provided by AIS Electronic Library (AISeL

Association for Information Systems AIS Electronic Library (AISeL)

AMCIS 2007 Proceedings

Americas Conference on Information Systems
(AMCIS)

December 2007

A Grounded Theory Approach to Investigate Patient Empowerment in E-Healthcare

Sherrie Cannoy University of North Carolina Greensboro

A. Salam *UNCG*

Lakshmi Iyer The University of North Carolina at Greensboro

Follow this and additional works at: http://aisel.aisnet.org/amcis2007

Recommended Citation

Cannoy, Sherrie; Salam, A.; and Iyer, Lakshmi, "A Grounded Theory Approach to Investigate Patient Empowerment in E-Healthcare" (2007). AMCIS 2007 Proceedings. 299.

http://aisel.aisnet.org/amcis2007/299

This material is brought to you by the Americas Conference on Information Systems (AMCIS) at AIS Electronic Library (AISeL). It has been accepted for inclusion in AMCIS 2007 Proceedings by an authorized administrator of AIS Electronic Library (AISeL). For more information, please contact elibrary@aisnet.org.

A Grounded Theory Investigation of Patient Empowerment in E-Healthcare

Sherrie Drye Cannoy A.F. Salam* and Lakshmi Iyer

University of North Carolina Greensboro
Information Systems and Operations Management
PO Box 26165
428 Bryan Building
Greensboro, NC 27402
336-334-5666 Dept.*
amsalam@uncg.edu
sdcannoy@uncg.edu
lsiyer@uncg.edu

Abstract

Emerging technological innovations such as electronic health records (EHRs), regional health information organizations (RHIOs), and the nationwide health information network (NHIN) have enabled increased sharing of medical records in the healthcare community. Recent studies have shown that patients do not trust their healthcare providers to keep their medical records safe from unauthorized release and want more control over their medical records. Patients seem to have focused their attention on negative media stories of information disclosures, both inside and outside of the healthcare community. Therefore, the notion of patient/consumer empowerment has emerged within the healthcare community's discussions regarding sharing of medical information and development of policy and technological innovations. In this research, facets of patient empowerment in e-Healthcare will be investigated through a Grounded theory approach to analyzing documents from both United Stated federal and state patient empowerment groups.

Keywords: patient, empowerment, healthcare, grounded theory, privacy, security

Introduction

"I think it is very important we make certain the consumer voice is heard." -Healthcare Consumer Empowerment Group member (Transcript Feb. 21, 2006)

The United States healthcare industry is currently experiencing a technological transformation. Due to recent technological advances, information can be shared among many healthcare providers with the goal being reduced medical errors and increased quality of care. With U.S. legislative mandates and calls for the adoption of a Nationwide Healthcare Information Network (NHIN), RHIOs (Regional Health Information Organizations), EHRs (Electronic Health Records), and PHRs (Personal Health Records), the awareness of patient empowerment is emerging. A survey by the California HealthCare Foundation (Broder, 2006) found that most consumers want to have control over who accesses their medical information. Janlori Goldman, privacy advocate and member of Health Privacy Project (1999) calls for a "reversal of the technological status quo by demanding that technology be designed to empower individuals" by shifting the balance of power between "the individual and those seeking personal information" for example, through giving control of medical information to the patients to decide how it will be shared across organizations such as Regional Health Information Organization (RHIO) and U.S. Nationwide Health Information Network (NHIN), both of which enable the infrastructure for sharing patient information across organizations such as hospitals and provider offices. Empowerment would enable self-determination of how and what medical information the patient chooses to share. Ultimately, a patient's trust in the security and privacy of their medical data will affect how they share their information, and, currently what is not clear is patients' awareness of "trade-offs between legitimate concerns about their privacy and the benefits of making more complete information available to the providers" so that they can provide optimal care based on more comprehensive information (Tang and Lansky, 2005).

