Technology-enabled Chronic Disease Management in Under-resourced Environments

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***Abstract*— With the large international effort directed against malaria, tuberculosis, HIV/AIDS, and water-borne illnesses comes the inevitable emergence of chronic diseases as a major worldwide health threat. Management of chronic illness requires a partnership of the person with the illness and the healthcare establishment in an ecosystem of information flow. Remote biosensors in a ubiquitous computing environment provided by mobile phones allows the constant participation of the person with the illness in his or her own health care by providing communications and disease indicators simultaneously and at low cost. The addition of a geographic information system allows the aggregation of individual data into a picture of the epidemiology of the illness and its control, thus facilitating regional and national health planning at low cost without compromising individual privacy. The dissemination of such a system is a complex political and social task with great potential benefit for improving individual and societal quality of life while reducing the cost burden of chronic disease.**

Keywords-technology; biosensing; chronic disease; congestive heart failure; mobile phones; wireless; health disparities

I. INTRODUCTION

The worldwide shortage of healthcare workers has been amply documented by the World Health Organization, United Nations, and other multinational groups. The World Health Organization, in particular, has drawn attention to the maldistribution of healthcare workers, with emerging economies, particularly in Africa, the subcontinent, and Southeast Asia, being most severely affected. Published data have called attention to severe shortages in skilled attendants to live births, many of which are overseen by traditional birth attendants with little or no medical training [1]. In addition, the changing face of illness in the world is contributing to an increased demand in emerging economies. As the traditional causes of early mortality, malaria, tuberculosis, HIV/AIDS, and waterborne illness are addressed, populations are living to an older age and therefore becoming susceptible to chronic illness. In fact, the global burden of chronic disease is on pace to be the major healthcare challenge in the coming several decades [2].

The issue of healthcare disparities, that is different delivery systems, outcomes, and quality of care worldwide, both contributes to and is a result of the maldistribution of healthcare workers. Certainly in developed economies there is little or no strict shortage of healthcare workers; however, the issue of maldistribution is quite daunting, even in places like the United States, Mexico, and Brazil [3]. Healthcare disparities are conventionally measured as mortality rates and access to care. These crude measures, although on the surface accurate, are misleading in that access to high intensity care with high utilization of technology does not guarantee good outcomes. The United States of America, with its extraordinary utilization of expensive medical interventions, ranks far from the top in developed economies' health outcomes statistics [4]. This is at least partly a result of internal disparities observed between racial and ethnic groups, and socioeconomic determinants. Factors such as early childhood education, access to immunizations, and health seeking behavior vary widely and are not a consequence of healthcare worker maldistribution. They result from complex and often poorly understood social and political factors that are present in all societies.

Conventional wisdom has it that the challenge for the world is to train more skilled healthcare workers. The thinking is that by providing more physicians, nurses, technicians, and other certified professionals, healthcare will be brought to the people who need it. There are few data that suggest that this is true. Even the most highly industrialized and wealthy nations experience dramatic healthcare disparities independent of the availability of healthcare professionals [5]. Even if the will existed to train the large number of healthcare professionals that would be required to fill the theoretical manpower lacunae it is not clear that short of unacceptable coercion they would migrate to the areas of need [6]. Experience with inducements for physicians to serve out their professional careers in areas of need has almost universally been a failure [7]. This is of course not to say that certain physicians have not dedicated their lives to serving under-resourced communities. This is likewise true with nurses, pharmacists, physical therapists, and many others of the healing professions. But as public policy, this strategy seems flawed.

II. Technology Interventions for Health

Fortunately, the technology undergirding healthcare decision-making and intervention has proceeded with remarkable speed. Important factors such as robust wireless transmission, miniaturization, long-lasting power sources, and high intensity computing have allowed, for the first time, the ability to carry medical expertise to the farthest reaches of the world. Thus the solution to the healthcare professional shortage and maldistribution may well involve the creative use of low- cost but highly specific medical devices to augment the abilities of professionals or trusted community members who are already in place in under-resourced areas or to extend the reach of professionals from richer places into under-resourced communities (e.g., through community health workers), rather than to attempt to replicate developed-country manpower structures in remote areas [8].

