America's founders did not come here because they liked the national governments they left behind; and the feeling of distrust of the government is pervasive still in the US. However, even so, it sometimes takes a governmental action to precipitate an important change in the culture of health. Thus for example in America, the Supreme Court has settled the question of who owns the patient's chart and medical records. The answer is "the Patient owns it!". However in the UK, the "Sidaway Case" concluded in 1990 that the medical record belonged to the doctor and not the patient. In Canada, compared to the general public in the US, there is a far more pervasive public trust in the national government. In the US, however, we are becoming increasingly aware of the ever-enhancing cultural diversity within our population. In many regions of the country, hospitals offer multilingual translation services for patients, nurses and doctors.

Cultural differences notwithstanding, access to modern health care is increasingly on international and national agendas and an awareness of differing cultural human values will require increasing attention all around. Thus, the new thrust to work on shaping a new Culture of Health for America should include an effort to define and refine the characteristics of the values that must shape this culture of health, and which should be used to measure its performance and evolution in the years ahead.

Footnote: *The next step in expanding the reach of a set of American cultural health values was carried out by the Association of Academic Health Centers with support from the Josiah Macy Foundation and the John McGovern Foundation (6).

The appendix to the book Healing America (7) describes a proposed OTI or Organizational Therapeutic Index, which is offered as a model for use by any interested health care organization to measure through repeated self-study it's performance in fulfilling the human values goals it has set for its own organizational fulfillment.

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