There are generally three different types of e-Health technology which are used to store patient health information—the EMR, EHR, and PHR. The EMR (electronic medical record) is the electronic equivalent of existing paper medical record, typically used within one organization (Larsen, 2006). The EHR (electronic health record) is a 'secure, real-time, point-of-care, patient-centric information resource for clinicians' (Handler et al., 2003), which allows sharing of patient information between organizations for improved quality of care. President Bush has mandated that healthcare organizations adopt an EHR by 2014. The PHR (Personal Health Record) is 'an electronic application through which individuals can maintain and manage their health information. . .in a private, secure, and confidential environment' (ONR, 2004). "Since this [PHR] approach empowers individuals to control all access to their own health information, it gives each consumer freedom to establish their own personalized privacy policy" (Enrado, 2006) and decide how it will be shared across organizations such as the Regional Health Information Organization (RHIO) and U.S. Nationwide Health Information Network (NHIN), both of which enable the infrastructure for sharing patient information across organizations such as hospitals and provider offices.

Research is needed to examine the variety of perspectives involved in these disparate communities for healthcare stakeholders such as patients, providers, legislators, and other organizations regarding patient empowerment in healthcare in the U.S. From literature reviewed in the healthcare, marketing, management, information systems, and sociological disciplines, we found that the concept of empowerment has many dimensions and that more importantly no well-defined theory for conducting research studies in e-Healthcare regarding patient empowerment exists. Since there is no theory on

Cannoy, Salam, Iyer—Grounded Theory and Patient Empowerment in e-Healthcare

patient empowerment in e-Healthcare (according to authors' knowledge), we here attempt to develop a preliminary theory of patient empowerment using the Grounded Theory research methodology and pose the following research questions:

- 1. What is the possible set of dimensions or factors of patient empowerment?
- 2. How do the perspectives of the stakeholders involved in e-healthcare affect consumer empowerment? And can we identify some stages through which stakeholders need to move to enable patient empowerment?

For the purpose of this study, e-Healthcare is defined as sharing of patient information in EHRs and PHRs among organizations through a RHIO or NHIN network. Since empowerment is the core focus of this investigation, we begin with a review of empowerment literature as it relates to the power of patient information, then discuss the grounded theory approach, data collection, analysis, and preliminary findings.

Literature Review

Given that empowerment is our central focus, we draw definitions of empowerment from healthcare, management, information systems (IS), marketing and sociology research streams.

Empowerment in Management and IS

Wilkinson (1997) suggests that although empowerment has been studied in management literature, it has not been studied in a historical context. From a managerial and IS perspective, the emphasis on modern empowerment began in the late 1980s through the management of organizational culture, creation of teamwork and employee involvement in innovation efforts to ensure that the company was profitable. For example, participatory design in information systems and knowledge management were key IS issues which were to empower employees while also creating a more efficient and profitable firm (Sjoberg et al, 1998). In the e-Healthcare context, lessons for participatory design and knowledge sharing for innovation can be utilized to provide feasible and user-friendly PHRs by conducting an examination of what features and capabilities the patients want from PHR technology.

Empowerment in Marketing

Inherent in the function of the empowerment and its benefit to those involved is the aspect of power. The aspect of empowerment in the marketing literature focuses primarily on the concept that consumers can enforce their power through marketplace economics (Shaw, Newholm, and Dickson, 2006; Wathieu et al, 2002). This suggests that the more choices the consumer has in their purchases, the more they are able to exercise power through consumption choices (Shaw et al, 2006). The purchases consumers make in the marketplace reflect their values, in an attempt to influence the suppliers. However, this premise presumes two things: that everyone has the same capacity to make the same types of choices, and that consumers are aware of the "re-configuration of power relationships that are emerging between consumers and producers" (Shaw, et al, 2006, pg. 1062). Shankar et al (2006) state that the lay view of consumer empowerment assumes that the power is shifted from producers to consumers and, since consumers know what they want, empowerment is beneficial to consumers. According the Shankar et al (2006), this also assumes that consumers are rational utility maximizers in making choices.

Such a marketplace and consumption situation discussed previously by Shaw et al (2006) therefore creates a further gap in the disparity between those who can afford to purposely choose another vendor, even if their product is more expensive, than someone who cannot afford to make that choice. There has been no determination of a model to provide

funding and resources for patient empowerment in e - Healthcare, either through the availability of technology or money for PHRs. Although insurance companies and employers have been the target stakeholder to provide PHRs to patients, this increases the disparity of those patients who are unemployed or uninsured.