Early strategies in using computation for healthcare focused on the decision-making aspects of diagnosis. Early programs such as MYCIN sought to remove the subjectivity from physician diagnosis and prescription therapy (e.g., [9]). Subsequent generations of decision-making software, culminating in the ill-fated drkoop.com, focused on replacing physician judgment and diagnostic skill with a program where the data were inputted by the person with the illness [10]. Of course these failures spawned further attempts culminating in the electronic health record used in advanced healthcare systems. In this system, the emphasis was placed on process rather than outcome with the assumption that when appropriate boxes are ticked, good outcomes will emerge. Thus far, the data on this strategy have been mixed as well [11].

An alternative strategy, focused on the specific challenges of under-resourced areas, is needed. Such a strategy would have salient characteristics not found in systematic interventions at this time. Table 1 identifies the major characteristics of a healthcare intervention using technology to leverage the abilities of the healthcare system and its professionals.

III. REQUIREMENTS FOR EFFECTIVE BIOSENSING CONNECTIVITY

If a novel transmission, computing, and interface configuration is necessary to support the dissemination of technology as leverage for healthcare professionals into under-resourced areas, success will be long in coming. The challenge therefore is to utilize existing modes of communication; inexpensive, flexible, and robust platforms; and simple biosensors that provide real-time information to nonmedical personnel. Ideally, such a system would live on a mobile phone and require little to no transmission in order to be functional. Fig. 1 identifies a schematic for such a system.

This system is characterized by a complex interplay between the user and the device where data are acquired through minimal or no effort on the part of the user, seamlessly transmitted to a processing device, ideally a mobile phone, and then reflected back to the user for decision-making using pre-agreed upon heuristics. The mobile phone characteristic of the system is exploited to allow monitoring and supervision but not in a day-to-day or moment-to-moment form. The classic "telemedicine" format requires a clinician to be responsible for data interpretation. Chronic diseases are slow in developing, and slow in deteriorating. Accordingly monitoring does not require the intense supervision that, for example, a tele-diagnostic or traditional telemedicine application would. Indeed, the challenge of remote monitoring and chronic disease is filtering the important signal from the vast amount of normal value noise.

Thus, a chronic disease infrastructure using remote

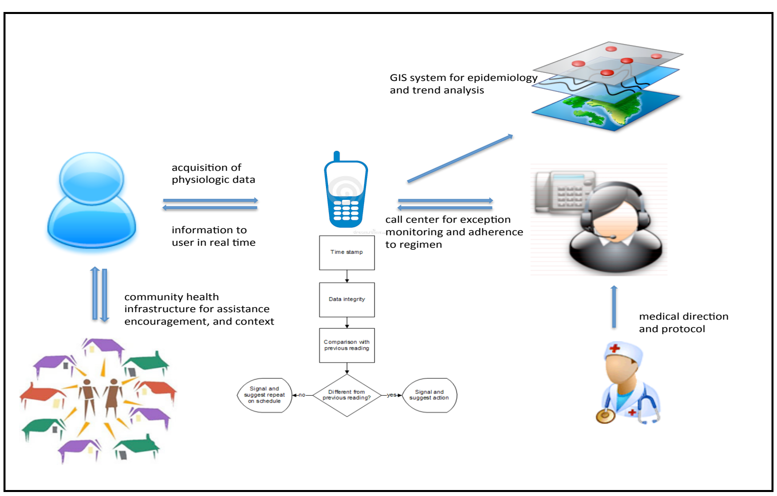


Figure 1. Structure-function model of a biosensor-ubiquitous computing-geographic information system cluster.

sensing and mobile phone technology must exploit the ability of the mobile phone to identify the user and to compare the user's values with his or her baseline. Additionally, the processing unit must have the sophistication sufficient to allow discarding of minor or clinically insignificant changes while at the same time preserving important trends.

An additional benefit of employing mobile phone technology as the processing power for remote bio sensing in chronic disease is the ability to mate it with geospatial imaging and begin to understand new aspects of the epidemiology of chronic disease. These aspects are unavailable for study currently because of the lack of ability of individual observations by individual clinicians to be easily rolled up into population-based data schemes. A complete schematic of a remote biosensor coupled with a geospatial information system is shown in Fig. 1. Some key features include an understanding of the ecosystem in which the biosensor lives, the interaction and exception monitoring function provided by the communications technology to a central point, and the important geospatial context. Intrinsic in the entire scheme is an appreciation of the unique population characteristics that will allow people to trust information gleaned from biosensors.

