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The Personal Health: A Systematic Review

Gilan Tavakoli Ordeghan
Islamic Azad University, Electronic Unit, Department of Health Services Management, Tehran, Iran
Corresponding Author Email: Gilantavakoli@yahoo.Com

ABSTRACT─ Despite several personal health record (PHR) product offerings from major technology sector players over the past years, the notion of tracking and maintaining one's personal health information electronically has failed to takeoff among consumers. Accordingly, we explore factors potentially shaping use of PHR applications. People's trust in the health system plays a role in explaining one's access to and utilization of medical care, adherence to medications, continuity of care, and even self-reported health status. Yet it is not easy to find trust measures and understand what they are measuring. We developed a health systems trust content area framework, where we identified that honesty, communication, confidence and competence were captured frequently in these measures, with less focus on concepts such as fidelity, system trust, confidentiality and fairness. Greater development and use of trust measures in the health system could improve monitoring and evaluation efforts, which may in turn result in better health outcomes.
KEYWORDS: Health, Mental health, Personal health, Psychosis

Introduction

A large body of literature has established that health problems, in particular mental health problems, are more prevalent in certain parts of society. Specifically, those of low 'socio-economic status' (SES) have been found to have increased risk of poor mental health [1], depression [2], poor physical health and even death [3]. In the UK, areas of higher socio-economic deprivation have higher levels of deliberate self-harm [4], and psychiatric hospital admissions [5]. A study of ten European countries demonstrated that socioeconomic deprivation increases the risk of suicide [6], and a study of 65 countries by the World Health Organisation found that rates of depression varied by levels of income equality. As a result there is "widespread albeit often implicit recognition of the importance of socioeconomic factors for diverse health outcomes" [7], with many studies either looking at the effects of SES on health directly, or controlling for it as a potential confounding variable [7]. However in recent years a number of studies have begun to examine what specific aspects of low socio-economic status are related to adverse health outcomes. Unemployment specifically has been found to be related to mental illness and suicide [8]. The potential of personal health records to improve healthcare delivery and reduce costs has been recognized in many countries worldwide [9, 10]. In recent years, numerous PHR systems and their associated tools have been developed [11]. This global interest and phenomenal growth of personal health records systems, motivates an on-going research towards the evaluation of their functionality, usability and usefulness. In this paper, we provide an evaluation study of numerous PHR systems which emphasizes on optimal PHR functionality and presents our development efforts towards an intelligent PHR system. Overall, the results of this paper can serve as a basis for future evaluation and implementation studies which should be conducted periodically in the constantly evolving field of PHR systems.

Method

Databases and search terms three databases were searched: Psychinfo, Medline and Embase.
The following search terms were used to search all fields: 'Health' or 'Mental disorder' or 'Mental illness' or 'Depression' or 'Stress' or 'Distress' or 'Psychosis'.

Personal health records

Personal health records (commonly referred to simply as PHRs) offer users avariety of advantages aimed at patient empow- erment. These applications can create a more balanced and complete view for users, when compared to existing health records maintained by each individual provider anindividual might be apatient of [12]. Furthermore, PHRs offer additional features and functionality such as making online appoint- ments, supplemental information specific toillnesses, infor- mation about different healthcare providers, and options for self-care opportunities, among others [13]. With apersonal health record, each individual patient maintains and controls their health record [14]. Information recorded in a PHR often includes allergies, medical history, prescriptions, treatment regiments, and so on. Noteworthy, differences exist between a PHR and an electronic health record (EHR), or electronic medical record (EMR). While one or more healthcare providers hold the latter two, an often cited definition for a personal health record, provided by the Markle Foundation1 notes that a "personal health record (PHR) is an Internet-based set of tools that allows people to access and coordinate their lifelong health information and make appropriate parts of it available