Empowerment in Sociology

Typically empowerment is examined sociologically by Rose (1999), Foucault (White, 2002), Parsons (White, 2002), and Marx (Kemka, 1983) as being perspectives of disparity in power, class, and control through surveillance. One way that the government and organizations can enact social control is through the control of information. Foucault, who perceives institutional medicine as a form of social control rather than healing states that surveillance of citizens is the "organization of information that can be stored by agencies and used to monitor the activities of an administered population. . . . [and that] modern medicine is a manifestation of an administered society in which the centralization of information about citizens is essential for social planning" (White, 2002, pg. 118-119) such as biosurveillance. Ultimately, empowerment in a sociological sense is socially constructed (Berger and Luckman, 1966) and is "an outcome of changes in fundamental structures and relations of power" (Anderson, 1996), whether instigated by those in control or those being controlled. Historically, the healthcare provider has controlled access to patient information, and this shift of control and access to the patient through PHRs also signifies a drastic shift in power from the provider to the patient.

Power of Patient Information

Traditionally, records in the healthcare industry have been paper-based, enabling strict accessibility to records. Due to advances in technology, managing the large amount of information involved in patient care has become much more important. Therefore, information has, in essence, become the 'key organizational currency' for which companies need to manage and control to 'harness the power of the politics' which comes from such control (Davenport, et al, 1992). Davenport suggests that as information becomes the 'basis for organizational structure and functions, politics will increasingly come into play' (pg. 54). Politics have become more important in the control and access of healthcare information, both internal and external to the organization.

From a preliminary search of privacy regulations it seems that there is no law to state who actually owns the patient medical record. Because control of either the paper-based medical record or electronic medical record is in the provider's hands, traditionally, the question has been that of patient access to the record rather than ownership. The American Medical Association (AMA) and state medical boards address the access issue only and advise that "medical records are confidential documents and should only be released when permitted by law or with proper written authorization of the patient. . .physicians are responsible for safeguarding and protecting the medical record and for providing adequate security measures" (www.ncmedboard.org). Also addressed is the fact that "physicians should not relinquish control over their patients' medical records to third parties unless there is an enforceable agreement that includes adequate provisions to protect patient confidentiality and to ensure access to those records" (www.ncmedboard.org).

There are concerns which have risen to question how PHI information will be shared. Currently, the patient gives a "blanket statement" for a single entity, but patients may not want to give such generic access across healthcare entities.

HIPAA (Healthcare Insurance Portability and Accountability Act of 1996) privacy policies will need to be edited to allow for different types of opt in/out procedures when more than one entity is involved. Technology must also be in place so that

PHI is not shared electronically with other entities when the patient opts out of sharing information with specific entities. Rep. Patrick Kennedy is interested in providing legislative assistance for providing opt-out clauses for patients and restoring the right of patient consent, along with better audit trails for patient knowledge of how their information is disclosed and improved enforcement of laws (Hayes, 2006). Technology such as the PHR gives a feeling of empowerment to the patient for control of their information as well as increased participation in the healthcare process.

Empowerment in Healthcare

In literature, empowerment has been viewed as self-determination over one's own life (Geller et al, 1998) as a result of having access to information and resources to enable an informed choice (Wowra et al, 1999). However, most healthcare-related literature discusses patient empowerment in four different contexts:

- 1. of e-Healthcare web sites and the availability of patients to access treatment on the web regarding their treatments, diagnoses, and support group options (Luo and Najdawi, 2004))
- 2. of specific areas such as mental health and enabling patients to recover with a sense of self-determination (Wowra et al. 1999)
- 3. of sharing information to organizations outside of the healthcare providers for secondary purposes such as genetic research (Botkin, 2001)
- 4. of health disparities and giving consumers more choices, power, and resources to reduce disparities (Anderson, 1996)

Empowerment holds multiple interpretations for the marketplace and business, the community, the public sector and the political system (Osborne, 1994), and over time, these interpretations have changed (Wilkinson, 1997). Our definition of e-Healthcare will examine empowerment in the technological realm of the EHR (electronic health record), RHIO (regional health information organization), NHIN (national health information network), and PHR (personal health record). For e-Healthcare, this involves analyzing patient access and control of *their own medical records* for self-determination of who the information will be shared with and for what purpose, based on the technology utilized. This is inherently different than empowerment that has previously been researched in the context of patients accessing internet information for health education purposes.

