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Underpinning a Guiding Theory of Patient-Centered E-Health

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Abstract:

Patient-centered e-health (PCEH) is an increasingly important part of health information technology. Yet the literature in this area is mainly descriptive and atheoretical, which greatly limits opportunities for research advancement. This observation motivated us to undertake a program to explore and identify essential components that can underpin development of a guiding theory of PCEH (i.e., a set of robust constructs and relationships that are generalizable and prescriptive across diverse PCEH services). Our work builds upon the proposition that benefits of PCEH can be increased by incorporating three essential characteristics: patient-focus, patient-activity, and patient-empowerment. We conduct a literature review of e-health research published between 2007 and 2011 to assess the relevance of these characteristics to the underlying domain and their relationships to one another. The results indicate the three characteristics are generalizable to the existing PCEH research literature, are abstract across place and time, and exhibit substantial interrelationships. These findings are encouraging to further development of a guiding theory of PCEH.

Keywords: health information systems; health information technology; health communication; healthcare interventions

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I. INTRODUCTION

Over the past decade, the concept of patient-centered e-health (PCEH) has gained significant traction. Yet we find there is little consensus as to what people mean when they refer to PCEH and only limited theory to guide what characteristics PCEH should incorporate. This situation motivated us to explore the conceptual and historical foundations of e-health in general and PCEH in detail. Our search identified several characteristics that are theorized to be essential to the effectiveness and success of PCEH. We subsequently conducted a qualitative analysis to assess the degree to which e-health services reported in the healthcare literature incorporate these characteristics. The resulting findings underpin further steps toward developing a guiding theory of PCEH.

II. BACKGROUND

The term “e-health” was coined in the late 1990s “in line with other ‘e-words’ such as e-commerce, e-business, e-solutions, and so on, in an attempt to convey the promises, principles, excitement (and hype) around e-commerce (electronic commerce) to the health arena, and to give an account of the new possibilities the Internet is opening up to the area of healthcare” [Eysenbach, 2001, p. e20].

Many e-health websites were commercial endeavors that provided encyclopedic health information to individual consumers, and most of these sites went out of business during the dot-com bust [Itagaki, Berlin and Schatz, 2002]. Nonetheless, consumer demand for e-health remained strong [Fox, 2005], and healthcare providers began to implement e-health services of their own, despite initial reluctance to enter this domain [Lazarus, 2001].

One reason for resistance by healthcare providers is constraints they faced in the types of e-health services they could offer. Potts [2006, p. e23] explains,

“Away from healthcare, the Internet has been revolutionary and transformational because it has democratized production and distribution. Traditional healthcare, given its safety critical context, utilizes an evidence base and a process of risk management that generally involves some sort of governance. These are conflicting trends: the great value of the Internet is how easy it is to make material available, but the strictures of safety and proof of efficacy run counter to that.”

Yet e-health that is supplied by healthcare providers offers important benefits, centering on the opportunity for individuals to be linked to their own health records, physicians, and clinical staff. This has proved to be a significant benefit, and Kaiser-Permanente [Silvestre, Sue and Allen, 2009] and other healthcare providers have drawn large subscriber bases by implementing e-health that incorporates services that appeal to patients, such as viewing test results, sending email to doctors, and viewing information about past office visits.

The need for e-health to appeal to patients should not be underestimated. Unlike health information technologies (IT) that are internal to healthcare provider organizations, it is difficult to enforce e-health adoption by patients. Numerous e-health services have been implemented that patients failed to adopt, leading to underutilization or abandonment of the service. Examples include diabetes decision support [Payton and Brennan, 1999], asthma self-management [Sassene and Hertzum, 2009], and personal health records [Greenhalgh, Hinder, Stramer, Bratan and Russell, 2010].

Defining Patient-Centered E-Health

In practice, “e-health” has come to be used as an umbrella term covering wide-ranging services including electronic patient records, telemedicine, and biomedical informatics [Pagliari et al., 2005]. At the same time, some sources, such as the U.S. Department of Health and Human Services [Health.gov, 2012], continue to use “e-health” to refer to services accessed by the public rather than services supporting health professionals, insurers, or third-party payers. Yet neither usage of the term adequately describes the form of e-health supplied by healthcare providers, which is targeted toward that small subset of the public that comprises the provider’s patients and their caregivers. Recognition of this ambiguity motivated researchers to become more specific in describing the type of e-health they studied, using such terms as “provider-delivered e-health” [Wilson and Lankton, 2004], “consumer health informatics” [Lewis, Chang and Friedman, 2005], and “personal health informatics” [Wilson, 2006].

