

Submaximal Decision Theory and Health Resource Conservation: The Example of Congestive Heart Failure

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Abstract

The challenge of eliminating disparities in chronic illness in the United States is hampered by the diversity of the epidemiology of the chronic conditions themselves, and by the individuality of the communities and patients affected by them. This article outlines some of the ways in which the complexity of chronic illness in underserved communities in the United States limits the data and the strategies available to clinicians and patients. We then present the example of chronic heart failure (CHF) to illustrate a possible solution that we are developing for supporting underserved patients' self-management of chronic illness: individualized health care (through "personal normals" derived from the patient's own clinical history combined with population-based data), and distributed health care (point of care through wireless biosensors and community health workers). We present some of the possible barriers to the implementation of the model. Conclusion: we believe that this approach is a pathway to empowering CHF patients in underserved communities. Further research is necessary to test the clinical viability of the model and the acceptability of the model for patients, physicians, and families.

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Introduction: The Challenge of Chronic Disease

Chronic disease is the health challenge of the 21st century. Today, any improvement in the health status of the United States depends upon the successful prevention and control of chronic diseases in all populations. According to the National Center for Chronic Disease Prevention and Health Promotion (National Center for Chronic Disease Prevention and Health Promotion [NCCDPHP], 2007), chronic conditions are the leading causes of death and disability in the United States. Chronic illnesses such as heart disease, COPD, and diabetes account for seven out of every ten deaths each year and affect the quality of life of 90 million Americans. Chronic illness seriously limits the activity of one in ten Americans, or 25 million people (NCCDPHP, 2005). As the U.S. population ages, these numbers are expected to increase, as are the attendant costs (78% of total health spending in 2000) (Anderson, 2004).

Chronic illness affects different populations differently. The examples of racial, ethnic, geographic, financial, and sex differences in access, utilization, and outcome are well-documented (Centers for Disease Control and Prevention, Office of Minority Health, n.d.; Hadley, Cunningham & Hargrave, 2006). In fact, the differences between and among populations are so numerous that any attempt to address disparities in chronic illness prevention and control in a culturally appropriate and effective manner is necessarily highly complex and fraught with uncertainty.

Cancer and Chronic Disease Management

The NCCDPHP lists cancer as a chronic condition and, certainly, cancer is a chronic systemic disease with local manifestations. Cancer also shares causes with other chronic conditions (behavioral, genetic, environmental).

For the purposes of this analysis, however, cancer is a unique case that is excluded from the

discussion because it is not a single disease, and because its lifelong management differs from that of other chronic conditions. Most cancer intervention programs rightly stress prevention, early detection, and treatment, rather than continuous management. The medical management of cancers is episodic and intense and although the person living with cancer lives with it at all times, his or her need of the medical care system generally comes in defined quanta. In contrast, for example, a patient with diabetes is completely dependent upon daily, even hourly, disease management (generally self-management).

Thus, this paper focuses upon chronic illnesses such as coronary artery disease/stroke, CHF, COPD/asthma, type 2 diabetes/metabolic syndrome, and depression. How these conditions are managed in the “real world” manifests the problems and the disparities in the U.S. health care system (Trans-HHS Cancer Health Disparities Progress Review Group, 2004, p. 8).

How Chronic Disease is Cared for Reflects the General Health Status and Disparities in a Community

People with chronic diseases are likely to engage with the health care system to a greater extent and for longer times than most other people. In the course of their illness (and, for some, their entire lives), most people with chronic conditions will experience the gamut of general medical visits, diagnostic tests, pharmaceutical prescriptions, consultations with specialists, visits to emergency rooms and hospitals, and (possibly) procedures. Because chronic disease patients and their families experience the health care system at almost every level, how successfully the system works for them can be viewed as a reflection of how well the system works for everyone—for the powerful and efficacious as well as for the underserved and under-resourced.

