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Finding A Grassroots Voice for Consumer Empowerment in E-Healthcare: A State Level Perspective Using the Grounded Theory Investigation

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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. 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 using a grounded theory approach.

Keywords

patient, empowerment, healthcare, grounded theory, privacy, security, control, access, trust

INTRODUCTION

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).

Research is needed to examine how consumer empowerment plays a role in e-Healthcare. 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 no well-defined theory for conducting research studies in e-Healthcare regarding patient empowerment exists. Since there is no theory on patient empowerment in e-Healthcare, we develop a theory of patient empowerment using the Grounded Theory research methodology and pose the following research questions:

1. What are the dimensions of consumer empowerment in e-Healthcare?
2. How can consumer empowerment be achieved in e-Healthcare?

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 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. Since consumers know what they want, empowerment is beneficial to consumers. According to 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 (Kamenka, 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.

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. 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 patients’ 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. Most definitions in literature view empowerment as “*an intentional ongoing process centered in the local community, involving mutual respect, critical reflection, caring, and group participation, through which people lacking an equal share of valued resources gain greater access to and control over those resources*” (Cornell Empowerment Group, 1989). 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. 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).

Examining consumer empowerment in e-Healthcare is necessary since the technological innovations allow for the sharing of a person's medical information between people in organizations. Because the technology creates new relationships between people and entities, the sociological aspects and technology intermingle to create a phenomenon of consumer empowerment in e-Healthcare. In order to investigate the phenomenon of consumer empowerment dimensions in e-Healthcare, the research questions will be broad since this area is emerging. Based on the preliminary analysis of consumer empowerment literature and the recent interest in the issues of consumer empowerment in societal venues, the following research questions are posed for this study.

1. What are the dimensions of consumer empowerment in e-Healthcare?
2. How can consumer empowerment be achieved in e-Healthcare?

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 the interactions of a Consumer Advisory Council on Health Information in North Carolina.

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). In the study of emerging phenomena, one should seek to generate theory by examining the environment in context "to discover what is going on, rather than assuming what should go on" (Fernandez and Lehmann, 2005, pg. 83).

The grounded theory methodology is systematic through theoretical sampling, the constant comparative method, developing and examining documentation and immersing oneself in a setting will enable one to generate a theory. The constant comparative method which is unique to Grounded Theory methodology allows for theory to be generated through jointly and systematically coding the data and analyzing the data for content. 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). There are three phases of coding: open coding, axial coding, and selective coding, which allow for patterns of codes to be generated, related, and reduced to make a parsimonious model (Glaser & Strauss, 1967). Determination for when to cease data collection was based on the concept of saturation. From these emerging sources and saturation of the data collected, the length of data collection was approximately one and one half years.

DATA SOURCE

The primary source of data for this study is the Consumer Advisory Council on Health Information (CACHI), a group formed by the North Carolina Health Information and Communications Alliance (NCHICA). As a nonprofit organization, NCHICA champions the adoption of information technology to improve healthcare through initiatives. (www.nchica.org/AboutNCHICA/CorpInfo/vision.htm). The impetus for the creation of the Consumer Advisory Council was when "NCHICA was working on a strategy for future activities and we had a major meeting in 2003 with the Board and important members . . . and I presented an organization chart showing the key players involved in medication management and one of our Board members asked the question: "Where are the consumers?" That started an introspective process that ended in the chartering of NC CACHI in 2006."

CACHI is "a unique health care consumer group formed for grassroots input and participation to explore ideas and issues surrounding health information, such as privacy and electronic health records (NCHICA CACHI Charter, 2007)." CACHI's membership includes consumers who want to voice their opinions on healthcare information issues, and individuals who represent consumer groups (such as HIV/AIDS or the elderly). They are supported by a Resource Panel of experts in different facets of healthcare. Because it is a local group, CACHI will be important to examine grassroots efforts of consumer empowerment in e-Healthcare to answer the research questions for this study.

FINDINGS

The CACHI data collection was generated through meeting notes, agendas, and supporting documentation such as PowerPoint presentations, email correspondence, and interviews with individual council members and resource panel members. During July 2006 to January 2008, meetings were attended and minutes were transcribed. These minutes were approved by the council members for accuracy. Analysis of the CACHI data collection was performed through systematic

grounded theory methods. Because a quote could be categorized underneath more than one code, this was due to the inherent relationships between the codes. So, instead of viewing this as a problem, the possibility to apply different codes to the quotes was a supportive mechanism for the underlying relationships between the codes.

Figure 1 shows the initial open coding categories from the CACHI analysis. These were generated through patterns in the incidents of codes.