Implications from Literature

The implication of the consumer empowerment literature in healthcare, marketing, management, information systems, and sociology for this study is important. As Shaw (2006) and Shankar et al (2006) suggest, power is often seen as being transferred from the producer to the consumer. To examine power and how it is held and transferred is important in e-Healthcare because traditionally the healthcare provider has held power, especially in the doctor/patient relationship. For a transfer of power to take place, the perspectives of the doctor, patient, and other stakeholders such as insurance companies, legislators, and pharmacies needs to be examined. Because there is no existing theory for patient empowerment in e-Healthcare, data that are rich and detailed in description are needed to be the source and foundation for such a theory. "We need consumers as part of the equation" as well as providers, legislators, advocacy organizations, and other healthcare stakeholders to create a more comprehensive view of patient empowerment (Hayes, 2007). Since grounded theory research methodology allows one to develop new theories where none exist, from data that is rich and detailed in description we use grounded theory in our research. Using grounded theory, this research examines patient empowerment in the context of e-Healthcare by analyzing meeting transcripts of a Consumer Empowerment Group led by a U.S. government effort.

Research Methodology

Grounded Theory Approach

We use the grounded theory approach to propose a tentative theory for patient empowerment in e-Healthcare since no such theory currently exists. Grounded theory is appropriate to use when there is no theory or if a phenomenon is not clearly understood, and such an approach seeks to better understand human behavior and experience (Bogdan and Biklen, 2003). Glaser and Strauss (1967) suggest that the grounded theory approach is the purposeful "discovery of theory from data systematically obtained" (pg. 2). Table 1 references some of the relevant articles from IS research in which grounded theory approach is used in different contexts.

Data Collection

The primary source of data for this phase of research is from the American Health Information Community (AHIC) group formed by the U.S. Department of Health and Human Services. "The American Health Information Community (AHIC) is a federal advisory body, chartered . . . to make recommendations to the Secretary of the U.S. Department of Health and Human Services on how to accelerate the development and adoption of health information technology" (http://www.hhs.gov/healthit/). AHIC formed the Consumer Empowerment group to make recommendations for widespread adoption of a personal health record that is "easy to use, portable, longitudinal, affordable, and consumer-centered" (Transcript, Feb. 21, 2006). These Workgroup meetings are held on a monthly basis and are open to the public; therefore, members of the public have access to detailed documentation such as minutes and transcription contents. Document analysis can be performed on these materials, which include agendas, testimony hearings, workplans, meeting summaries, transcripts, and streaming archives. Participants in the Consumer Empowerment Group include individuals representing patient advocacy organizations, the Department of Health and Human Services, insurance companies, vendors, and the Centers for Medicare and Medicaid Services. For this preliminary analysis phase, only the meeting transcriptions are analyzed. Other documents such as presentation slides and articles supplied by AHIC members for supporting evidence will be included in the next phase of this study. It is anticipated that the content of these meetings can provide a preliminary conceptual foundation for the factors driving patient empowerment in e-Healthcare.

Table 1--Examples of Grounded Theory Approach Used in IS-Related Studies

Source	Concepts Studied
De Vreede et al, 1998-1999, <i>Journal of Management</i> Information Systems	Acceptance of GSS
Orlikowski, 1993, MIS Quarterly	CASE Tools and Organizational Change
Crook & Kumar, 1998, Information and Management	EDI Use in Multiple Industries
Sjoberg et al, 1998, Journal of the American Medical Informatics Association	IS Participatory Design in Healthcare
Scott, 2000, Journal of Management Information Systems	Interorganizational Learning
Galal, 2001, European Journal of Information Systems	Operationalizing Contingent Process Models
Sarker et al, 2001, DATA BASE	Virtual Team Development
Pauleen, 2003, Journal of Management Information Systems	Virtual Team Leader Relationship Building
Zahedi et al, 2006, Journal of Management Information Systems	Cultural Aspects of Web Documentation

Analysis

Using the grounded theory approach, we have analyzed the data by examining the source documents carefully, and using the constant comparative method to begin generating concepts for theory. The constant comparative method is one in which, "both implicitly and explicitly, the analyst continually checks out his theory as the data pour in" (Glaser and Strauss, 1967, pg. 26). In essence, the researcher performs joint coding and analysis at the same time by using systematic procedures (Glaser and Strauss, 1967, pg. 102). Initial open coding is includes developing concepts and overall categories that emerge from the data. The second type of coding is axial coding in which the relationships between these categories are examined. The third type of coding is to examine the open and axial coding, and with the insights developed from thoroughly investigating the data, developing parsimonious categories and their relationships (Glaser and Strauss, 1967).