to those who need it" [15]. Unfortunately, within the existing literature, few clinical trials and systematic reviews focusing on the effects of providing patients with the option of using and maintaining PHRs, particularly standalone applications, exist. A query of PubMed resulted in only a handful of relevant publications. Specifically, Tenforde, Jain, and Hickner [16] found limited evidence of the value of PHRs, identifying only three randomized trials in their research. Furthermore, the authors note these trials were plagued by "study limitations that obscure a clear interpretation of their results," with inconsistent results reported in original works reviewed [16]. Another recent publication reports on a pilot study comparing Google Health and Microsoft HealthVault, when tethered to an advanced HER application maintained by the United States military [17]. Noteworthy, the study context, namely, a highly tethered system within a large centrally maintained comprehensive healthcare network that includes the full spectrum of primary care and specialty providers, laboratory and diagnostic facilities, and so on, undermines our ability to gain a greater understanding of the PHR adoption challenges in other more fragmented contexts or as applicable to the general population. On a related note, Collins et al. [18] found such highly tethered PHR applications limited to healthcare institutions with "sufficient financial, intellectual, and human capital resources" capable of supporting large-scale initiatives fostering adoption within such environments. Accordingly, given systems not limited to aspecific user population, exploring the challenges to standalone PHR adoption constitutes an important pursuit. Archer et al. [19] purport several reasons for maintaining a PHR:

1. Patient–Provider communication: The benefits of, and satisfaction with, PHR applications include easier access to test results and faster communications with healthcare practitioners.
2. Education and lifestyle changes: In addition to personal data and data from the provider, a PHR can store other data on, for instance, social status, family history, and work environment. Moreover, lifestyle related data, like diet, exercise, smoking, and weight, can be stored.
3. Health self-management: Patient health self-management can be supported by PHRs that allow end-users to record, edit, and retrieve their healthcare data, including, as an example, blood glucose and blood pressure measurements, weight and activity logs, and stress scales. Frequent monitoring can lead to early detection of critical situations and timely intervention.
4. Patient empowerment: Maintaining even limited information about their own health status, finds patients empowered to make more informed decisions with their providers. Closely aligned with the notion of empowerment, Collins et al.'s [18] telephone survey of 17 organizations with tethered PHR applications notes increased patient engagement.

Studies with students

Thirteen studies looked at the relationship between debt and health in university students, primarily in the UK and US. Many of the studies in the US consisted of secondary analyses of existing data sets from large national surveys, and hence had large sample sizes, for example [20] had more than forty thousand participants. However these larger studies tended to rely on author constructed questions on health. The US studies also tended to focus on other health risk behaviours, such as unprotected sex and drink driving, and also focused on credit card debt specifically. Studies in the UK had smaller sample sizes, but all used a standardised measure of mental or physical health. Across the thirteen studies, there was one which was longitudinal [21], which followed British students across the three years of their degree. There was also a cohort study, which compared UK students to students in Finland where tuition fees are lower [22]. Demographics such as age and gender were controlled for by many studies, though six studies did not control for any variables. No study controlled for socio-economic status or other economic variables. In terms of findings, those with higher debt or financial concern were more likely to smoke [23] and drink excessively [24], though found no effect [25]. They were also more likely to use drugs [24], though Adams and Moore (2007) found those in debt were less likely to have used cannabis [25]. It is important to note the differences in how debt groups were defined, for example [26], looked at debt-to-income ratio, whilst [27] compared those who had considered dropping out for financial reasons, Adams and Moore (2007) compared groups based on level of credit card debt [27] and Stuhldreher et al. (2007) examined those with past gambling related debt[24]. Debt was found to be related to higher scores on the SF-36, a measure of both physical and mental health by four studies [28], and higher scores on the GHQ, a measure of global mental health [27]. However Ross et al. (2006) found that those with higher GHQ scores had lower debts [25]. Stuhldreher et al. (2007) found that those with past debt were more likely to score positive for depression on the BDI, and report higher stress levels [24]. Norvilitis et al. (2003) reported that debt-to-income ratio and attitudes to debt did not predict stress but financial well-being did [26]. Nelson et al. (2008) also reported greater body dissatisfaction in those with debt [29], and Adams and Moore (2007) reported higher BMI [20]. Cooke et al. (2004) used the CORE, a measure of global mental health to demonstrate that higher scores were related to levels of debt worry and financial concern [21]. Finally, Roberts et al. (1999) conducted path analyses demonstrating that amount of debt let to worse mental health via considering abandoning university and working longer hoursx [27]. Lange and Byrd (1998) similarly found that debt levels led to anxiety and depression via increase financial stress and strain, and cognitions such as locus of control around finances [30].