Initial NC CACHI Open Coding Categories
Awareness
Communication
Education
Participation
Equity
Resources
Rights
Control
Access
Goals
Deliverables
Actions
Documentation
Technology
Trust
Accountability
Security
Privacy
Policy
Enforcement
Processes
Standardization

Figure 1- CACHI Initial Open Coding

When performing the open coding analysis, it became apparent that some of these codes could be combined into categories. Based on the properties of the codes and relationships of the codes to one another, it was determined that these codes could be reduced. This involves the steps of axial (relationship) coding and selective coding. Selective coding involves finding uniformities in the coding and properties or contexts for which a smaller set of concepts is developed. These reduced codes can be seen in Figure 2.

Categories from NC CACHI Open Coding
Awareness/Communication
Education
Participation
Equity/Resources/Rights/Enforcement
Control/Access/Accountability
Goals/Deliverables/Actions/Documentation
Technology
Trust
Policy
Security/Privacy
Processes/Standardization

Figure 2--NC CACHI Categories from Open Coding

Figure 3 shows a description of the categories and a context for each which reveals the relationships of the merged codes. Due to limited space and the need for rich, thick description, a selected number of the categories will be discussed in detail next.

Description of NC CACHI Categories	
Category	Context
Awareness/Communication	Awareness through communication to understand new information
Education	Deeper level of understanding than awareness; includes health literacy
Participation	Engagement within the group and outside of the group; how to engage others to be involved
Equity/Resources/Rights/Enforcement	There are several dimensions for the context of equity. There is a 'Digital Divide' disparity in how the internet is accessed since some populations do not have access to the Internet. There is also an inequity in access to resources for information that provides awareness and education. This also involves another dimensions of equity in consumer civil rights to be able to participate, become informed, and control their private medical information. The other dimension of equity is within the realm of policy and legal enforcement. Enforcement is often not equitably distributed.
Control/Access/Accountability	These are primarily in context of control and access to the medical information, but also has a dimension of external people controlling the lives of others by making healthcare IT decisions for them (such as the government or insurance companies); The aspect of accountability is focused in how these external entities would be accountable for their decisions. This affects the perceived locus of control for the council members.
Goals/Deliverables/Actions/Documentation	Primarily these are the goals of the CACHI group which are achieved by actions and producing deliverables and documenting the process through minutes and other products
Technology	Includes the types of technologies and the role of technology in empowering consumers; does it improve health outcomes?
Trust	Within the group; trusting healthcare providers and stakeholders
Policy	Legislative and organizational
Security/Privacy	These are also inherent within the contexts of other categories, such as technology, policy, education
Processes/Standardization	Best practices; consistency for consumer understanding

Figure 3--NC CACHI Category Contexts

Awareness/Communication, Education, and Participation

There is a strong relationship between Awareness, Communication, Education, and Participation, so these will be discussed congruently. The Executive Director of NCHICA felt strongly that NCHICA serves as an enabler of education, and his contacts in the industry are what allowed the CACHI group to experience the well-known speakers that they did. The following is an excerpt from a conversation during the January 2008 meeting, and emphasizes the Executive Director’s commitment to the importance of education:

Executive Director: *“This is an opportunity for consumers to be informed on what is going on and get a voice in there.”*

Member 20: *“I don’t know enough to be able to input.”*

Executive Director: *“What can we do to help inform you?”*

Member 20: *“Lots more information.”*

The CACHI group was experienced in healthcare and IT which helped them understand the issues involved. As the Executive Director stated, *“We characterize the council based on their backgrounds. The credibility of the council is that you know what’s behind the curtain and have a background.”* However, after listening to several external speakers and after attending the NCHICA Annual Conference, they realized that, although they were fairly well-educated and had some type of work experience in either healthcare or IT, they found it difficult to understand much of the terminology and jargon discussed by the presenters. One council member asked, *“How do we involve and educate the consumers? There are professional representatives to speak on behalf of other people. I’m fairly educated and still find it hard enough to understand. . . .and to know what kinds of information to ask.”* From the NCHICA Conference, members were clearly concerned that they weren’t as aware or informed of issues as they originally felt. Comments made included:

