Evidence-based Practice
Findings from the Section on Education and Consumer Health Informatics

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Summary

Objectives: To provide an overview of outstanding current research conducted in Education and Consumer Informatics.

Method: Synopsis of the articles on education and consumer health informatics published in 2012 and selected for the IMIA Yearbook of Medical Informatics 2013.

Results: Architecture of monitoring or telehealth information systems for patients with chronic disease must include wireless devices to aid in the collection of personal data. Data acquisition technologies have an impact on patients' willingness to participate in telehealth programmes. Patients are more likely to prefer mobile applications over web-based applications. Social media is widely used by clinicians. Especially younger clinicians use it for personal purposes and for reference materials retrieval. Questions remain on optimal training requirements and on the effects on clinician behavior and on patient outcomes. A high level of e-Health literacy by patients will promote increased adoption and utilization of personal health records.

Conclusion: The selected articles highlight the need for training of clinicians to become aware of existing telehealth systems, in order to correctly inform and guide patients to take part in telehealth systems and adopt personal healthcare records (PHR).

Keywords

Consumer health information, consumer participation, information services, health education, medical informatics

Introduction

In 2005, as Consumer Health Informatics (CHI) was rapidly evolving, Bakker and al [1] published the results of a pilot study aiming to develop a "toolbox" of research and evaluation instruments to promote reuse of validated or semi-validated tools by CHI researchers. According to the study, the process of designing a CHI toolbox needed an operational definition of consumer health research and a standardization of key terms across disciplines (e.g., a "CHI metathesaurus"). Nowadays, the term "consumer health IT applications" still remains underspecified and not well defined. It generally refers to a wide range of hardware, software, and web-based applications that allow patients to participate in their own health care via electronic means. The American Medical Informatics Association (AMIA) considers the field of consumer health informatics as "a subspecialty of medical informatics which studies from a patient/consumer perspective the use of electronic information and communication to improve medical outcomes and the health care decision-making process." Consumer informatics stands at the crossroads of other disciplines, such as nursing informatics, public health, health promotion, health education, library science, and communication science.

Methodology

The term "consumer health informatics" is not a MeSH term. The closest term is "consumer health information", introduced in 2008. It is defined as: "Information intended for potential users of medical and healthcare services. There is an emphasis on self-care and preventive approaches as well as information for communi-

ty-wide dissemination and use." In order to build the query to identify papers for this synopsis, the approach was influenced by various prior efforts. The first one was published in 2009 by the Agency for Healthcare Research and Quality [2]. This report reviewed the evidence on the impact of consumer health informatics applications on health outcomes. The appendix C of this report provides the detailed search strategies. Then we analyzed the sections of the Consumer Health Informatics Research Resource website [3], which provides a list of terms that can be considered as qualifiers. We also used the website KNALIJ (pronounced as "knowledge") [4] to help us at finding the most frequently related terms to customized expressions.

1   Pubmed Search

First, we identified two queries: "consumer health informatics [Text Word]" and "personal health informatics"[Text Word][1]. Searching Pubmed retrieved respectively 72 articles (from 1995 to 2012) and 5 articles (all published in 2012 and indexed for the Yearbook of Medical Informatics). We analysed the sets of MeSH terms indexing the latest articles. We then used the KNALIJ tool to identify other related terms. Retrieving parameters set for KNALIJ retrieval were "maximum number of

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[1]   Terms that are qualified with the Text Word [tw] field tag will be searched in the following fields: Title; Abstract; MeSH headings and Subheadings (includes single words and phrases); Other Terms field (which includes author-supplied keywords); Chemical Names of Substances; Secondary Source Identifier, which identifies a secondary source that supplies information, e.g., other data sources, databanks and accession numbers of molecular sequences (e.g., GenBank; ClinicalTrials.gov – beginning in July 2005); Personal Name as Subject

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articles: 2500", "number of iterations: 300" and "map decrowding factor: 2.50". We asked for the "Search Results Map (MeSH)" map type. The main related MeSH terms found were:

- Internet
- Consumer Health Information
- Medical Informatics
- Health Education
- Consumer Participation
- Information services

We added a few other terms in order to specify usage topics or tools:

- Community networks
- Consumer product safety
- Consumer satisfaction
- mhealth
- Patient portals
- Patient safety
- Personal health
- Personal health records
- Personalized medicine
- Social media