On a macro level, how well does the current system serve the chronically ill? Tens of surveys and audits have shown that large numbers of chronically ill people are not receiving high-quality care, have problems controlling their conditions, and are not satisfied with their

medical care (Bodenheimer, Wagner, & Grumbach, 2002; Casalino, 2005; Wagner, 1997; Wennberg, Fisher, Baker, Sharp, & Bronner, 2005). While consistent management of chronic illness has the potential to reduce complications, improve patients’ quality of life, and reduce the cost of care, in reality chronic disease sufferers tend to receive episodic, crisis-oriented, uncoordinated care, with sporadic follow-up and inadequate support to manage their illnesses themselves. The U.S. health care system privileges acute, office- and hospital-based care over preventive care and patient self-management. It is a “disease care system” not a health care system.

At a micro level, chronic disease allows one to biopsy the health status and disparities of our communities themselves. According to the NCCDPHP, chronic disease management requires prevention, access to care, continuity of care, patient education, and support for self-management (NCCDPHP, 2006). The National Healthcare Disparities Report shows that, at every level of this continuum, disparities are systemic, and affect people by virtue of their race, ethnicity, income, education, place of residence, and age (Agency for Healthcare Research and Quality [AHRQ], 2003). Even more troubling, racial and ethnic minority patients receive lower-quality care — even when controlling for income and insurance coverage (Institute of Medicine, 2003). Finally, in the area of support for self-management, an essential to controlling chronic disease, the Disparities Report demonstrates that disparities are exacerbated by problems underserved patients encounter communicating with their providers and accessing information about their conditions (Agency for Healthcare Research and Quality [AHRQ], pp. 120-127).

Individualized Medicine Disparate Conditions

When dealing with the variety of chronic illness in the United States today and the diverse needs of underserved populations, traditional epidemiological strategies are blunt weapons. While the causes of chronic illness can be reduced to a relatively short list — diet, physical inactivity, tobacco use, environment, and

genetics — addressing the reality of chronic disease is far more complicated. Describing, understanding and, ultimately, affecting the pandemic of chronic disorders is considerably complex because each chronic illness and population has its own epidemiology, and the scientific datasets on specific health conditions can be unwieldy, contradictory, uneven in quality, or simply not available. In addition, chronic conditions often occur jointly (e.g., diabetes and hypertension), with unknown conjoint effects.

Disparate Populations

Significant variations in risk factors and chronic conditions among underserved populations indicate that chronic-disease management practices should “vary among different racial/ethnic groups, and even among communities within each group,” and that culturally sensitive treatment programs should be tailored to meet community-specific needs (Liao, Tucker, & Giles, 2004). Thus, meeting the challenge of chronic illness management in the United States requires acknowledging the fact that societal-level data must be balanced by individual-level approaches that originate in the specific needs of the patient (disease-specific; age-, gender-, and lifestyle-specific; community-specific).

Disparate Data: The Example of Heart Failure

This need to individualize the management of chronic illness becomes even more acute when one considers the origin of the guidelines upon which most interventions are based: medicine’s gold standard — randomized controlled trials. Despite recent efforts to the contrary, most randomized controlled trials under-represent the very people who suffer from health disparities, so it is not clear whether the treatment guidelines derived from them are valid for underserved patients (Bartlett, Doyal, & Ebrahim, 2005). Yet, the management of chronic conditions continues to be based upon guidelines derived from those data, perhaps because there does not appear to be an alternative.

Finally, there is the issue of what to measure. The management of chronic disease is highly

data-dependent, and yet sometimes it is not clear which data should be monitored. For example, frequent occurrences of decompensated congestive heart failure (CHF), which can be caused by several different factors, are a significant challenge in the outpatient treatment of CHF patients. Once patients with CHF undergo decompensation, CHF requires movement of clinical management from the outpatient to the more-costly emergency center or inpatient hospital setting, with the inevitable disruption to the patient and family. However, most CHF decompensation episodes are preceded by changes in vital signs in the previous days that, if detected early, might have led to self-care or intervention while the patient was at home and avoided a hospital readmission. In fact, studies have shown that home-monitoring with self-reported or electronically transmitted daily measurements of vital signs (usually weight, blood pressure, heart rate, and oxygen saturation level) has the potential to reduce hospital admissions and improve patient satisfaction (Joseph, 2006).

