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A Holistic Approach for Prevention and Early diagnostics:Personal Health Management With Web-Based Personal Health Records

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Abstract

Prevention and early diagnostics are actual topics in today's healthcare. A structured and integrated approach is desired to optimize and benefit from preventive healthcare. We envision personal health records (PHRs) to be a platform for personal health services. The current PHRs, however, mainly provide services that are focussed on cost reduction and management of specific diseases. Integrated prevention and early diagnostics approach is currently not a part of PHRs, whereas an expansion with such a service is desired to create a direct value proposition for health consumers. PHR-based services thus need to focus on prevention, early diagnostics and subsequent early intervention, next to disease management. In this paper we propose a holistic approach for preventive health services via PHRs and identify the issues related to this approach.

Keywords:

personal health records, medical records, prevention, early diagnosis, personal health management

Introduction

The rising costs in healthcare are mainly due to the major burden caused by diseases for which prevention and early intervention options are gaining scientific acceptance [1, 2]. As a consequence, there seems to be an increasing consensus that prevention and early diagnostics deserve more attention. Diseases and other conditions that are recognized early, often have better treatment options and better changes of success.

The efforts to realize a more preventive healthcare are countless, ranging from over the counter diagnostic tests, to warning stickers on lifestyle consumables. The same is true for personal healthcare services via the Internet. Several population based screening programs are offered, each with its own infrastructure and analytic process. Studies on efficacy of preventive healthcare and screening methods have shown that a fragmented approach of prevention, early diagnostics, and possible subsequent early intervention, lack efficacy. Instead, an integrated approach is opted for an optimal system.

Another important disadvantage of the current lack of structure for prevention and early diagnostics is the existing gap between relevant evidence-based advances and the actual implementation of these in preventive services [2-4]. A structural approach can play a crucial role in overcoming this problem as well.

The objective of this paper is to:

1. Identify issues in personal health services via web-based personal health records (PHRs).
2. Propose a framework for a holistic approach for services targeting prevention and early diagnostics.

First, we describe how PHRs have evolved to become a potential platform for personal healthcare services. Second, we describe a holistic approach for the provision of personal health services via PHRs.

Web-based Personal Health Records:first generation

The emergent PHRs development is the results of increasing concern about extent to which decentralization of healthcare has lead to scattering of personal medical information [5, 6]. The dispersal of individual health information is the consequence of increasing mobility and freedom to seek care from different providers and on-line personal health services. Due to this trend, consumer advocates have recommended patients to adopt a more proactive attitude towards collecting and organizing their own medical information [7].

The first description of an electronic PHR was in 1978, but it was not until the recent years that a number of online applications allowed patients to enter and manage information abstracted from medical records [8-10]. Currently, an increasing number of Internet users are adopting PHRs to control and manage their health data [11].

The first generation PHRs are characterized by the fact that they were created, owned and managed by individual patients, as opposed to provider-entered records. Configured along the lines of the professional medical records, these PHRs allowed patients to directly enter health information. Some of these PHRs were stored on standalone

devices such as UBS sticks or standalone applications on personal computers, while others were web-based systems (Figure1). The web-based applications use stored information to generate records that could be reviewed or transmitted to reviewers who are authorized by the patient. The main pitfall of the first generation of web-based PHRs is that professional caregivers did not adopt these systems, mainly due to conflicting workflows and distrust of stored information [7].

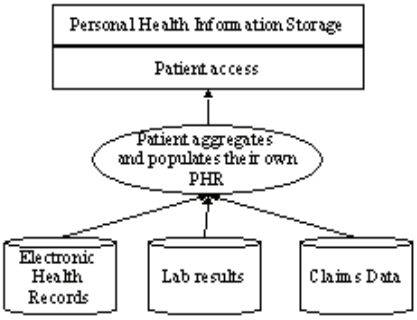

Figure 1 - Architecture of the first generation PHRs. Here the main focus was on aggregation and personal management of data from different sources in the healthcare system. Most of these systems are standalone application e.g. USB sticks, CDs, desktop application

Second generation of web-based PHR

The first generation web-based PHRs were promoted as a mean of providing patients and providers with universal access to up-to-date medical information. Evaluation shows that the primary focus on universal access resulted in limited functionalities [7].

The second generation web-based PHRs comprise longitudinal health information, sourced by both the patient and healthcare professional (Figure 2). This information typically comprises major illnesses, family history, medication, allergies, immunizations, social history, lifestyle data, diagnostic test results and sometimes home-monitored data like blood pressure and glucose levels. While first generation PHR vendors focused on users sourcing their own records, second generation PHRs are also populated by linkage with professional electronic medical or patient records and insurance claim databases. Hence, they are classified as integrated PHRs and enable additional services based on reliable data.

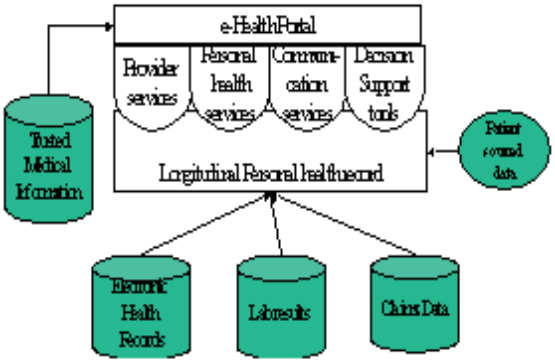

Figure 2 - Architecture of second generation PHR. Through an e-health portal, users can access trusted medical information. In addition, users can make use of different kind of services ranging from provider specific services to decision support tools. Web-based PHR integrates the patient's information from different sources

While many studies demonstrated the potential benefits of integrated PHRs [7, 12, 13], evaluation exposed concerns about lack of value proposition for the individual [7]. Most of the integrated PHRs were develop to lower healthcare expenses and not mainly to empower health consumers. As a consequence health consumers adopt the second generation PHRs very slow. As for now, vendors recognize that the value for the individual lies in the transformation of data into information that empowers individual health management [14]. As a means to this end, integrated PHRs also comprise decision support tools ranging from generating alerts and reminders to treatment comparisons.