TABLE I. CHARACTERISTICS OF EFFECTIVE BIOSENSOR COMMUNICATION

Characteristics of Effective Biosensor Communication
Cost
Population acceptance
Efficacy
Independence from supervision
Ability to compel a decision
Robust form
Narrow focus – doing one thing well
Disease/epidemiology targeted

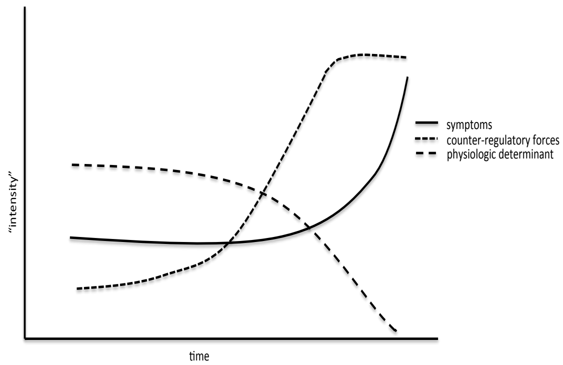
IV. THE CHALLENGE OF CHRONIC DISEASE

Health is very personal. To be able to participate in someone else's healthcare is a privilege not lightly granted and easily violated. Accordingly, for a remote patient monitoring system to be accepted in communities several characteristics have to be fulfilled. Table 1 identifies some of these characteristics. Broadly speaking, these characteristics are subsumed under the larger heading of "cultural competence." This means that, among other things, it is important that the population using remote sensing devices be active participants in the design of systems, accumulation of data, processing of data, implications of geospatial mapping, and the determination of research, if any, emanating from the system. Regardless of the obvious ethical issues at hand, remote patient monitoring systems will fail to impact the health of the population if they are developed and disseminated independent of the population for which they are intended. This imperative includes the participation of the medical establishment (however it is defined by the community) without whose active support and encouragement an intervention is unlikely to succeed. Although such anthropological and sociological considerations are sometimes elided in the planning of a technology intervention, it is not legitimate to begin without in-depth consideration of these factors.

As is now evident, remote bio sensing systems with or without geospatial information systems present substantive challenges not encountered in typical telemedicine. Tele-dermatology, teleradiology, and even tele-psychiatry require high fidelity images or information or voice to be transmitted from a user (professional or "patient") to a medical source. For example, a teleradiology installation may acquire images under the supervision of a technologist and transmit those images to a radiologist for interpretation. The information is then returned to the clinician who ordered the study and who makes the clinical correlation. Similarly, in tele-dermatology, a skin image is transmitted from a healthcare professional to a consulting dermatologist for interpretation. Once again, the interpretation or diagnosis is reflected back to the healthcare professional who prescribes a course of therapy based on the information. In chronic disease, the information must be immediately useful for the person with the illness independent of professional supervision.

This is akin to the type of information generated from a finger stick blood sugar determination in an experienced diabetic. The diabetic has a heuristic that has been developed in consultation with a healthcare professional allowing him or her to make meaningful decisions about diet, exercise, and drug dosing based on the readings obtained. While the healthcare professional may review these data at periodic visits, moment-to-moment involvement is neither necessary nor desired. Remote patient sensing provides the same type of information to the user served up in a form that allows meaningful decisions to be made. Ideally, remote patient monitoring can serve as a substrate for prevention of deterioration of chronic disease.