- *“The jargon of the CIO made it difficult to understand.”*
- *“I wouldn’t have thought about those security issues.”*
- *“They went through it quickly; it was a lot of information, like a fire hose.”*
- *“There was an assumption that we knew the acronyms. He glided over the Congressional part and thought we knew. There was an assumption that you were IT and watched CSpan*
- *“I understand more clearly the opt-in/opt-out range and the negatives/positives of those. I’m much more educated about that. I was much more open with an ‘I don’t care attitude’ and am now more sensitized to the gradation.”*
- *“I saw a lot of new and different problems that could happen.”*
- *“I was a little overwhelmed by the . . . presentation. I think there was so much detail and acronyms that consumers needed so much background [to understand]. I was not adequately prepared myself and my background is in IT policy. I was snowed.”*

After they became aware of the complex set of issues in understanding e-Healthcare, they were more outspoken when asking questions and wanting clarification on issues. **Ironically, it seemed that after they were willing to reveal their weaknesses in what they didn’t know by asking questions, that they felt more empowered.** So, as part of being empowered, one would need to be comfortable in revealing those weaknesses and in taking action to correct the weakness (by looking for more information, for example).

During her presentation, Dr. Peel stated that there is a wide variety of people involved in these e-Healthcare issues. She suggests its complexity: *“IT people don’t get healthcare. Healthcare reporters don’t understand the issues; legal reporters don’t know about health or IT. This issue sits right in the middle. Conceptually, very few people have all of the pieces. It’s hard to talk about policy at a level people can understand.”* Healthcare IT poses many facets which can be difficult to understand, because very few people have a thorough understanding of the issues involved. As one council member suggested, *“We all have a healthcare background. It’s hard to remove ourselves from our professional roles. We need to communicate and become aware of the terminology. We all bring a unique perspective.”* They were concerned with being able to separate themselves from their professional roles at times to understand the ‘everyday consumer’ point of view.

Since the council members felt that they also needed to be more educated to participate effectively, they also were cognizant of the change this could create in their identities. A council member states it clearly, *“To advocate, it’s representation. We have to know the alphabet soup and be uberconsumers to understand where these people are coming from and talk at the same level. But then you may not have the consumer perspective anymore.”* As the council progressed through time, some members came to see themselves as advocates for individual consumers. In essence, the transformation through education which they needed to pursue to actively and effectively participate in e-Healthcare initiatives paradoxically places them in the role of being representatives that creates a type of barrier between them and the ‘everyday consumer.’

From the CACHI analysis, the preliminary axial coding would suggest that at some level, a consumer would need to begin with some kind of concern or care that would prompt her to want to be more aware of e-Healthcare issues. One comment by a Council member was *“I don’t have health issues. People with real health concerns—how would they see this [potential for information disclosure]? I have a different level of concern and may be more forgiving. There’s no stigma for me”* (CACHI#5 9-07). So, perhaps having some type of health issue or concern for privacy would be that motivation for a consumer to want to be more aware of the issues.

One of the issues that the council experienced was the difficulty to find members who could participate consistently. Inherent in the process of being able to commit time to the group was that the person had the capability to take time from work to participate. Even those who could take time from work still experienced work responsibilities which prevented them from attending some of the meetings. *“The problem is to reach out and get people involved with time commitment to come”* suggests that consumers who work hourly jobs would experience difficulty getting time from work than those at higher-paying salaried jobs. This creates a disparity in the types of people who could participate. Therefore, the concept of Equity will be discussed next.

Equity/Resources/Rights/Enforcement

There is an underlying theme within the concept of consumer empowerment which included power and the distribution of resources. The Digital Divide of electronic inequity is often not as apparent because many people have

Internet access either at home or through work. There is also inequity in access to resources for information which provides awareness and education.

For people to feel that they have been treated equitably, the notion of civil rights is important. As one speaker stated, *“We need to protect privacy and civil liberty while ensuring privacy and security.”* Another speaker stated that privacy is *“the essence of freedom and liberty to be left alone.”* The following are excerpts of a CACHI meeting:

Member 16: *“What about the data that is out there now? We’ve got to make it a crime to use it or hold it without consent. It should be a crime to re-identify data and to keep secret databases. There are still a lot of things that are really private and we still need privacy for stigmatizing conditions.”*

Member 1: *“It’s civil rights violations in those cases [of stigmatizing conditions].”*

Member 16: *“There has been compliance through consequences [which are monetary]. Sixty percent of reported compliance issues are not considered violations because HIPAA allows so much to be shared. Shouldn’t someone defend the consumer? Who can afford lawyers? Should the Attorney General in each state be the one to defend consumers?”*

Member 1: *“Especially if you’re still sick and need treatment.”*

Member 16: *“People pay cash for care, and go to Mexico for care as a method of black market care.”*