The Pubmed query we built is detailed below:
" ((" 2 0 1 2 / 0 1 / 0 1 " [P P D A T] : "2012/12/31"[PPDAT]) NOT Bibliography[pt] NOT Comment[pt] NOT Editorial[pt] NOT Letter[pt] NOT News[pt] NOT Case Reports[pt] NOT Published Erratum[pt] NOT Historical Article[pt] NOT Legal Cases[pt] NOT legislation[pt]) AND ("community networks"[TIAB] OR "consumer health informatics"[TIAB] OR "consumer health information"[TIAB] OR "consumer product safety"[TIAB] OR "consumer satisfaction"[TIAB] OR "decision support techniques"[TIAB] OR "ehealth"[TIAB] OR "electronic patient-physician communication"[TIAB] OR "mhealth"[TIAB] OR "mind games"[TIAB] OR "patient centered care"[TIAB] OR "patient portals"[TIAB] OR "patient safety"[TIAB] OR "personal health"[TIAB] OR "personal health records"[TIAB] OR "personalised medicine"[TIAB] OR "telehealth"[TIAB] OR "social media"[TIAB] OR "telemedicine"[TIAB]) NOT medline[sb] AND English[lang]"

2 Web of Science Search (WoS)

We used an advanced query based on a list of keywords: consumer health informatics, consumer product safety, consumer satisfaction, personalized medicine, telehealth. We selected only specialized fields, such

as "medical informatics", "computer sciences interdisciplinary application". The WoS query we built is detailed below:

"(TI=(consumer health information) OR TI=(consumer health informatics) OR TI=(consumer product safety) OR TI=(consumer satisfaction) OR TI=(electronic patient-physician communication) OR TI=(patient centered care) OR TI=(patient portals) OR TI=(patient safety) OR TI=(personal health) OR TI=(personal health records) OR TI=(personalized medicine) OR TI=(telehealth) OR TI=(social media) OR TI=(telemedicine)) AND Language=(English) AND Document Types=(Article) Refined by: Document Types=(ARTICLE) AND Web of Science Categories=(INFORMATION SCIENCE LIBRARY SCIENCE OR COMPUTER SCIENCE ARTIFICIAL INTELLIGENCE OR PUBLIC ENVIRONMENTAL OCCUPATIONAL HEALTH OR MEDICAL INFORMATICS OR COMPUTER SCIENCE INFORMATION SYSTEMS OR COMPUTER SCIENCE INTERDISCIPLINARY APPLICATIONS) Databases=SCI-EXPANDED, CPCI-S, CPCI-SSH, IC Timespan=2012-01-01 - 2012-12-31 (Processing Date) Lemmatization=On"

We identified 148 papers. There were duplicated items retrieved both by Pubmed and WoS queries.

The first set of identified papers had been published in the following journals (alphabetical order) and sent to reviewers.

- Appl Clin Inform
- BMJ Open
- Diabetes Obes Metab
- IEEE Trans Biomed Eng
- Int J Gen Med
- Int J Med Inform
- Int J Telemed Appl
- J Am Med Inform Assoc
- J Consum Health Internet
- J Dent Educ
- J Med Syst
- J Telemed Telecare
- Perspect Health Inf Manag
- Telemed J E Health

Results

Based on the reviewer feedback, we selected four papers. One is presenting the key features of a system implemented to monitor cardiac and diabetic conditions, and highlights improvements compared to previous systems. The second paper explores the compliance of diabetic patients using two technologies (web-based versus mobile application) to monitor their conditions. As clinicians provide part of patient education, we also selected a paper that reviewed social media use by clinicians. The last paper tested patient's e-health literacy level as function of improved adoption of a personal health record.

References

1. Bakker TA, Ryce AN, Logan RA, Tse T, Hutcherson L. A Consumer Health Informatics (CHI) Toolbox: Challenges and Implications. AMIA Annu Symp Proc 2005;2005:21–5.
2. Gibbons MC, Wilson RF, Samal L, Lehmann CU, Dickersin K, et al. Impact of Consumer Health Informatics Applications. Evidence Report/Technology Assessment No. 188. (Prepared by Johns Hopkins University Evidence-based Practice Center under contract No. HHSA 290-2007-10061-I). AHRQ Publication No. 09(10)-E019. Rockville, MD. Agency for Healthcare Research and Quality. October 2009.
3. Consumer Health Informatics Research Resource. http://http://chirr.nlm.nih.gov/ (last visit: 05.01.2013).

Table 1 Best paper selection of articles for the IMIA Yearbook of Medical Informatics 2013 in the sections 'Education and Consumer Health Informatics'. The articles are listed in alphabetical order of the first author's surname.

Section
Education and Consumer Health Informatics

- Mulvaney D, Woodward B, Datta S, Harvey P, Vyas A, Thakker B, Farooq O, Istepanian R. Monitoring heart disease and diabetes with mobile internet communications. Int J Telemed Appl 2012;2012:195970.
- Noblin AM, Wan TT, Fottler M. The impact of health literacy on a patient's decision to adopt a personal health record. Perspect Health Inf Manag 2012;9:1-13.
- Schreier G, Eckmann H, Hayn D, Kreiner K, Kastner P, Lovell N. Web versus app: compliance of patients in a telehealth diabetes management programme using two different technologies. J Telemed Telecare 2012;18(8):476-80.
- von Muhlen M, Ohno-Machado L. Reviewing social media use by clinicians. J Am Med Inform Assoc 2012 Sep-Oct;19(5):777-81.