The first scholarly reference we find to “patient-centered e-health” appears in the doctoral dissertation of Christopher Lau [2003]. He describes several e-health services that healthcare providers frequently offered at the time, including content delivery, appointment scheduling, and patient-provider email. He goes on to propose that PCEH could be extended by adding such transformative capabilities as personal health knowledge management (which we have since come to know as personal health records), referral support, and home monitoring applications. Lau used the term “patient-centered” descriptively, as a means to reference e-health that is oriented toward use by patients. Similar use of the phrase “patient-centered e-health” as an atheoretical description continues in recent studies [Binczewski, Kurowski, Mazurek and Stroinski, 2011; Resnicow et al., 2010].

Healthcare is frequently criticized for its reluctance to build and follow theory-based research frameworks [Eccles, Grimshaw, Walker, Johnston and Pitts, 2005; Grimshaw et al., 2004], even though there is recognized need “to establish the theoretical basis of interventions and undertake exploratory studies to choose and refine interventions” [Grimshaw et al., 2004, p. 107]. The U.S. National Cancer Institute advises,

“Using theory as a foundation for program planning and development is consistent with the current emphasis on using evidence-based interventions in public health, behavioral medicine, and medicine. Theory provides a road map for studying problems, developing appropriate interventions, and evaluating their successes. It can inform the planner’s thinking during all of these stages, offering insights that translate into stronger programs. Theory can also help to explain the dynamics of health behaviors, including processes for changing them, and the influences of the many forces that affect health behaviors, including social and physical environments.” [NCI, 2005, p. 5]

Developing theoretical underpinnings for PCEH is both timely and important. The underlying idea that healthcare should be patient-centered has a strong theoretical component. The Institute of Medicine defines patient-centered as “providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions” and theorizes that a patient-centered approach will contribute to “care that is safer, more reliable, more responsive to their needs, more integrated, and more available” [IOM, 2001, p. 3]. From this perspective, no aspect of healthcare, including e-health, can be patient-centered unless it derives from patients themselves rather than from the “preferences, needs, and values” of healthcare providers or software developers.

Wilson [2009] presents an initial discussion of patient-centering in e-health by arguing that, although demand is building among patients for e-health services and consensus has emerged among healthcare providers that IT should be used to improve healthcare, thoughtful attention still must be paid to center e-health design around patients in order to develop e-health services that patients will choose to adopt and use. He contends that three characteristics are essential in order for e-health to be patient-centered: *patient-focus*, *patient-activity*, and *patient-empowerment*. Definitions and descriptions of these characteristics are summarized in the following sections.

Patient-Focus

Patient-focus requires PCEH designs to be based primarily on the needs and perspectives of patients. This is an extension to the healthcare context of the central premise of “user-centered design,” which holds that design of all products and services should be guided by the needs of the intended users [Norman, 2002].

In contrast, much of the e-health that has been designed for patients’ use is *not* patient-focused [Winkelman and Leonard, 2004]. Designs have tended to focus excessively on objectives of the organization rather than the patients. Healthcare is a profession of compassion and concern, yet the culture of healthcare has been based to a large extent on a paternalistic model of physician-patient relationships in which physicians control virtually all aspects of their interaction with patients [Emanuel and Emanuel, 1992; Eysenbach and Jadad, 2001]. In addition, the health IT field has emphasized development of clinical and transactional systems for internal organizational use rather than supporting patients. Where user interactions were given any consideration, typically it was the provider’s clinicians and support staff rather than patients who were targeted for study [Jamar, Mattion, Orland, Giatt, Karat, and Coble, 1998].

Although this type of *organization-focus* still may be appropriate in the development of internal software, such as hospital clinical systems, it is not effective for the design of patient-centered e-health. As Winkelman and his associates argue,

“The patient-user’s perspective on what constitutes technology usefulness is both distinct from and complementary to that of physicians and developers. To build useful ICT tools for patients, direct patient participation must be made part of all steps in the design and development process and,

most importantly, in the earliest conceptual stages.” [Winkelman, Leonard and Rossos, 2005, p. 312]

In practice, patients typically have alternatives to using e-health services, for example, by making phone calls and office visits. It is key for designers to recognize that patients will reject e-health that does not meet their actual needs—even if the designers’ intentions are directed toward benefitting patients [Greenhalgh et al., 2010; Payton and Brennan, 1999; Sassene and Hertzum, 2009]. We recognize that cases will arise where healthcare providers may argue for including elements that patients do not desire, such as intrusive reminder notices. Conflicts of this sort potentially may be mitigated through development and testing of alternative approaches, such as allowing patients to control the form and frequency of reminders. However, we can never recommend *replacing* desires of patients with desires of the healthcare provider in guiding e-health design where the goal is to increase voluntary adoption and use of e-health by patients, as we anticipate such actions will instead serve to decrease patient participation.