For the current study, an initial analysis was performed on one year of AHIC meeting transcripts (Jan. 2006 to Jan. 2007), which included 495 pages of meeting notes. The documents were reviewed for content and context so that codes generated are grounded in the data. The transcripts were entered into the qualitative software package, QSR NVIVO 7.0 to make the management of the data and analysis and coding more effective. Included in NVIVOs functionality is the ability to code across documents to investigate the data for open codes. As the transcripts were analyzed manually for content, NVIVO was utilized to hold open codes generated during the analysis. A constant comparative analysis was performed between the transcript data and the open codes to determine the context of the open codes being generated. As the analysis progressed, the open codes were grouped into similar concepts. For example, consumers and patients were grouped together as the concept Consumer. From this analysis, six concepts were generated.

Preliminary Research Results

Based upon the context of the documents and concepts that emerged frequently during the meetings and were emphasized by AHIC members as being important, the following open coding map (Figure 1) was generated. It includes the initial open coding concepts in shaded blocks—Consumers (here we use interchangeably with patients), Record, Policy, Stakeholders, Technology-Related, and Action-Related. Underneath each concept block are associated terms which were aggregated underneath each concept. For example, the concept for Record also was associated with the concepts of information and data included in a patient's medical record. Underneath each concept and its associated items are preliminary attributes associated with each concept. For example, for information included in the patient's medical record, the transcripts often referred to it as being sensitive, or shared for primary or secondary purposes, as well as being portable for the patient to transfer to each healthcare provider's office.

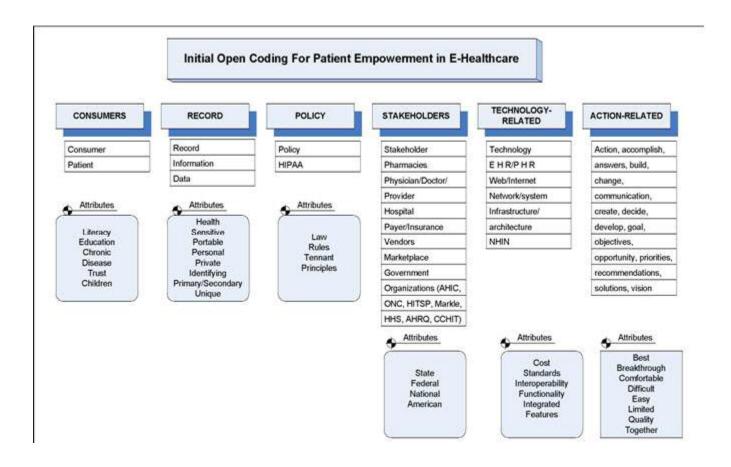


Figure 1--Open Coding from Data with Associated Terms and Attributes

These concepts reveal that empowerment for patients in sharing their healthcare information between stakeholders may be related in some manner to the type of medical information in the record, trust between the patient and other stakeholders, privacy and security policies such as HIPAA, and to the features of technology such as the personal health record (PHR) and the Nationwide Health Information Network (NHIN). From the frequently discussed proposed actions, the Consumer Empowerment Workgroup seems to be dedicated to the cause of encouraging empowerment issues and making recommendations to the AHIC Community Group. Since qualitative approaches such as grounded theory should be rich in description, quotes from the AHIC minutes are given in

Table 2 to support the reasoning for these conceptual categories.