4. KNALIJ for PubMed. http://knalij.com (last visit: 05.01.2013).

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Appendix: Content Summaries of Selected Best Papers for the IMIA Yearbook 2013[2]

Mulvaney D, Woodward B, Datta S, Harvey P, Vyas A, Thakker B, Farooq O, Istepanian R

Monitoring heart disease and diabetes with mobile internet communications

Int J Telemed Appl 2012;2012:195970

Five institutions in England and India, who are part of the UK-India Education and Research Initiative (UKIERI project), report the implementation of a telemedicine system specifically for cardiac and diabetic monitoring using mobile telecommunications networks in India. By leveraging prior work, the authors identified, addressed, and tested new features to provide improved accuracy and granularity of monitoring. This included allowing the patients to record typical vital signs by means of an enhanced network of wireless sensor nodes; identifying specific and relevant measurements to provide indicators for trend analysis and possible early alerts for complications; allowing an increased use of web browsers on mobile devices; enhancing the security level of transmitted patient data. The schematic of the telemedicine architecture shows how the patient is involved to enter and validate his/her own data. Data dictionary and value sets for cardiac and diabetic monitoring were defined and tested. Despite its descriptive aspect, this article gives a pragmatic and detailed view of the information system designed and implemented for both patients and physicians.

Schreier G, Eckmann H, Hayn D, Kreiner K, Kastner P, Lovell N

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[2] The complete papers can be accessed in the Yearbook's full electronic version, provided that the article is freely accessible or that your institution has access to the respective journal.

Web versus app: compliance of patients in a telehealth diabetes management programme using two different technologies

J Telemed Telecare 2012;18(8):476-80

The objective of this study was to compare two methods of collecting and communicating health-related data among a population of diabetic patients. Main criterion was patients' dropout rates for each data acquisition technology. The experimental design was not randomised and patients were asked to choose between a browser-based user interface (web), a mobile phone and NFC (Near Field Communication)-based patient terminal (app), or both. Patients who used both methods were assigned to the group with which they transmitted more than 50% of the data. The Kaplan-Meier curve was used to compare compliance in the two groups. 403 patients were enrolled in the programme and completed it. The mean length of time that a patient used the system was 374 days (range 1-767). 291 patients transmitted data using the App and 112 via the Web. The two groups did not differ significantly with respect to age or type of diabetes, but the percentage of women in the two groups was significantly different, with more women choosing the App method. The Kaplan-Meier curve comparing compliance between males and females was not significant (p=0.30). Patients using the App remained active significantly longer than patients mainly submitting data via the Web (p=0.027). The authors concluded that the type of data acquisition technology has an effect on patient's willingness to participate in telehealth programmes in the long-term.

von Muhlen M, Ohno-Machado L

Reviewing social media use by clinicians

J Am Med Inform Assoc 2012;19(5):777-81

Social media has broadly affected medicine and has motivated research quantifying social media adoption and its impact on clinician communities. Among 370 articles retrieved until July 26th, 2011, 50 were selected for review and classified into five mutually exclusive and exhaustive categories: overviews, adoption surveys, reference materials retrieval, educational impact and use, and professional conduct. Fifteen studies reporting on surveys of the adoption of social media were identified; the most commonly used metric surveyed

was the utilization of Facebook. Students generally showed high usage (64-96%) and professionals lower (12.8-46.7%). Clinicians' concerns over consumers' use of social media center on 1.) potential negative consequences from breaches in patient confidentiality and 2.) publication of unprofessional content. The appropriateness of this student-faculty 'friend' relationship 'friending' also raises new ethical questions. Guidelines for physicians have been proposed: avoid accepting patient friend request; avoid adding private information gathered online to a patient's medical record; restrain from disclosing personal information online; understand privacy settings to ensure that content meant for private access does not becomes public. It is still unclear whether social media will become a critical part of healthcare or remain an 'adjunct' technology. Awareness and interest are evident across multiple disciplines as are concerns regarding potential misuses. It will take several years to understand the effects of social media on clinician behavior and patient outcomes.

Noblin AM, Wan TT, Fottler M

The impact of health literacy on a patient's decision to adopt a personal health record

Perspect Health Inf Manag 2012;9:1-13

Health literacy is defined as the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions. This study aimed at identifying factors statistically linked to the adoption and persistent usage of a personal health record (PHR). Two factors were chosen: demographic characteristics (age: younger versus older people) and e-health literacy (high versus low level) measured by the eHealth Literacy Scale (eHEALS). The research was a cross-sectional study of patients who intended to use a PHR. It evaluated the association of PHR use and perceived health literacy, income, education, and age. 562 patients were included. None of the three demographic characteristics was significantly associated with the adoption of a PHR. Among patients who intended to adopt a PHR, 65 percent indicated a high-perceived health literacy level (p<0.01). Authors recommended that physicians, who plan to provide a PHR for their patients, should look beyond the demographic characteristics and seek to understand how well patients perceive their health literacy level.