E-business software designers have come to understand that it is essential to create a high-quality *user experience* in order to build and retain Web traffic and avoid rejection by intended users [Becker and Mottay, 2001; Harris and Weistroffer, 2009; Molla and Licker, 2001]. This objective can be achieved only by focusing on needs of the software user [Alpert, Karat, Karat, Brodie and Vergo, 2003]. E-health designers serve a population of patients who are increasingly dependent upon the Web and proficient in using it. These Web-savvy patients expect their user experience to be as satisfying with e-health as it is with other e-business services. Instead of treating patients as objects to be manipulated through e-health—as simple consumers of pharmaceuticals or receivers of medical instructions—it is necessary for designers to understand and act upon patients’ needs, preferences, and perspectives in order to achieve patient-focus.

Patient-Activity

Patient-activity requires meaningful, interactive participation by patients in providing information about themselves and representing their own perspectives as well as consuming information of interest to them. Patient-activity is inherent in certain e-health services, including online prescription refills, appointment scheduling, and provider/patient communication. However, achieving high patient-activity in other e-health services may require reconceptualization of healthcare processes and information flows in order to provide opportunity to patients to add information they perceive to be relevant.

One example is the personal health record (PHR). The PHR is a comprehensive personal health information repository that is controlled by the patient [Lafky, Tulu and Horan, 2006]. E-health that offers a PHR inherently provides a certain level of patient-activity in that patients have primary responsibility to make accurate, timely entries and to maintain these records. Yet although PHR software is offered by a number of vendors, including freely accessible versions, hardly anyone uses it [Markle 2006; Taylor, 2004]. A number of reasons have been offered for this situation, ranging from poor usability to privacy issues and lack of health content integration [Wilson, 2006], but numerous other types of software have overcome similar handicaps, especially where the software services are perceived to be useful by intended users [Lee, Kozar and Larsen, 2003].

The PHR is conceptualized as being distinct from the medical record that healthcare providers are legally required to maintain [AHIMA, 2005]. This distinction typically has been implemented by creating a wall between the patient’s PHR and the provider’s medical record that effectively obstructs much of the value that patients could gain from maintaining a PHR. The patient typically cannot enter any information into the provider’s medical record nor incorporate information from the medical record back into the PHR. This situation constrains the PHR to simply storing and organizing information that is provided by the patient, a process that requires substantial effort in order to achieve few benefits. To build a PHR that is highly patient-active, linkage should be provided to the provider’s medical record as well as other data sources to which the patient has legitimate interests, including medical records held by employers, insurers, and governmental agencies. This would make patients’ interactions with PHR more meaningful and motivate PHR adoption.

Achieving patient-activity will require e-health designers to develop effective strategies for removing barriers to information exchange in an environment that is policy-driven and highly regulated. Although this represents a difficult challenge, similar user-activity barriers have been overcome in numerous online activities, including personal banking and investment, commercial sales and auctions, and social networking.

Patient-Empowerment

Patient-empowerment requires that patients are able to apply e-health to control far-ranging aspects of their healthcare. Increasingly, patients expect to be empowered in their own healthcare decisions [IOM, 2001], and the expectation of personal control is especially strong for e-health services [Lafky, Tulu and Horan, 2006]. From the

PCEH perspective, however, patient-empowerment centers on providing similar levels of control via e-health that exist for patients in other modes of interaction with their healthcare providers.

Patient-empowerment has several dimensions. First, patients must have meaningful control of e-health services, requiring e-health designers to overcome two important obstacles. Paternalistic biases against patient-empowerment can take many forms and are often couched in concerns for the patient's well-being [Ross et al., 2005]. Tension between paternalism and empowerment in healthcare has long been recognized [Yeo, 1993], yet it is important to note that e-health does not create new conflicts. Patients mainly expect e-health to support activities that they can control through other methods, such as acquiring vaccination records via a phone call or personal visit to the provider.

A second dimension is related to security and financial issues that block patient-empowerment. Healthcare provider organizations have the legal responsibility to maintain security and privacy of patient and provider data, and providing patients additional access increases potential exposure to security breaches. In addition, connecting e-health services to internal provider systems can increase development expenses, especially where the internal systems have limited interoperability.

A third dimension of patient-empowerment is ensuring that e-health provides a high level of usability and support for patients to understand and communicate effectively within the e-health environment. From the patient's perspective, e-health is an extension of the healthcare providers' other services; thus, it is reasonable for patients to expect e-health to be generally understandable. It is not acceptable for designers to insist that patients' health literacy must increase before they can use e-health services, for example, as is argued by Norman and Skinner [2006]. Need for healthcare services does not depend upon patients' level of literacy, and requiring patients to be highly literate in order to use e-health is no more defensible than requiring literacy in order to schedule medical examinations or other healthcare services. Online banking and financial e-businesses demonstrate that people who are only marginally literate can successfully interact with online services when they are provided with an effective user interface, and application of user-centered design principles has proved to be similarly effective in healthcare contexts [Arsand and Demiris, 2008; Johnson, Johnson and Zhang, 2005].