Table 2--Foundational Quotes from the Data for Each Open Coded Concept

Concept	Supporting Quotes
Consumers	"When I look at these issues, and when I put the lens on that, this is a consumer empowerment issue. I think a lot of these can be addressed if we kind of stead fastly maintain that the focus of this is in giving the patient control" (Transcript, Jan. 10, 2007)
Record	"And I think that since our broad charge is really sort of all encompassing when it comes to personal health records and our recommendation should be addressing interoperability, affordability, patient-centric focus in terms of making sure PHRs meet the needs of consumers, and making sure that these records are longitudinal from birth to death." (Transcript, Nov. 28, 2006)
Policy	"Just building on that and some of the comments that David Lansky madedescribing that very comprehensive but unreadable privacy policy. A role that we could play as well, or some entity, presumably us, would be as you find that idealized language about what the lawyers need to see to say yep, this is a policy that does have consumer protections built into it, is for the major components of that, create a language that would be understandable concepts in the public environment, what do you say, privacy should have commonly understood meaning among all vendors and some phrase that says when it says your data will be made available and in anonymized fashion for secondary uses, that there's a phrase for that that can be in 4th-grade readable kind of terms." (Transcript, Jan. 10, 2007)
Stakeholders	"If we look at related Federal efforts and resources, although CMS and VA and DOD and OPM have access to different types of health care information. Each operates under different legislative authorities and regulatory schemas. The DOD uses clinical data and counterdata claims data from external providers and information on eligibility, whereas OPM has only eligibility and benefit information available. CMS has both eligibility, benefit data, and claims but no access to patient-specific clinical information" (Transcript, Jan. 30, 2006)
Technology- Related	"ideally personal health data can be exchanged among PHRs and EHRs under the control of the patient while preserving the meaning of the data. And what I tried to do there is to address this movement of data between and among PHRs and EHRs, which I think everyone just said they agreed with, while preserving the controls for the patient, and the interoperability, which is preserving the meaning of the data." (Transcript, Jan. 10, 2007)
Action-Related	"Nancy, I want to congratulate you for really identifying — and ONC staff as well here — really identifying how quickly we come upon and confront all of these policy issues. They really are an important crux of what has to be addressed in order to have a real breakthrough here." (Transcript, Jan. 30, 2006)

Based on this initial analysis of coding and relationships, a theory of patient empowerment in e - Healthcare is proposed.

Proposed Initial Theoretical Model of Patient Empowerment

One aspect that seems to unfold from this initial analysis is that empowerment is a multi-dimensional and complex concept. There are most likely other concepts that may emerge through additional coding, such as barriers, which may overlap with other concepts because policy and technology, for example, could each create barriers to the sharing of medical information. The next steps of clarifying the initial coding and then conducting axial coding for the relationships help generate theory for the relationships between the concepts.

Figure 2 shows our proposed framework for stages of patient empowerment. The activities to improve empowerment at each stage--information sharing, attitudinal shaping, efficient problem solving, self-management, and task autonomy—have been utilized by Wilkinson (1997) to examine empowerment in a historical, activity-based context. Stage one of the process is to involve the stakeholders by sharing information regarding the technology and privacy issues related to e-Healthcare and to shape attitudes among the stakeholders such that efficient problem solving and active participation can

occur to achieve quality healthcare. Attitudinal shaping needs to occur to enable the patient to control appropriate sharing of accurate information for improved quality of care. In essence, information sharing and problem solving are mediated through attitudinal shaping.

In stage two, the goal is to allow patients to control and access their medical records to share information in such a way that they become self-managers and achieve task autonomy with the technology. This will allow the patients to be more empowered and in patients becoming more proactive in managing their own health through preventive medicine that allows them to remain healthy for a longer time. This will allow for a more economically efficient healthcare system. As one member of AHIC said during the meeting, ". . . . it is our hope that electronic personal health records will focus in on managing the patient, not the disease or disability, providing a much more holistic view leading to major improvements for clinical health outcomes for these individuals" (Transcript, Sept. 18, 2006). We propose that these activities should ultimately lead to patient empowerment.

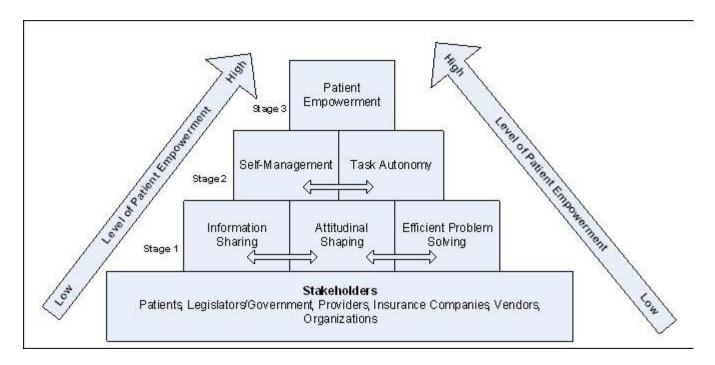


Figure 2--Stages of Patient Empowerment in e-Healthcare

In order to achieve the stages of patient empowerment (shown in Figure 2) by the relevant stakeholders, we present the tentative theoretical model for patient empowerment in e-Healthcare in Figure 3.