Unfortunately, as indicated by their limited enrollment under the auspices of research programs at academic medical centers, remote monitoring programs as currently implemented are labor intensive and costly, dependent on highly trained clinical personnel. Thus remote monitoring for CHF in underserved populations will remain economically infeasible until it is possible to determine exactly which patients will benefit under which circumstances.

Patient responses to treatment tend to be idiosyncratic. There is no single number for any of the vital signs usually measured by CHF remote monitoring studies that can be clearly associated with decompensation for every patient. Instead, each patient’s record is a time-course of events, some of them repeated, others of which are measured by multiple measurements or are simply errors. The data collected for each patient are multileveled, and their distribution, whose parameters must be estimated, will have a multidimensional structure.

Possible Solutions

Together, the issue of under-represented populations in clinical trials and the example of CHF illustrate one of the largest obstacles facing management of chronic disease in underserved populations: the uncertainty involved in interpretation and individualization of the available data. We propose two possible solutions. One supplement to averages of data from clinical trials and multidimensional data from individuals is the concept of “personal normal.” A “personal normal” is a value that reflects the normal situation for that particular patient (which may not be the “norm” for any other person, or the one from the medical literature). However, deviation from this personalized normal, derived from the patient him or herself, over time, may be a better indicator of the patient’s true condition than a “standardized” normal or reams of undifferentiated measurements.

Another method for overcoming the gaps in the data available for the management of chronic disease in underserved communities is the use of info-gap decision theory (Ben-Haim, 2006). Info-gap decision theory uncouples the distribution of data from probability theory, allowing patients and physicians to make robust decisions even when the data available are sparse or incomplete, or severely uncertain. The mathematical application of info-gap can be done real-time, and the resulting individualized recommendations served up to patients and their physicians quickly and in a form that is easy for patients to understand.

Distributed (Point of Care) Health Care

The first objective of the “19th National Conference on Chronic Disease Prevention and Control (NCCDPHP, 2005): Health Disparities” was to “engage people more directly where they live, work, and play, and encourage them to do what they can to protect and preserve their health and the health of those they care about” (National Center for Chronic Disease Prevention and Health Promotion, 2005). This objective reflects a fundamental truth about chronic disease: chronic disease is managed in the home, not treated in a doctor’s office. Distributed health care — health care delivered to patients

where and when they need it — keeps the management of chronic disease in the homes and in the hands of patients themselves.

An important insight from the literature on health disparities is that patients can be empowered by their communities. When healthcare is delivered to patients by people they trust, in a place where they feel comfortable, patients are better able to understand and participate in the health management process (Trans-HHS Cancer Health Disparities Progress Review Group, 2004, pp. 11-12). Patients with chronic illness are responsible for their own health in ways that few acute patients are, and successful management ultimately depends upon empowering them (Von Korff, Gruman, Schaefer, Curry, & Wagner, 1997). Delivering healthcare to patients where they live is an important step toward that goal.

What most patients lack, however, and what underserved patients lack even more frequently, is the authority and information to match their responsibility (Trans-HHS Cancer Health Disparities Progress Review Group, 2004, pp. 11-12). The following section describes a pathway that we are taking to resolve this problem and give chronic disease patients the authority and information support to manage their health in their homes and communities.

Pathway to a Solution

The key to effective care of chronic illness is management of the underlying condition to prevent acute episodes. However, such management is dependent upon empowered patients receiving timely, accurate data that they understand. In order to manage their conditions, chronic disease patients need careful, longitudinal monitoring with real-time feedback that they can trust and use. This feedback also needs to be available to them wherever they are. One approach to providing feedback to underserved patients is the distribution of inexpensive but effective biosensors to monitor a parameter of a chronic illness.

Such a sensor is a biomedical measurement device designed to capture data through non-invasive monitoring, perform analysis and

interpretation of the data using info-gap decision theory or simple linear analysis when appropriate, and provide guided intervention including communication with a health professional when individuals exceed their “personal normal” range.