To promote patient-empowerment, e-health designers should implement existing forms of patient control in the online environment wherever this can be done. In addition, designers should press for long-term commitment toward interconnecting e-health with other organizational IT even if pragmatic constraints prevail in the short term. Patient-empowered e-health is not a call to give patients controversial new forms of control or to require patients to change how they interact with healthcare providers. Instead, the key objective is to bring as many aspects of patients' existing empowerment online as possible.

Underpinning a Theory

Definitions, as provided by Wilson [2009], are a necessary requirement for theory, but they are not sufficient to *create* theory. Wacker [2008, p. 7] defines theory as an "explained set of conceptual relationships" comprising four essential properties, each of which must exhibit several further subproperties to qualify as "good" theory:

1. Definitions describe who and what the essential components are. In "good" theory, definitions are characterized by conservatism (distinct from similar terms already in existence), uniqueness (to the specific concept), and parsimony.
2. Domain describes when and where the theory applies. In "good" theory, the domain outlines the degree to which the theory will be generalizable to existing populations and to which it may be abstracted across place and time.
3. Relationships describe how and why empirical findings occur. In "good" theory, relationships exhibit fecundity (suggesting new areas of research), internal consistency, statistical parsimony (not requiring complex statistical explanations), and substantive significance.
4. Predictions describe effects that should, could, and would occur. In "good" theory, predictions must be falsifiable.

We argue that Wilson's [2009] definitions of PCEH characteristics meet Wacker's logical criteria for conservatism, uniqueness, and parsimony as described in point 1 above.

- Conservatism is demonstrated in the following way. As previously explained, the terms "patient-centered" and "e-health" already exist as established concepts. Their marriage into the phrase "patient-centered e-health" has been used descriptively in prior research, but not as part of a theoretical model. Alternative

conceptualizations, such as “consumer health informatics” [Eysenbach and Jadad, 2001] and “personal health informatics” [Wilson, 2006], do not explicitly address the patient orientation of PCEH; thus, PCEH is distinct from these alternatives. “Patient-focus,” “patient-activity,” and “patient-empowerment” are descriptive terms that Wilson applies within the generally accepted meanings of each term. The definitions are conservative in that they do not add unnecessarily to the conceptual definitions already extant in this domain.

- Uniqueness is demonstrated through specificity of each term to the patient context. This aspect constrains any theoretical propositions to be directed toward individuals in the role of patient (i.e., addressing their own healthcare providers and health conditions).
- Parsimony is demonstrated through logical means. “Patient-focus,” “patient-activity,” and “patient-empowerment” each have important aspects that can vary independently of the other terms. For example, e-health may implement patient-activity in a manner that is not empowering to patients, such as requiring them to upload a daily list of foods they consumed. It is not possible to remove any of the terms without reducing the range of conceptual content that the terms encompass.

Having satisfied the Wacker [2008] requirement to define the proposed theory components, the next step in underpinning a theory is to ascertain the generalizability and abstraction properties of the theoretical domain, as described by Wacker in point 2 above. A subsequent step is to explore emergent relationships among the characteristics as described in point 3 above. These aspects are key to ensuring that the concepts comprising PCEH are relevant to the underlying domain as well as to one another.

In the following sections we describe our approach to investigate the PCEH theoretical domain and explore relationships among the three PCEH components, corresponding to Wacker’s points 2 and 3. We recognize that further research will be necessary to address Wacker’s point 4, the ability to make theoretical predictions of effects that should, could, and would occur.

III. RESEARCH MODEL

We present in Figure 1 an initial formulation of a theoretical model of PCEH. We propose that antecedent factors *patient-focus*, *patient-activity*, and *patient-empowerment* jointly contribute to *patient-centering*, a second-order construct [Thurstone, 1944], which acts to increase *e-health adoption and use by patients*. Our rationale for this proposition is that patients value each of these antecedent factors, that their perceptions are jointly applied in developing an overall evaluation of whether e-health services are centered on their needs as patients, and that this overall evaluation guides the decision to initially adopt and to continue to use e-health services. Adoption and use are frequently applied to assess software applications in technology acceptance research (Lee et al., 2003). From the perspective of Wacker [2008] a “good” final theory incorporates *components*, represented in the model by patient-focus, patient-activity, patient-empowerment, and e-health adoption and use by patients, and *relationships*, represented in the model by relationships of the first three listed components with patient-centering and subsequent effects of patient-centering on e-health adoption and use by patients. (We note that this latter relationship is not studied in the present research.) The model provides a structure for assessing generalizability and abstraction properties of PCEH as well as relationships among the constructs.