Interactive prevention and early diagnostics services

The majority of online personal health services today are much more like the healthcare system itself. Online personal health services mainly focus on diseases or a particular health condition like diabetes and related self-management tools. Prevention and early diagnostics services seem to be in the scope of personal health services providers but they lack a holistic approach.

We spotted an opportunity to propose a holistic health management approach by incorporating an integrated tool for prevention and early diagnostics into a web-based PHR (Figure 1).

A holistic approach for prevention and early diagnostics

Healthy consumers could know their health status if PHR vendors would incorporate an integrated health risk assessment and management tool, based on a knowledge system for prevention and early diagnostics. The knowledge system itself should be based on evidence-based medicine

rules and methods, and should also be supported by the medical profession, to guarantee acceptance and for quality assurance.

Evidence-based algorithms within the knowledge system can processes data in the PHR into personal risk profiles for specific disorders. A risk profile indicates the risk of 'catching' a particular disorder, given the presence of the risk factors within a predefined time frame in the PHR. The risk profiles can than be communicated through personalized health services to educate the individuals how to reduce high-risk or maintain low-risk for a specific condition.

The personal health service could comprise a personalized health plan, that empowers individuals to be a 'co-pilot' own health by offering advise on how to adjust lifestyle variables (e.g. smoking, activity or nutritional habits) or implementing early intervention (e.g. a prescription drug). Guidance towards risk reduction could continue until the risk for a specific condition reaches a certain target, from whereon the focus shifts to low-risk maintenance. The workflow in this approach can be done simultaneously for all disorders with solid evidence-based prevention and early intervention options, creating the desired holistic approach. The PHR serves as a platform to incorporate the risk assessment, risk profile generation and health plan.

Challenges posed by the holistic approach

The proposed holistic health management approach pose some challenges that needs to be address before this can be a reality.

Data quality assurance

The first challenge that needs to be addressed is the completeness of the data in order to calculate risk profiles. As one can imagine, not all information will be stored in PHRs, not even when the PHR is linked with professional electronic medical records. As a consequence the risk profiles may not be based on complete datasets. To deal with this issue we may have to introduce a periodic health assessment check in which a minimal dataset of health variables are measured from the patient directly. The frequency of these health checks may depend on the patients' risk profiles. High-risk individuals can be advised to do a follow-up check at smaller time intervals as opposed to low-risk individuals. The check itself may consist of questionnaires to acquire or update the minimal dataset, combined with a standardized physical and laboratory examinations.

Between health assessment checks, changes that affect health status could occur. If the changes are severe, however, it may result in a reason to encounter the general practitioner or the specialist. Given the presence of integrated PHR systems, the data will automatically end up in the PHR.

The gap between health check may also be filled with sensor technology. In the past decade sensor technology build to measure and store medical signal information, such as blood pressure, have reached a stage of maturity. Depending on the disease and which variable is required, these sensors could be of value for the continuous update of the PHR content.

Compliance

Compliance of health consumers to health plans is known to be an issue in preventive medicine [7]. Patients usually comply but lose interest or fail to finish programs before predefined targets have been reached. One of the key issues here is the absence of immediate observable results for the patient. There is a need for an overall objective measure indicating one's health based on measurable health variables, e.g. a 'health index'. This measure or index could serve as a mean to help individuals observe the effect of compliance to formulated health plans. The health-index itself poses the requirement that it should be sensitive enough to generate changes between short periods of time. Technically this means that the PHR should include tools to create awareness about the effects of compliance to tailored health plans.

Recurrence of interaction

Many web-based personal health services face the problem of low recurrence of interaction rate [15]. This issue is related to the compliance. Providers, aware of this issue, engaged their subscribers by providing them e-health portal functionalities with personalized and accurate medical and health information services.

An e-health portal is a framework for integration of health information, applications and services. E-Health portals should play a key role in the housing of integrated PHR systems and the provision of different services and personalized health information (Figure 2).

Medical literacy

Even though there is a growing amount of individuals using the web for medical information, medical literacy is still an issue. Medical 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 [16]. Since medical literacy is regarded as a problem to effectively consume medical information, an e-health portal should provide interpretive information. The portal should be able to adjust its content to the individual's level of understanding, i.e. educational or predefined level of understanding of the end-user.

Providers of PHRs and personal health services will face the challenge to communicate their services and information in such a way that it fits all user groups with respect to difference in level of medical literacy.

Discussion

Integrated personal health records incorporated in e-health portals could serve as a platform for the provisioning of preventive and early diagnostic services. While most preventive and early diagnostic services are scattered over a number of service provider locations, this platform provides a unique opportunity to implement a holistic approach for prevention and early diagnostics. Current PHRs and e-health portals are rather disease oriented and do not go beyond disease management. To broadly implement effective prevention, early diagnostics and subsequent early intervention, a PHR with the functionality of health risk assessments and tailored health plan generation is necessary. The proposed approach can forfill this need. Most of the components to implement this approach are already at hand.

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