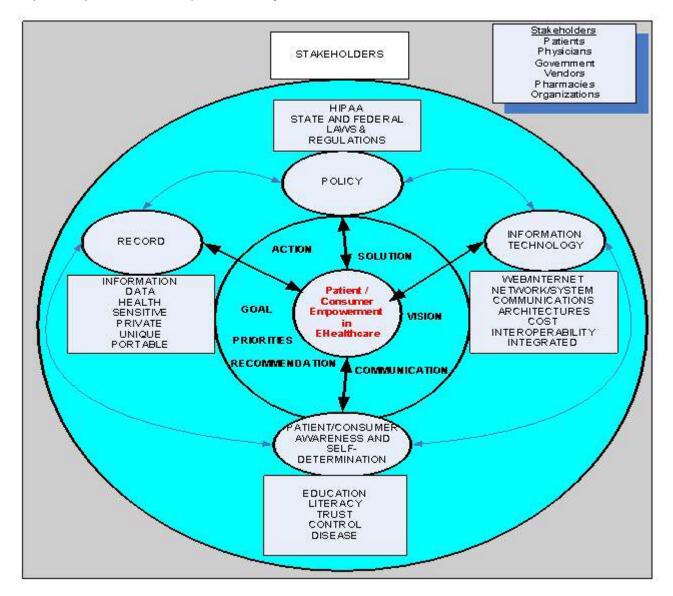


Figure 3--Theoretical Model for Patient Empowerment in e-Healthcare

In this tentative theoretical model, we have both internal (to providing healthcare) and external (for secondary data purposes outside of providing healthcare, such as clinical researchers) stakeholders who are interested in patient/consumer empowerment in e-Healthcare. Through our preliminary analysis of the data and the relevant literature on empowerment, we have identified patient/consumer empowerment to be a complex construct. In our model, we identify that policy representing regulations as enacted by federal and state government through active participation of patient/consumer advocacy groups affect the policy construct that has a direct bearing on patient empowerment. For example, HIPAA itself is not sufficient to empower patients in e-Healthcare and we need either modification or additional regulations that will truly empower patients and make them active participants in the healthcare system (Stein, 2006). On the part of the proposed model, we have a patient/consumer awareness and self-determination construct that we believe is also critical for patient empowerment. Without patients being aware and fully educated in terms of the level of control that they have, it seems critical that effective education, awareness, and programs be initiated so that patients begin to become aware and feel more self-determined in their healthcare information as participants in the healthcare system. Additionally, the concept of record, which implies information and data

related to sensitive healthcare information of patients, coupled with information technology as a delivery and sharing mechanism for this information among stakeholders, our proposed model brings to the forefront the role of these concepts in patient empowerment in e-Healthcare. From the AHIC meeting notes, the PHR technology was discussed quite often, in terms of getting people educated and informed about PHRs and the technological capability so that they are willing to use the technology self-sufficiently. A member of AHIC stated that for their future plans, there are "a number of critical success factors. One is getting the patient-consumers involved and educated, and advocating for this. Two is getting the docs on to EHRs. Three is having the whole system integrated, because that work flow issue, and the shared information, is what we're after. . . And it's really about the connectivity with the physicians, the patients, the health care team, and the care givers who is going to be really an important force in the not too distant future. It's really about the relationship, not a product, not software, not a technology" (Transcript, Sept. 18, 2006). This supports our proposed states of patient empowerment in e-Healthcare. These four interdependent concepts of patient/consumer awareness, record, information technology, and policy taken together represent the tools in the hands of the stakeholders to achieve patient empowerment in e-Healthcare through specific actions, goals, communication to reach for a solution that truly empowers the patients.