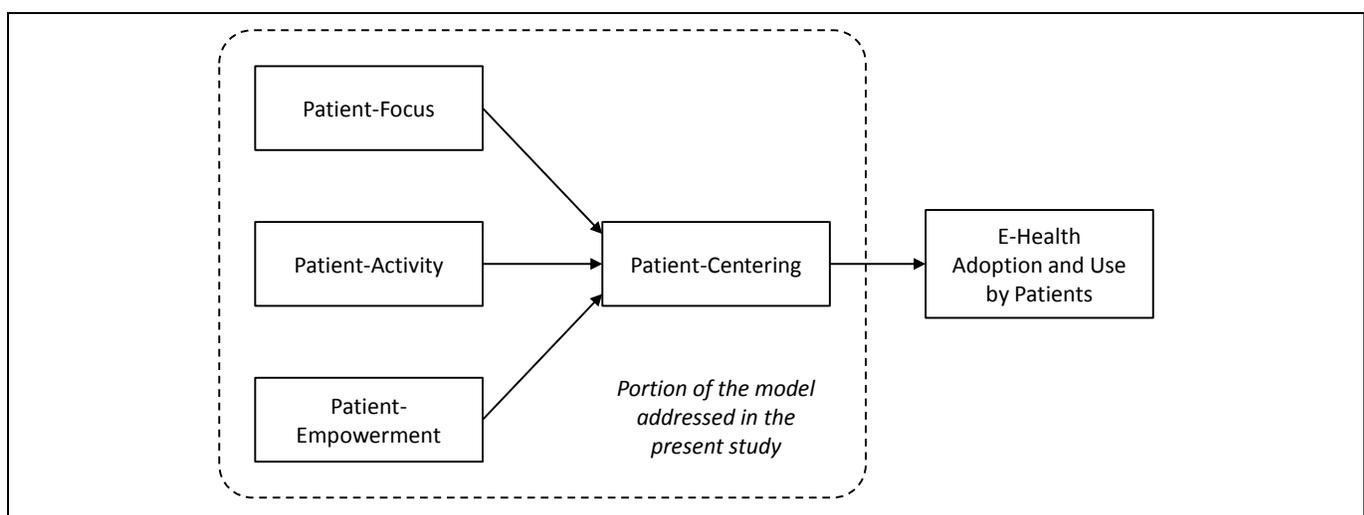


Figure 1. A Theoretical Model of Patient-Centered E-Health

In the following sections, we apply the Wilson [2009] definition of PCEH to create an assessment protocol to determine levels of patient-focus, patient-activity, and patient-empowerment in e-health. We then apply this protocol to review recent studies of e-health services supplied by healthcare providers.

IV. RESEARCH METHOD

Our method in this research was to assess a representative selection of relevant recent studies. The research was conducted as a keyword-based literature search and review of peer-reviewed journal articles published during the five-year period of 2007–2011. We conducted our search using the PubMed database, which currently indexes more than 21 million citations for biomedical literature [PubMed, 2012].

We entered the keyword search “(e-health OR ehealth) AND (patient OR patients)” on all fields in PubMed and set the date range between January 1, 2007, and December 31, 2011. This query resulted in 2,920 initial results.

Screening

Our objective in screening was to retain papers that described identifiable, unique e-health services supplied by a healthcare provider. These included papers that address the use of e-health services by patients as well as papers that describe e-health services that are designed for such use, such as prototype software. Screening proceeded in three stages. In the first stage, one of the researchers reviewed titles to remove papers that clearly did not meet our criteria, including conceptual articles, frameworks, reviews, and meta-analyses. In the second stage, one of the researchers applied the same criteria to review abstracts of the remaining papers. In the third stage, copies of the sixty-two papers retained after prior reviews were obtained and their research designs were reviewed by two of the researchers using the previously described criteria plus the criteria that the papers were published in peer-reviewed journals and that no two papers described the same e-health services. Following screening, seventeen papers were identified as meeting our criteria for final assessment.

Assessment Protocol

To determine the extent to which the e-health services described in each paper met the theoretical definitions of patient-focus, patient-activity, and patient-empowerment components described by Wilson (2009), we applied the protocol instructions presented in the following sections to guide coding (instructions are presented here in the exact form used in the assessments). High, low, and medium categories were developed for each component based on the theoretical definition of the component.