Member 3: *“But they can afford it. How about the incarcerated?”*

Member 7: *“It’s not on their radar—it’s Maslow’s hierarchy [of needs].”*

This fragment of conversation relays the argument for enforcement of civil rights and privacy laws to be equitably distributed. In a discussion of HIPAA enforcement, it is known that HIPAA regulation has been inconsistently enforced, partially because it doesn’t provide real protection, and because providers still don’t seem to understand the regulatory issues. As one consumer mentioned, *“The penalties are not enforced. . . If they were enforced, it would go a long way.”*

The council members realize that there is a fine line between helping other consumers to become informed through increased resources such as information or opportunities to participate; and in telling the consumers that they **should be** concerned with privacy of health information. The reference above to Maslow’s Hierarchy of Needs is important to understand. One exchange of quotes during the November 2007 meeting included the following:

Member #19: *“The people in Tennessee want healthcare in the first place. They have a lack of access to healthcare. We, the insured people, should find a way to speak for people who have no access to healthcare. They [people in Tennessee] probably don’t care about privacy”*

Member #21: *“There is an issue as to how to engage consumers; It’s Maslow’s hierarchy of needs. If you don’t have healthcare, then you don’t care and don’t have information to exchange”*

Member #19: *“Consumers have a lot to face in healthcare before privacy [can be addressed].”*

The inherent power inequities in the institution of healthcare and politics were a matter of discussion. In response to one of the presentations (by Dr. Kolodner) at the NCHICA Annual Conference, one member said, *“It sounded like a political situation of powers that be and that [power] obviously not being the consumer. There’s a whole lot of politics back there.”* This was reiterated by another council member: *“I see us as being considered gnats by some; people we have to be polite to or otherwise it won’t be kosher; how are we going to do that?”* Sometimes this understanding of power inequities was communicated against the vendors and providers, as suggested by the following exchange of comments by members:

Member 9: *“There’s a business model piece and a political piece. The vendors see it as how to make them [consumers] convinced that [their] product is good. That’s not necessarily bad, they want a happy consumer; they sell the technology and are not providing the care”*

Member 5: *“They didn’t see the consumer as equal stakeholder but as objects to consider.”*

Member 9: *“They almost saw the consumer as an obstacle.”*

The idea that there was a background political and organizational component in which consumers were not privy resulted in a perceived lack of consumer control. Because of the *'powers that be'* and perception of their lack of understanding in at least some areas of healthcare information technology, the consumers stressed the notion of control and access of their medical records and accountability for that capability.

DISCUSSION

In relating the findings back to the initial research questions, we find that from the CACHI analysis, there is evidence that both of the research questions were thoroughly investigated through the grounded theory approach. In response to the first research question "What are the dimensions of consumer empowerment in e-Healthcare?" The proposed dimensions are listed in Figure 2 and described in Figure 3.

The second research question, "How can consumer empowerment be achieved in e-Healthcare?" was also examined through the CACHI meeting transcripts. From the goals generated by the council members, there are three recurring themes that developed. The council members want to have a voice in the following ways:

1. By educating themselves so that they are more informed consumers.
2. By helping other consumers to learn more and become more informed.
3. By participating and providing feedback in e-Healthcare initiatives.

One member suggested that *"We need outreach tools beyond a web page; something more interactive. There is a limit to the time we can spend going out to reach consumers."* It was agreed by council members that *"it will take more than one strategy"* to realize empowerment in e-Healthcare initiatives. A variety of strategies were discussed, including education for the council members through speakers and the creation of the Resources web page, a glossary of healthcare IT terms and acronyms. Watershed events for the council members included presentations by Dr. Deborah Peel (Patient Privacy Rights Organization), Alison Rein (AcademyHealth), Carol Diamond (Connecting for Health), and Intel (about Dossia's PHR); attendance at the NCHICA Annual Conference; and participation in generating a Consumer Toolkit for the NC HISPC (Health Information Security and Privacy Collaboration) project. Dr. Peel captured their attention by asking, "It's 11:00 at night, who's got your data?" After hearing Dr. Peel's thought-provoking presentation on patient privacy as a civil right, one council member stated, *"The best thing that happened to us was Deborah Peel. . . I will remember her until my dying days because it was a stunning presentation."* The NCHICA Conference was also a watershed event because it gave the council members an opportunity to hear about recent innovations in healthcare IT from vendors, policy makers, and providers. From these presentations, the council members felt that consumer empowerment was discussed superficially and that consumers needed to be involved in more e-Healthcare initiatives. This was also a pivotal point in which the members realized that the jargon and terminology of the field made it difficult even for the educated person to understand what was taking place. Another opportunity for the CACHI to provide input into the NC HISPC (Health Information Security and Privacy Collaboration) project was in the development of the Consumer Empowerment Toolkit. The purpose of the Toolkit was to develop a guide for other states to follow, based on the efforts of the CACHI group. The participation of the council members was to agree to include their documentation, policies, and procedures as samples for other states to utilize.

