Fighting Diabetes with Information: 
Where Social Informatics Meets Health Informatics

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ABSTRACT
This abstract sets out a research agenda for information scientists and technologists interested in the interrelationships among patients, health care providers, and information technology. Using the complex and costly diagnosis of diabetes as a vehicle for exploration, this work suggests addressing a set of problems that will improve the lives of patients, their families, and friends, as well as making the provision of diabetes care more effective and cost efficient. Information technology tools and methods are used, but with sensitivity to the social and organization complexities of health care. I-Schools graduates, with their interdisciplinary mindset, social science methodologies, and familiarity with IT and its applications can increase the success rate of IT interventions in health care. Topics include public health and community informatics, knowledge dissemination, information alerts, decision support, clinical guidelines, health literacy, patient, pharmacy, and laboratory feedback systems, interface design, reminder systems, consumer informatics, and privacy and security issues.

Categories and Subject Descriptors
J.3 [Life and Medical Science]: Health, Medical Information Systems

General Terms
Management, Documentation, Design, Economics, Reliability, Security, Human Factors, Legal Aspects

Keywords
Information research, diabetes, informatics research, public health and community informatics, knowledge dissemination, management alerts, information alerts, decision support, health literacy, technological literacy, patient feedback systems, pharmacy feedback systems, laboratory feedback systems.

1. INTRODUCTION
Careful study of the complex interrelationships among people, information, and technology holds great promise for improving American health care. Health care professionals have attempted to use various forms of information technology (IT) to improve the fragmented health delivery system for decades, but financial resources, technical expertise, and interdisciplinary research by information and health researchers have been scarce. The Obama administration has decided to infuse billions into health information technology (HIT). Here, finally, is a chance to “jumpstart” the process of improvement. But do information researchers really know how to spend this money? Will they deploy it effectively? Are technologists and health care professionals actually ready to join forces to create effective new solutions for patients?

This research examines several information challenges associated with Type 2 diabetes to allow information researchers unfamiliar with healthcare to observe the social and organizational factors in the ebb and flow of information around complex diagnoses. Diabetes is a widespread, debilitating and expensive disease. The Centers for Disease Control and Prevention estimated the prevalence of diagnosed and undiagnosed diabetes in the United States in 2007 at all ages was 23.6 million people or 7.8% of the population. The Center further estimates that at least 57 million American adults had prediabetes in 2007 (Centers for Disease Control and Prevention 2007). Prediabetes is a condition in which individuals have blood glucose levels that are higher than normal but not yet high enough to be diagnosed as diabetes (American Diabetes Association 2007).

The American Diabetes Association reports that $174 billion was spent on diabetes in 2007, which is $42 billion more than was spent in 2002 (Berger 2007; American Diabetes Association 2008). The indirect costs of diabetes due to reduced performance, lost productivity, early mortality, and disability are estimated at close to $58 billion (American Diabetes Association, 2008a; Berger, 2007). Diabetes also takes a high toll on individuals and families. Medical expenses of patients diagnosed with diabetes are 2.3% higher than those who do not have the disease (American Diabetes Association, 2008). In 2007, the per capita annual health care costs for people with diabetes were estimated at $11,744 per year (American Diabetes Association, 2008).

The management of diabetes requires a partnership between health care providers and patients that is largely driven by information needs. Health care providers, patients, and families must all be armed with adequate information to attenuate risk factors, make the almost daily essential adjustments in diet, exercise, medications, and manage complications that are required to return people with diabetes to good health. While major advances are being made in metabolic and pharmacologic science,
there has been no systematic assessment of patients’ information and technology needs and how to go about addressing them. This abstract focuses on some of the initial efforts that information scientists and technologists have made to help patients with diabetes, as well as a resulting research agenda that will soon be published in collected form. An examination of diabetes will allow information scientists to explore the use of information technology as a tool to manage any kind of chronic illness.

Methods

Utilizing literature review, the authors identified five domains of the disease that lend themselves to the identification and provision of important information. These areas of inquiry are: (1) risk assessment and mitigation (2) pre-diabetes (3) receiving and assimilating a new diagnosis of diabetes (4) understanding, preventing, and managing complications of diabetes and (5) end-stage disease

Medical, nursing, information science and technology researchers working in the area of diabetes were then identified and asked to discuss the complex interrelationships among genetic and environmental factors; patient characteristics; health care provider knowledge and behaviors; and the information and technology needed to manage these complexities to lead to better health outcomes for persons with diabetes. These discussions provide a robust framework for an information research and teaching agenda to address these critical information needs.

Results

The research and development agenda emanating from this work is organized into six sections of an edited book currently in press (Hayes and Aspray 2010). The work begins with an overview of improving all aspects of diabetes care through information technology. Ensuing chapters examine early efforts to create and adapt technologies to improve diabetes care. They are organized into sections on ubiquitous computing; using educational gaming to educate and treat diabetes; other technological explorations of diabetes care; using technology to improve patient access to information; and methodological and theoretical considerations.

The last chapter of the book examines these kinds of collaborations, their challenges, and ways to foster them. The disciplines of health care and technology differ greatly in their approaches to problems, training, and publishing. Health care professionals are used to “running the show.” They have extensive content knowledge. Information technologists can gauge how difficult it may be to build and deploy useful tools and they have more knowledge of usability as it applies to digital tools. Health care providers, technologists, and patients who have firsthand knowledge of the disease must all come together at the drawing board in an interdisciplinary, collaborative way.

Using the complications of diabetes for illustration, it becomes apparent that there are many ways in which technology may be applied to help patients cope with disease burden. The following table provides examples:

<table>
<thead>
<tr>
<th>Information Need</th>
<th>Technology Intervention</th>
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<tbody>
<tr>
<td>Information exchange/sharing among multiple specialists</td>
<td>“Hand-off” systems incorporated into digital electronic records</td>
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<tr>
<td>Education for patients dealing with ophthalmologic, cardiovascular,</td>
<td>Assistive information technologies built to accommodate poor</td>
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<tr>
<th>Information Need</th>
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<tr>
<td>Barriers to visiting providers because of increasing infirmity or episodes of illness</td>
<td>Secure communication portals and mobile devices that can upload and assess data on patient status</td>
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<td>Coordinating care of patients taking multiple medications and visiting multiple healthcare providers</td>
<td>Decision support systems that can give visual “snapshots” of patients’ recent care and advise generalist physicians on specialty topics</td>
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<td>Ways to monitor frail patients in their homes</td>
<td>Sensors/ubiquitous computing to provide in-home monitoring</td>
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Significance

Information technology has had an impact on health care, but only at the most superficial level. IT is used primarily to document episodes of care and secure payment for care. It has often fallen short as a tool to support medical decision making and improve the lives of patients and their families (Committee on Engaging the Computer Science Research Community in Health Care Informatics 2009). Opportunities abound to build transformative, intelligent information systems that meet the needs of sick people. At the same time, we risk squandering huge sums of money on poorly designed systems that fail to meet those needs because they underestimate the complex social and organizational health care milieu. This book is a beginning effort to inform those efforts.

References