Patient-Focus

Central criterion: Attention of e-health designers and administrators is primarily directed toward the patient-users; evidenced by prior study of patients’ needs or desires (e.g., through observation, interviews, surveys, or focus groups); contradicted by evidence the e-health design is primarily dictated by organizational or commercial interests or use of a top-down development approach. Evaluate as:

High = overwhelmingly patient-focused (coded as 2)

Moderate = comprised of a mix of patient-focused and non-patient-focused parts (coded as 1)

Low = minimally patient-focused (coded as 0)

Patient-Activity

Central criterion: Patients are given meaningful abilities to provide information as well as consume it within the context of the e-health service; evidenced by capability for patients to use the system to communicate with healthcare providers and/or to update or augment personal health information in a form that is viewable by healthcare providers as well as the patient; contradicted by storage not viewable by healthcare providers, by firewalls between patient data and provider staff, or by other obstructions to patient input or feedback. Evaluate as:

High = overwhelmingly patient-active (coded as 2)

Moderate = comprised of a mix of patient-active and non-patient-active parts (coded as 1)

Low = minimally patient-active (coded as 0)

Patient-Empowerment

Central criteria: Meaningful control and a high level of usability; evidenced by including features that provide a similar level of control over the target processes that would be available to the patient in alternative contexts (e.g., via the phone or office visit), and by evidence of usability testing; contradicted by failure to include control options

that are commonly available in that use context, by lack of usability testing, and/or by evidence that in-depth patient training is needed in order to achieve adequate usability. Evaluate as:

High = evidence of usability testing AND no obvious missing control functionality (coded as 2)

Moderate = evidence of usability testing OR no obvious missing control functionality (coded as 1)

Low = obvious missing control functionality AND no evidence of usability testing (coded as 0)

V. ANALYSIS PROCEDURE AND RESULTS

Two of the researchers reviewed each of the seventeen selected papers and independently applied the assessment protocol to create an evaluation based on the overall reported characteristics of the profiled e-health services. The researchers then met to compare their evaluations. Where evaluations did not match, each researcher explained his rationale for assessing the paper, and all differences were resolved by consensus (coding differences occurred in five of the fifty-one initial evaluations). The final evaluations are shown in Table 1. Keys to numeric coding are explained in the Assessment Protocol section (above).

Table 1: Results of Qualitative Analysis

Papers under assessment	Patient-focus	Patient-activity	Patient-empowerment
Adams, Adams, Thorogood, and Buckingham (2007)	0	1	0
Andreassen (2011)	1	2	1
Arsand and Demiris (2008)	2	2	2
Atkinson, Massett, Mylks, McCormack, Kish-Doto, Hesse, and Wang (2011)	2	2	2
Chang and Chang (2008)	1	1	0
France (2011)	0	1	0
Gustafson, Hawkins, McTavish, Pingree, Chen, Volrathongchai, Stengle, Stewart, and Serlin (2008)	1	2	1
Han, Wise, Kim, Pingree, Hawkins, Pingree, McTavish, and Gustafson (2010)	1	2	1
Hansen, Gurney, Morgan, and Barraclough (2011)	0	1	0
Hogan, Wakefield, Nazi, Houston, and Weaver (2011)	1	2	2
Kollmann, Riedl, Kastner, Schreier, and Ludvik (2007)	1	2	0
Lee and Lee (2008)	1	2	2
Madhavan, Sanders, Chou, Shuster, Boone, Dente, Shad, and Hesse (2011)	2	2	2
Marziali (2009)	2	2	2
Nijland, van Gemert-Pijnen, Boer, Stehouder, and Seydel (2008)	2	2	1
Sheaves, Jones, Williamson, and Chauhan (2011)	1	1	0
Tripathi, Delano, Lund, and Rudolph (2008)	2	2	2
Mean Assessment by Characteristic	1.18	1.71	1.06

Every e-health example we assessed exhibited moderate or high levels of at least one PCEH characteristic, and five examples (29 percent) fully implemented all PCEH characteristics. The mean assessments for patient-focus, patient-activity, and patient-empowerment were all > 1, indicating that the e-health services we studied exhibited moderate to high levels of these characteristics on average. Of the fifty-one total assessments we made (three assessments each of seventeen e-health examples), twenty-five were high level, seventeen moderate level, and only nine low level; 82 percent were moderate or high level (see Figure 2). The results indicate PCEH characteristics are broadly represented across the studies we assessed. Presence levels were highest for patient-activity and lowest for patient-empowerment.

VI. DISCUSSION

Our research objectives were to ascertain the generalizability and abstraction properties of patient-focus, patient-activity, and patient-empowerment to the theoretical domain and to explore relationships among the PCEH characteristics. These objectives are part of an overarching goal to move toward a guiding theory of PCEH that may at some future time become useful for explaining relationships in this area as well as predicting empirical effects of those relationships. We explain in the following sections how these research objectives were supported by our research design and findings.