Discussion and Future Research

In analyzing the transcripts from AHIC's Consumer Empowerment Group, there were moments where the committee members realized that focusing on empowerment entailed many issues and the need to emphasize patient empowerment was their main charge. One member stated that "I mean, it seems to me the word "empowerment" should be the watch word of what we're doing here. And rather than saying our goal is to display in front of people a set of data they may or may not have any interest in, we should say what is it people feel empowered by." (Transcript, March 20, 2006). At a meeting on a different date, the conversation returned to the notion of understanding patient empowerment and ensuring that their deliverables were provided with the patient's interest in mind. One member stated that "the comment about taking a step back and looking at the consumer empowerment notion and reviewing the perspective from that look may lead us to want to take a stronger role at defining the consumer's requirements." (Transcript, April 25, 2006). This reveals the need to further understand what patients want and need to feel empowered.

It is anticipated that patient empowerment will likely remain a multi-dimensional construct, and further literature in security, privacy, policy, conflict theory, socio-organizational aspects (such as culture, change, training, enforcement), information as an asset, healthcare supply chain, and business processes will be investigated as a theory of patient empowerment in e - Healthcare unfolds. In the context of patient empowerment in e-Healthcare and the struggle to determine power issues over patient information, literature on intellectual property/copyright and e - commerce opt in and out could be beneficial to examine. As the AHIC documents are analyzed further and focus groups provide additional rich descriptions of a variety of perspectives, previous literature will also enable a foundation for which to generate parsimonious constructs for understanding patient empowerment in e-Healthcare. One AHIC member states this very succinctly, what is needed is to: ". . . [take] all the stakeholders and, from the patient's point of view, make something recommendations about what should be done or what should be researched that will really enhance and bring value to all the work that I don't think anyone else is doing" (Transcript, March 20, 2006). Further examination of these issues will be important to these grassroots efforts for building patient empowerment in e-Healthcare efforts through in-depth investigation of the specific stages of patient empowerment and detailed interrelationships between the stakeholders.

The initial theoretical model presented in this research is the first step towards developing a conceptual model of patient empowerment in e-Healthcare. In this study, we have presented our initial findings about patient empowerment. We plan to investigate the issues identified here further so that we can develop a more comprehensive theory of patient empowerment in e-Healthcare. We hope that this study will stimulate more research in this important area to make the U.S. healthcare system more efficient and effective.

Abbreviated References (full reference list available upon request)

- 1. American Medical Informatics Association (AM IA). (September 14, 2006). *Toward a National Framework for the Secondary Use of Health Data*. Accessed September 2006 at www.amia.org.
- 2. Anderson, Joan. (1996) Empowering Patients: Issues and Strategies, Social Sciences Medicine, 43:5, 697-705.
- 3. Bogdan, Robert C., & Biklen, Sari Knopp (2003) *Qualitative Research for Education: An Introduction to Theories and Methods*. 4th Edition. Allyn and Bacon, Boston.
- 4. Creswell, John. (1998) *Qualitative Inquiry and Research Design: Choosing Among Five Traditions*. Sage Publications: Thousand Oaks, CA.
- 5. Davenport, Thomas, Eccles, Robert, Prusak, Laurence. (Fall 1992) *Information Politics*. Sloan Management Review. 34:1, 53-65.
- 6. Enrado, Patty. (Dec. 18, 2006) *Washington State Unveils Health Data Exchange Map.* Healthcare IT News. Accessed Feb. 2007 at http://www.healthcareitnews.com/story.cms?id=6068.
- 7. Glaser, Barney, Strauss, Anselm. (1967) *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Aldine Publishing Company: Chicago, IL.
- 8. Shankar, Avi, Cherrier, Helene, Canniford, Robin. (2006) *Consumer Empowerment: A Foucaultian Interpretation*. European Journal of Marketing. 40:9/10, 1013-1030.
- 9. Shaw, Deirdre, Newholm, Terry, and Dickinson, Roger. (2006) *Consumption as Voting: An Exploration of Consumer Empowerment*. European Journal of Marketing. 40:9/10, 1049-1067. White, Kevin. (2003) Foucault and the Sociology of Medical Knowledge. *An Introduction to the Sociology of Health and Illness*. Sage Publications.
- 10. Wilkinson, Adrian. (1997) Empowerment: Theory and Practice. Personnel Review. 27:1, 40-56.