A biosensor can be designed for ease of use, accuracy, and low cost. Unlike top-down disease management models, which are expensive to implement and externally directed, the distributed health care approach begins and ends with individuals in their communities. By incorporating individualized medicine, personal normals, distributed health care, and community health workers, a biosensor empowers chronic illness patients with the authority, support, and information they need to manage their illnesses and minimize emergency room visits, hospitalizations, and complications.

Barriers to Implementation

How data are collected and communicated to the individual to make them useful to patients and their families is the user-interface challenge of the CHF biosensor model discussed above. The biosensor itself and the transmission of data are the engineering challenges.

Also important is the societal issue of the diffusion of technology, particularly in underserved communities. An electronic device can hold meanings for its intended users that prevent them from employing it. For example, undocumented immigrants in the United States might refuse a remote heart monitor because they are concerned about being watched or tracked by the government. In fact, most communities and the individuals within them have concerns about trust and confidence in health care technology. These concerns often take two forms: (1) Can I believe the information emanating from the device? (2) Can I trust the person who is promoting it? These issues need to be addressed in a culturally competent manner prior to introducing a distributed health program that relies upon technology (Johnston, Wheeler, Deuser, & Sousa, 2000).

In addition, it is tempting, as researchers, to define people as belonging to communities without verifying that such a bond exists (Oakes, 2004). Often, this assumption is justified; but occasionally it is pernicious and dismissive. The well-structured distributed health program takes into account the autonomy and authority of the individual as well as the role of the community or neighborhood in which he or she lives before seeking to augment his or her efficacy with a technological or communications intervention.

Cost is sometimes held out as a barrier to the implementation in underserved communities of a distributed health care system such as we propose. The “giant killer” question often posed is “who is going to pay for it?” In the face of a coordinated health care system, this question would not arise because there would be obvious savings to the “system.” In the fragmented and multi-tiered system extant in the United States, the answer is less obvious and may vary by locale. Closed systems such as Kaiser Permanente and the Department of Veterans Affairs are pioneers in distributed health because individual cost reverberates through the system. In the absence of an integrated health system, the cost has to be born by the party that suffers the most financially from unmanaged chronic conditions. This may be the hospital trying to bar early readmissions, the insurer trying to decrease utilization and payouts, the government seeking to conserve Medicare or Medicaid dollars or, even, in rare cases, the individual seeing a cost benefit to minimizing the frequency of encounters with the institutions of health care.

A similar argument is often raised that the “doctors” will not accept the introduction of remote monitoring system for patients. This also flies in the face of reason. What irks physicians is not that people with illness take on the authority of self-management. Rather the physician simply cannot shoulder the accountability for decisions that he or she does not make. In a distributed health care model, the physician can be responsible for providing the diagnosis and the overall direction for treatment as well as for setting the context of treatment

(ideally by a community health worker who has formed a relationship with the patient).

In this model, the physician provides a mechanism for recourse should people desire more structure or consultation. Dispersal of authority matched to accountability puts people on a course to making informed judgments about their own health and requiring the physician only for high-value questions where the doctor can exercise professional judgment. This “best use” of their time should increase physicians’ satisfaction and effectiveness.

Conclusion

The challenge of eliminating disparities in chronic illness in the United States requires understanding and addressing the complexity and variety of chronic conditions themselves, and of the communities and individuals affected

by them. Most importantly, however, it requires empowering and supporting patients and their families to manage the illnesses effectively. This article outlined some of the ways in which those complexities manifest themselves in the data and the strategies available to clinicians and patients as they struggle to control chronic illness. We then used the example of chronic heart failure to illustrate a possible solution that we are developing: individualized health care through “personal normals” derived from the patient’s own clinical history analyzed by info-gap, and distributed health care (point of care through wireless biosensors and community health workers). In conclusion, we examined some of the possible barriers to the implementation of this model. Further research is necessary to test the clinical viability of the model and the acceptability of the sensor for underserved patients and their families and physicians.

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