Chronic illnesses are characterized by stability punctuated by episodes of decompensation. Often, these decompensation events are presaged by alterations in physiology that may be subclinical, and thus go unnoticed by the person with the illness. For example, it is known that patients with chronic congestive heart failure often have measurable declines in their cardiac output days prior to the clinical appearance of symptoms. The clinical symptoms are a result of a failure of these compensatory mechanisms as shown in Fig. 2. From this diagram it is evident that there is opportunity for detection in advance of the decompensation if the appropriate parameters are determined at the appropriate time and they are acted upon judiciously. In order for this to occur, biosensors must be able to detect not only the effects of the decompensation but also the counter regulatory forces. This requires an intimate understanding of pathophysiology coupled with the engineering challenges of limits of detection and signal-to-noise evaluation. With these problems solved, however, assessment of physiologic



although the physiologic alteration has been apparent for some time. Only when the counter-regulatory forces fail to compensate do symptoms appear.

parameters allows the user to make informed judgments about varying medication regimens and to seek additional medical care based on personally designed heuristics. When these physiologic parameters are determined in the context of knowledgeable and authoritative community health workers, the outcome of improved management of chronic disease, decreased utilization of resources, and improved health of the community at large can be realized.

V. Case Study: The Blue Scale

About 5 million Americans suffer from congestive heart failure (CHF), causing great public health burden and >$40 billion in annual costs, including more than $20 billion in hospital days alone. But CHF is not a problem for developed economies alone. Worldwide, heart failure's incidence is rising, for three main reasons, 1. generally improvement in the treatment of cardiovascular disease, 2. an aging population in many countries of the world, and 3. changes in lifestyle worldwide with attendant increasing rates of diabetes, metabolic syndrome, and particularly coronary artery disease [12].

An estimated 50-60% of CHF hospitalizations are avoidable through proper self-management [13], and studies show that in-home monitoring of CHF patients leads to better clinical outcomes. However, most currently available in-home CHF monitors are prohibitively expensive, provide only one-way communication, and are difficult for elderly and underserved patients to use.

Thus, technology alone cannot solve the problem of unplanned readmissions for exacerbations of chronic illness. Technology-enabled case management, though, in the context of an ecosystem where the patient is an active participant, has the promise of being able to anticipate a decompensation event by identifying early, subclinical signs, thus transforming a 2 AM emergency into a 10 AM urgency.

To this end, we have established a collaboration around a non-invasive device (the Blue Scale) developed in our laboratories that focuses on technology-enabled disease management in heart failure (CHF). This integrated approach involves the hospital, clinicians, engineers, and Technology for All (TFA), a community organization leveraging the benefits of ubiquitous computing in under-resourced environments. This unique collaboration has a track record of success and is the core of a NSF award now in its third year.

The Blue Scale is a wireless personalized CHF-monitoring device that is easy-to-use, inexpensive, scalable, and is designed to improve clinical outcomes in under-resourced communities. The development process that led to a device relied heavily upon community-based participatory research and usability studies in an under-resourced Houston community.

The Blue Scale form-factor is a cardiac-monitor in a modified bathroom scale, a form that is immediately intuitive for CHF patients. The low-cost device comprises a scale, a photoplethysmograph, a 4-lead EKG, and 2 bioimpedance sensors. Algorithms calculate weight, systolic time interval, blood pressure and R-R interval variability and calibrate them directly to an individual allowing for early warning of decompensation.

The results of in-hospital validity trials and a usability study in an inner-city under-resourced Houston neighborhood show that the Blue Scale is clinically reliable and relevant, and meets the needs of elderly patients in the real-world by providing two-way connectivity and long-term, personalized health data trends. We have completed software and hardware design and development, including database management, data transmission, Web-based user-interface and the backend solution. In-home beta testing of the Blue Scale will identify CHF patients as they near discharge from the acute care hospital, introduce them to the technology while they are inpatients, install it in their homes, and provide a rigorous case management structure that includes the primary care physician and community health workers. Evaluation will be performed using instruments employed by TFA to gauge the acceptance and use of the device. Outcomes will be assessed using clinician and patient satisfaction, clinician interactions, and readmission rates.

VI. Conclusion

Deployment of remote biosensors in the context of chronic disease management contains numerous challenges not seen in general telemedicine. However, these are not insurmountable. Attention to cost, the ethics of intervention in health, the understanding of trust and caring, and a deep understanding of the relationship of physiologic parameters can provide an intervention at scale for low resource areas to alleviate the coming epidemic of chronic disease.

Acknowledgment

This material is based upon work supported by the National Science Foundation under Grant No. 0751165 (C. C. D. and E. K.). C. C. D. acknowledges support from the Morrie and Rolaine Abramson Family Foundation and the John S. Dunn Sr. Research Foundation, both of Houston, Texas, USA.

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