Underpinning a Guiding Theory of Patient-Centered E-Health

*Presentation of Wilson, Wang, and Sheetz (2014)*

**E. Vance Wilson, Ph.D.**

**Weiyi Wang, M.S.**
Worcester Polytechnic Institute

**Steven D. Sheetz, Ph.D.**
Virginia Tech
Agenda for the presentation

- Historical antecedents of
  - e-health,
  - patient-centering, and
  - patient-centered e-health (PCEH)
- Theory-building in the context of PCEH
- Literature study: 2007-2011
- Specific discussion of the findings
- A larger discussion of the role of IS researchers in PCEH and other health-IS topics
- References cited in the presentation
Origins of e-health

- *E-health* was coined in the late 1990’s to describe commercial ventures supplying encyclopedic health information to consumers, most of which vanished in the dot-com bust of 2000-2001.

- Healthcare providers began to implement e-health in the early 2000s despite their early resistance that arose from:
  - Unsettled security, privacy, and liability issues.
  - Lack of governance in the web environment.
  - Difficulty competing with commercial ventures.
The e-health build-out

- “E-health” has become an umbrella term used to describe services as diverse as electronic patient records, telemedicine, and biomedical informatics.
- Researchers studying e-health supplied by healthcare providers began floating new labels to describe this more specialized domain, including:
  - Provider-delivered e-health
  - Consumer health informatics
  - Personal health informatics
Patient centering

- Patient-centered care is “providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions” (IOM, 2001)
  - Patient centering theorized to improve quality of care
  - Patient centering implicitly derives from problems perceived with physician-centered care
Patient-centered e-health

The first scholarly use of the phrase *patient-centered e-health* in the doctoral dissertation of Christopher Lau (Lau, 2003) who used it to describe e-health services offered by healthcare providers to their patients, including

- health information
- appointment scheduling
- prescription refills, and
- patient-provider email
Why is patient centering important to e-health?

- Patients can choose to adopt or not adopt e-health
- Expensive e-health services designed with an *organizational focus* frequently fail
  - Diabetes decision support (Payton and Brennan, 1999)
  - Asthma self-management (Sassene and Hertzum, 2009)
  - Personal health records (Greenhalgh et al., 2010)
- Kaiser-Permanente and some other pioneering healthcare providers have proven the concept that patients will adopt e-health offering features and functions that meet their actual needs (Silvestre et al., 2009)
Why is theory important to PCEH?

- Theory can provide
  - Clarification
    - of concepts and relationships among them
  - Justification
    - through ability of relationships to be tested and, potentially, falsified
  - Prediction
    - of future outcomes based on theorized relationships
  - Explanation
    - why the relationships exist and how they can be modified
What are the key PCEH concepts?

- Wilson (2009) proposed that three properties are key to achieve ideal benefits of patient centering in e-health
  - **Patient-focus**: PCEH is developed based primarily on the needs and perspectives of patients
  - **Patient-activity**: PCEH supports meaningful participation by patients in providing information about themselves and consuming information of interest to them
  - **Patient-empowerment**: PCEH provides the ability for patients to control far-ranging aspects of their healthcare, similar to other venues (e.g., office visits)
What would a guiding theory of PCEH look like?

Original PCEH model (Wilson, 2009)
What would a guiding theory of PCEH look like?

- In this paper, we theorize that joint presence of these three properties will increase patients’ adoption and use of e-health, illustrated within a nomological network.

Proposed PCEH research model
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Focus of this study

Proposed PCEH research model

Patient-Focus
Patient-Activity
Patient-Empowerment
Patient-Centering

E-Health Adoption and Use by Patients
Study of PCEH domain and relationships

- Goal: Assess the theoretical domain and fundamental aspects of relationships among the PCEH properties within a representative selection of studies of e-health services that are designed for use by patients

- Wacker (2008) explains that “good” theory incorporates:
  - **Definitions** – explained terms (provided by Wilson, 2009)
  - **Domain relevance** – ability of findings to be generalized across research settings and abstracted across time
  - **Relationships** – ability to explain how the theorized factors are related
  - **Predictions** – ability to predict future findings
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Study methods

- Keyword-based literature search of peer-reviewed journal articles published in 2007-2011 period
  - “(e-health OR ehealth) AND (patient OR patients)” entered on all fields in PubMed database (21 million articles)
  - Query resulted in 2920 initial results
- Results were screened to retain papers that describe e-health services for patients, supplied by a healthcare provider:
  - Titles and abstracts of papers were reviewed by one researcher
  - Contents of 62 papers remaining after initial screening were read by two researchers
Study methods

- Two researchers independently evaluated 17 remaining papers using the following assessment protocol
  - Coded each property as:
    - low (0) – no evidence of meaningful presence of the property
    - moderate presence (1) – evidence of limited or partial presence
    - high presence (2) – evidence of substantial presence
  - Coding differences were resolved by consensus
Study methods