CONCLUSION AND FUTURE RESEARCH

There are limitations to utilizing this one group to represent a comprehensive view of consumer empowerment in e-Healthcare. The members are typically more educated than the 'everyday' consumer, and have the resources to participate at the meetings. Because the goal is to discover the facets of consumer empowerment from as broad a representation of people as possible, other data sources will be utilized as part of this research stream. This is part of a larger research study in which three groups: a federal, state (CACHI), and individual consumers will be investigated to determine how consumer empowerment is defined across each group and how each perceives that consumer empowerment can be achieved in e-Healthcare. The grounded theory process utilized for this study will be applied to each of the three data sources and then the findings from each will be aggregated to form a parsimonious model of consumer empowerment in e-Healthcare. So far, there have been some similarities and some differences in the ways that each group views consumer empowerment in e-Healthcare. As a result, a set of models from the preliminary analysis of each group is shown in Figure 4 and Figure 5. It is anticipated that the second-level constructs (from axial coding in Figure 4) will fall into the parsimonious conceptual categories of Consumer Engagement, Consumer Control, and Social Justice (Figure 5). Consumer Empowerment in e-Healthcare should be realized through the incorporation of these dimensions into e-Healthcare initiatives. This goal to further understand consumer empowerment in e-Healthcare is to ultimately aid in the improvement of human health. This stream of research strives to further investigate this phenomenon.



4--Proposed Theoretical Detailed Model of Consumer Empowerment in E-Healthcare

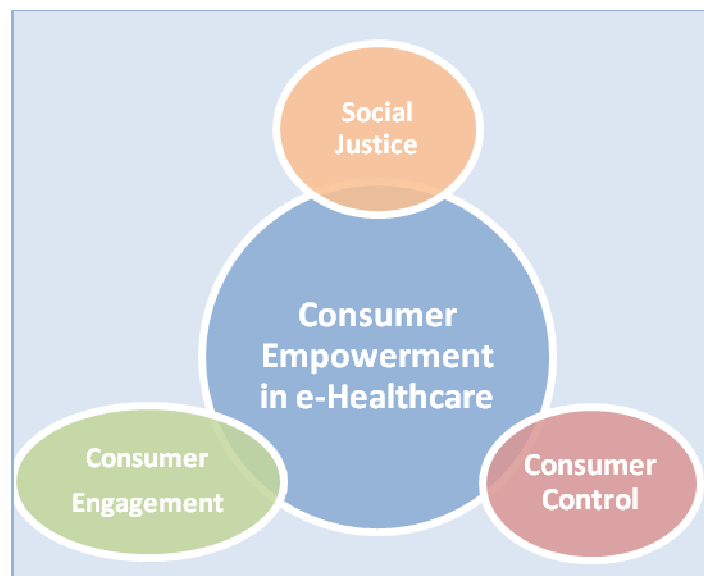


Figure 5--Proposed Theoretical Model of Consumer Empowerment in e-Healthcare

ABBREVIATED REFERENCES (FULL REFERENCE LIST AVAILABLE UPON REQUEST)

1. Anderson, Joan. (1996) *Empowering Patients: Issues and Strategies*. Social Sciences Medicine. 43:5, 697-705.
2. Berger, Peter, & Luckman. (1966) *The Social Construction of Reality*. Anchor Books, NY, NY.
3. Davenport, Thomas, Eccles, Robert, Prusak, Laurence. (Fall 1992) *Information Politics*. Sloan Management Review. 34:1, 53-65.
4. Fernandez, Walter, and Lehmann, Hans. (2005) *Achieving Rigor and Relevance in Information Systems Studies: Using Grounded Theory to Investigate Organizational Cases*. The Grounded Theory Review. 5:1, 79-107.
5. Glaser, Barney, Strauss, Anselm. (1967) *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Aldine Publishing Company: Chicago, IL.
6. Glaser, Barney. (November 2004) *Remodeling Grounded Theory*. The Grounded Theory Review: An International Journal. 4:1, 1-24.
7. Osborne, Stephen. (1994) *The Language of Empowerment*. International Journal of Public Sector Management. 7:3, 56-62.
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.
10. Wilkinson, Adrian. (1997) *Empowerment: Theory and Practice*. Personnel Review. 27:1, 40-56.