Health service user populations

As specific populations were studied sample sizes were inevitably small, ranging from 43 to 87. Standardised measures of health were used in all of these studies, however only two controlled for confounds. Patel et al. (1998) and Pothen, Kuruvilla, Philip, Joseph, and Jacob (2003) found that debt increased the risk of common mental disorders and depression specifically amongst primary care attenders in India after controlling for demographics [31, 32]. Abbo et al. (2008) found that those attending

traditional healers were more likely to be psychologically distressed if they were in debt [34]. Hatcher (1994) examined self-harmers, finding higher levels of depression, psychiatric diagnosis and suicidal intent in those with debt. Finally Battersby, Tolchard, Scurrah, and Thomas (2006) found that pathological gamblers with gambling-related debt were more likely to have suicidal ideation [35], whilst Maccallum and Blaszczynski (2003) found no relationship between amount of debt and suicidal ideation in gamblers [36].

Personal Health Record Framework

In this section we describe our development efforts towards an intelligent PHR system. Essentially, we selected an efficient PHR system based on the results of the previously described evaluation process and extended it into further intelligent behavior. The evaluation results which were presented in section 4 revealed that the most appropriate PHR system, according to our specified requirements, is the Indivo-X PHR system. Other PHR systems with high level of functionality are the Microsoft HealthVault and Dossia systems. On the other hand, the systems Tolven, MyOscar, and OpenMRS which were successful on the W-FOSS requirements presented limited functionality compared to Indivo-X system. Having selected our PHR system we decided to customize and extend further its intelligence factors. In the following subsections we describe our software additions to Indivo-X and argue about our extensions. However due to space restrictions we do not explain them in detail.

Intelligent Data Exchange

Since PHR consolidate patient health information, it is of great benefit to be able to share this
integrated, comprehensive source of health information with health care providers and/or other family members [37]. This could potentially bridge gaps in understanding, promoting more effective patient-provider dialogue, and improving care coordination for patients seeing multiple providers. To this direction, we have extended Indivo-X in order to be able to communicate with other health systems. Indivo-X has already implemented mechanisms for exporting data as JSON, XML and RDFS. However, although this is useful, most of the systems in the health domain understand HL7 messages. So, we have implemented an adapter that can transmit HL7 messages. We have to note that the content of this HL7 messages is also compatible with well-established terminologies such as SNOMED, RxNorm and LOINC. For data sharing, the patient can either accept to share data with a specific family member of health care provider or he can directly export his data to an HL7 message consumer. On the other hand besides exporting, importing is also a useful functionality since usually PHR systems require the error-prone and time-consuming process of manual data entry. So, in our case we extended the Indivo-X system to accept HL7 messages that directly insert patient data. Another import functionality that we provided is to link Indivo-X to other systems that can answer SPARQL queries. So, forms, lists etc. can be directly retrieved from SPARQL endpoints and stored within Indivo-X database. This way, information is made more useful to the patients and can play a larger role in their health care.

Profiling Services

A profiling server collects information from different sources and combines them to construct patient profiles. Incorporating a profiling server give us the ability to (i) optimize information delivery from doctors to patients, (ii) optimize information delivery to patients according to each specific profile and (iii) identify relevant clinical information, such as trials for enrollment, automatically. Central sources for our profiling services approach are the PHR (with its extensions) and the patient's psycho-cognitive information. Towards this direction we have implement a patient profiling questionnaire which is incorporated into the Indivo-X PHR system as an extension.

Conclusions

In an effort to better understand end-user motivations hindering adoption of personal health records offered by leading IT firms, we conducted a qualitative research effort integrating a literature review with potential end-user interviews. Our study aimed for establishing qualitative reasoning why PHR has not been successful to date. We find relevance, as seen by potential adopters, a major challenge to ultimately achieve widespread adoption of PHRs absent clear utility for users. Notwithstanding favorable potential user perceptions of system and service quality, trust in vendors and significant perceived risks in storing personal health information ultimately undermine adoption efforts.

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