- Mean ratings of properties

![Bar chart showing average ratings for Patient-Focus (Avg. = 1.18), Patient-Activity (Avg. = 1.71), and Patient-Empowerment (Avg. = 1.06).]
Study results

- **Domain relevance** was established by presence of PCEH properties in our sample; we found evidence of
  - Generalizability across representative studies
  - Abstraction across time (five-year review period)
- **Relationships among properties** were substantial in size (Spearman’s rho correlation ranges between .69 and .77)
  - Indicates the theorized PCEH properties tend to be implemented together rather than independently
  - Encourages the idea that patient-centering can be evaluated as a distinct second-order factor in predicting patients’ adoption and use of e-health
Each theorized PCEH property was present in the majority of studies we reviewed.
Our research model proposes that a second-order factor titled “patient centering” will arise from the joint contribution of PCEH properties; future research will be needed to completely test this proposition.
Some questions raised by the research

- Of the 21 million papers indexed in PubMed only 17 met our criteria—does this imply a gap in research interest?
  - Our finding is consistent with recent research on patient empowerment that found only 14 studies across major medical databases (Samoocha et al., 2010)

- Only 53% of papers in our study came from health informatics journals
  - Does this finding point to a bias on the part of health informatics journals against patient e-health studies?
Some questions raised by the research

- Why is patient-activity higher than the other properties?
  - Activity is required for certain services to function
  - Future research should explore whether e-health designers resist focusing on patients or empowering patients
Study conclusion

- The 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 relevant, 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.
A Larger Discussion
of the role of IS researchers in PCEH
and other health-IS topics
Needed: Health-IS research communities

- I use the term *Health-IS* to describe the activities of IS scholars and IS-educated practitioners when they work in the general areas of health and wellness

- Benefits of a health-IS research community:
  - A pool of reviewers who are interested in both IS perspectives and healthcare topics
  - A subset of this review pool containing scholars who are willing to take on editorial positions and are knowledgeable regarding IS and healthcare topics
  - Publication outlets for health-IS research that are valued by deans, peers, and promotion and tenure committees
Example case: A PCEH community

- As you know from this presentation, PCEH terminology
  - was coined to address the then-new phenomenon of healthcare providers supplying patient services via the Internet
- and has now been used in numerous scientific papers,
- but no consensus regarding PCEH terminology or movement toward theoretical development has emerged from the health informatics field, so in 2007 we set about constructing a PCEH health-IS research community
Example case: A PCEH community

- Initial book (Wilson, 2009)
  - Established context for considering PCEH as a special application of user-centered design principles
  - Called for a emergence of a research community

- Laid out key principles of what PCEH “should be”
- Illustrated the PCEH framework and several applications

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Example case: A PCEH community

- 2014 *Communications of the AIS* Special Section on Patient-Centered E-Health
  - Tested initial propositions of PCEH
  - Began developing “underpinnings” of a PCEH theory
  - Focused heavily on adoption and use of PCEH
    - (Note the strong IS perspective in play here)
  - Drew heavily from a pool of health-IS reviewers that *CAIS* has developed over the past decade
    - (Paul Gray authorized the IS and Healthcare Department at *CAIS* beginning in January of 2004)
Example case: A PCEH community

- Results of developing a health-IS research community...
  - Editors said “Yes” when approached with ideas for special publication venues
  - Reviewers said “Yes” when asked to review this topic, providing quick turnaround and supportive comments
  - 15 papers were published in the 2014 CAIS Special Section on PCEH (see http://aisel.aisnet.org/cais/vol34/iss1/)
  - The health-IS research community now leads this research stream
  - Publication of leading research on PCEH increases respect for health-IS topics in general
Summary of the “larger discussion”

- There are practical benefits in a **health-IS perspective**
  - Publications in the IS field reinforce value of health-related topics
  - Researchers gain better support for succeeding in their careers
- Health-IS researchers can draw on unique IS skills to address topics that are important yet understudied in the existing health informatics literature
- By developing health-IS research communities, we can direct the course of research streams and major topics of study rather than simply follow the lead of other fields
Resources for health-IS researchers

- **AIS SIGHealth** (Special Interest Group on Information Technology in Healthcare)
  - AIS members are invited to join SIGHealth, which
    - Coordinates health-IS conference tracks at AMCIS, ECIS, and PACIS
    - Organizes workshops and special issues around health-IS topics
    - Provides a collegial and supportive environment for networking with fellow health-IS researchers

- **CAIS** Information Systems and Healthcare Department
  - Consider submitting your health-IS manuscript to CAIS, where the IS and Healthcare Department has published more than 60 articles since 2004
References cited in the presentation


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