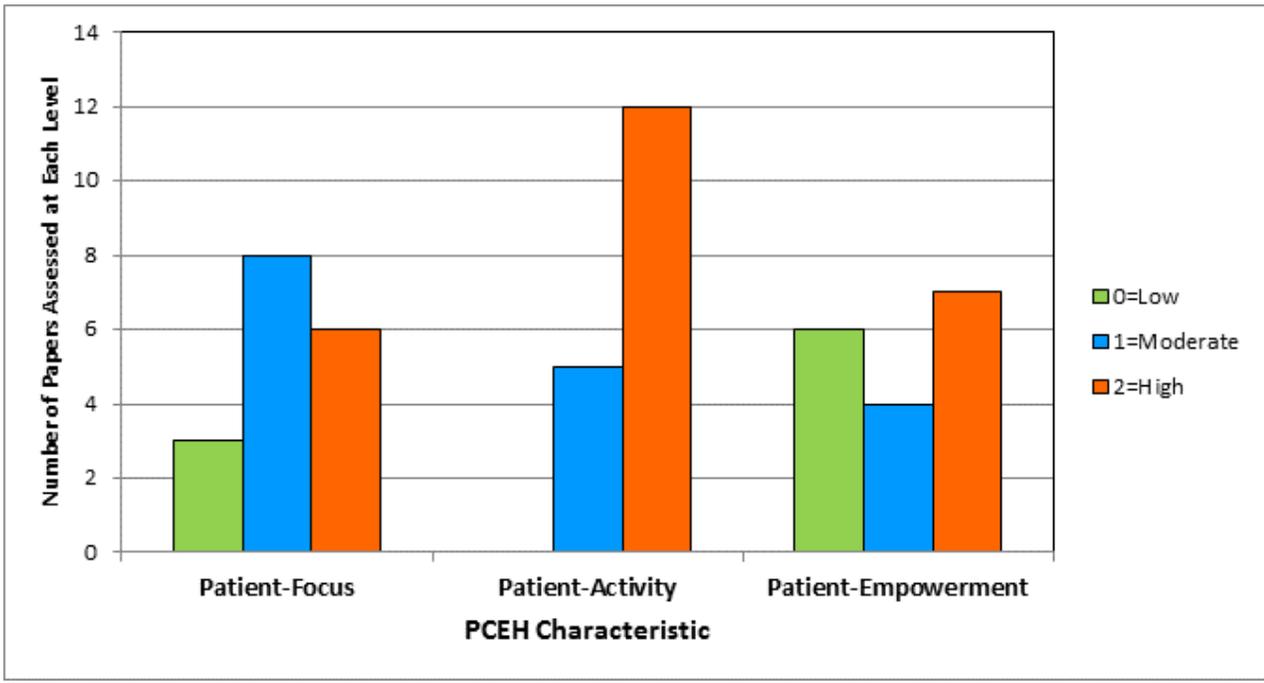


Figure 2: Histogram of Patient-Centered E-Health Characteristics

Generalizability and Abstraction

The findings show that a substantial portion of the e-health literature in this area has incorporated the PCEH characteristics proposed by Wilson [2009]. Nearly a third of the e-health examples we reviewed showed high levels of all three characteristics. The ubiquitous presence of patient-focus, patient-activity, and patient-empowerment characteristics in the studies we reviewed implies that the characteristics meet the theoretical criteria of generalizability and abstraction.

Generalizability. Our selection of the literature was drawn by entering search terms related to patients and e-health into the PubMed database, resulting in over 2,900 results. We recognize that numerous other search terms could have been entered, such as “online,” “Internet,” “portal,” “consumer,” or “e-patient,” and other research databases could have been searched in order to find additional papers that described specific e-health services supplied by a healthcare provider. Given our goal of assessing a representative selection of studies rather than exhaustively identifying studies, we argue that the findings obtained in this manner are adequately generalizable across the research literature domain that we intended to sample.

Abstraction. E-health services are supported and transported via Internet technologies, which are dynamic and fast-changing. Our approach to ensure adequate abstraction across time in our research design was to search across the most recent five years of published studies rather than extending the search back to an era of limited bandwidth and reduced computational capabilities. Abstraction across space was ensured by the wide reach of publications indexed in the PubMed database. We argue that this approach ensures adequate abstraction in assessment of the PCEH domain.

Relationships Among PCEH Characteristics

To explore relationships, follow-up correlational analysis was conducted using the ordinal coded data from the patient-focus, patient-activity, and patient-empowerment columns in Table 1. We find the PCEH characteristics to be substantially intercorrelated (Spearman’s rho ranged from 0.69 to 0.77 between columns). This indicates that, although conceptually distinct, these characteristics are strongly related in the manner in which they are implemented in e-health services. The significant shared variance exhibited by these characteristics further suggests that it may be appropriate to model a distinct PCEH construct as a second-order latent factor in future theory development [Liu, Li and Zhu, 2012; Thurstone, 1944]. Further research will be necessary to confirm this interpretation; however, the initial finding is encouraging to further development and testing of our research model.

Additional Implications

There are two further implications from observations we made during screening and analysis in this study.

First, despite retrieving nearly 3,000 initial papers, we found only seventeen peer-reviewed journal articles published between 2007 and 2011 that describe e-health services supplied by a healthcare provider. As discussed previously, this could be due to our choice of search keywords and exclusive use of the PubMed database. However, related research suggests the small representation is more likely due to a bias in the healthcare informatics research community toward topics that do *not* involve patients' use of e-health. Samoocha, Bruinvels, Elbers, Anema and van der Beek [2010] report a review and meta-analysis of randomized controlled trials that studied effects of Web-based interventions on patient-empowerment. Their study searched the Medline, Embase, and PsychInfo databases from January 1985 to January 2009 and netted only fourteen studies.

Our suspicion of systematic bias is further supported by Table 2, which shows the proportion of papers we reviewed that were published in healthcare informatics journals, non-informatics healthcare journals, and journals outside healthcare. Nearly half the papers (47 percent) come from journals outside the healthcare informatics category.

Table 2: Proportion of Papers in Three Journal Categories

Category	Journal	Journal total	Category total
Healthcare informatics journals	<i>BMC Medical Informatics and Decision Making</i>	1	9
	<i>Informatics in Primary Care</i>	1	
	<i>Informatics for Health & Social Care</i>	1	
	<i>International Journal of Medical Informatics</i>	1	
	<i>Journal of the American Medical Informatics Association</i>	1	
	<i>Journal of Medical Internet Research</i>	2	
	<i>Telemedicine Journal and E-Health</i>	2	
Non-informatics healthcare journals	<i>American Journal of Preventative Medicine</i>	1	6
	<i>BMC Health Services Research</i>	1	
	<i>Health Affairs</i>	1	
	<i>Journal of General Internal Medicine</i>	1	
	<i>Medical Journal of Australia</i>	1	
	<i>Social Science & Medicine</i>	1	
Journals outside healthcare	<i>Journal of Communication</i>	1	2
	<i>Journal of Computer Mediated Communications</i>	1	

The implications of this analysis reprise the situation information systems (IS) researchers once faced in publishing health-related work in IS journals. Prior to 2003, only 1.2 percent of all papers published by mainstream IS journals addressed *any* aspect of healthcare [Chiasson and Davidson, 2004], although the healthcare sector accounted for up to 14 percent of the U.S. GDP during that time. In recent years the percentage of health IS papers has increased dramatically in IS journals, suggesting that perseverance by authors, reviewers, and editors can raise the visibility of underreported topics [Wilson and Tulu, 2010].

Second, while mean assessments of patient-focus, patient-activity, and patient-empowerment exceeded the midpoint value of the measurement scale (1.00), these assessments varied significantly among the characteristics. Patient-activity (mean = 1.71) was implemented at higher levels than either patient-focus (mean = 1.18) or patient-empowerment (mean = 1.06). Results from the nonparametric Wilcoxon Signed Ranks test of mean differences shows $Z \geq 3.0$ and probability $\leq .01$ in both contrasts. One interpretation is that some e-health designers resist giving patients control by failing to *focus* on patients' desires or to *empower* patients with capabilities beyond the minimal actions required to use basic features of the e-health service. Winkelman makes a similar observation in reviewing a study of a patient-accessible electronic patient record system:

[The system] shares a common identity paradox with these other systems in that it portends to be patient-centered while employing physician-centered design and evaluation frameworks. It is therefore not surprising that, in their study, patient access has little measureable impact on patient-specific health outcomes. [Winkelman, 2004, p. 1]

The findings suggest that e-health designers and managers need to reflect on the technological context their products are going to be viewed within. Earlier in the paper we noted that e-health must appeal to patients or they will not adopt it. We further cited several examples where adoption efforts failed [Greenhalgh et al., 2010; Payton and Brennan, 1999; Sassene and Hertzum, 2009]. The Web is no longer new and users are not naïve in evaluating e-health. Web users have come to expect applications that satisfy their needs and give them extensive capabilities. *E-health that is designed without meeting these basic expectations of Web users is designed to fail.*

VII. CONCLUSION

Our study represents a new stage in PCEH research that moves beyond the initial definitions presented by Wilson [2009]. By supporting the proposition that patient-focus, patient-activity, and patient-empowerment are generalizable and abstract within the theoretical domain, and by exploring relationships among these characteristics, we move toward the “explained set of conceptual relationships” that constitutes theory [Wacker, 2008, p. 7]. In this way, our findings underpin and encourage future research that can develop and test relationships and predictions based on our proposed PCEH research model.

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Editor's Note: The following reference list contains hyperlinks to World Wide Web pages. Readers who have the ability to access the Web directly from their word processor or are reading the article on the Web can gain direct access to these linked references. Readers are warned, however, that:

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