FUNCTIONS AND OUTCOMES OF PERSONAL HEALTH RECORDS FOR PATIENTS WITH CHRONIC DISEASES: A SYSTEMATIC REVIEW

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Abstract

Introduction: The personal health record (PHR) makes it possible for patients to access, manage, track, and share their health information. By engaging patients in chronic disease care, they will be active members in decision-making and healthcare management.

Objectives: This study aimed to identify the functions and outcomes of PHR for patients with four major groups of chronic diseases (cardiovascular diseases, cancers, diabetes, and chronic respiratory diseases).

Method: A systematic review was conducted on studies published in PubMed, Scopus, Web of Science, and Embase. Searching and screening were performed using the keyword of "Personal Health Record" without time limitation, and ended in August 2018.

Results: In total, 3742 studies were retrieved, 35 of which met the inclusion criteria. Out of these 35, 18 studies were conducted in the United States, 24 studies were related to patients with diabetes, and 32 studies focused on tethered PHRs. Moreover, in 25 studies, the function of viewing and reading medical records and personal health information was provided for three groups of chronic patients. Results showed that the use of PHRs helps the management and control of chronic diseases (10 studies).

Conclusion: It is recommended that integrated PHRs with comprehensive functions and features were designed in order to support patient independence and empowerment in self-management, decrease the number of referrals to health centers, and reduce the costs imposed on families and society.

Keywords: personal health record, chronic diseases, cardiovascular diseases, cancer, diabetes, chronic respiratory diseases

Introduction

The global burden of chronic diseases has posed a major challenge to public health and health systems in the 21st century, thereby decreasing the social and economic development.[1,2] There is now a growing spread of chronic diseases worldwide as a result of improvement in living standards, change in eating habits, change in sex ratio, increase in life expectancy, expansion of urbanism, improvements in management and treatment of diseases, and a better understanding of factors affecting health.[1,3,4]

Almost every year, 41 million people die from chronic diseases, which is equivalent to 71% of the world mortality rate; 15 million of deaths from chronic diseases happen to patients aged 30 to 69

years, and more than 85% of these premature deaths occur in low- and middle-income countries.[5,6] The World Health Organization (WHO) has predicted that, by the year 2030, the death rate of chronic diseases will reach from 38 million to 52 million cases.[7,8] The four major groups of chronic diseases are cardiovascular diseases (e.g. heart attacks and strokes), cancers, chronic respiratory diseases (e.g. chronic obstructive pulmonary disease and asthma), and diabetes.[2,9,10]

According to Shimada et al., the Institute of Medicine (IOM) stated that the patients with chronic diseases require better self-management, effective patient-provider communication, management and control of side-effects, and monitoring of physiological processes. This institute recommends changes toward continuous and coordinated care and application of information technology to support self-management for patients with chronic diseases.[11]

A powerful health information technology (HIT) tool for helping patients with chronic diseases to more efficiently manage their own health condition is the personal health record (PHR), enabling patients to play an active role.[12,13] The PHR is an electronic record containing the individuals' health information by which they can access, manage, track, and share their health information. Authorized persons can also access such data in a secure, confidential, and private environment.[7,14-17]

Today, there are numerous types of PHR, the most important of which include three categories: *(1) Stand-alone PHRs* are the simplest form of PHR which are not connected to other systems. People should manually enter, maintain, and update their health information; (2) *tethered or institution-specific PHRs* are connected to the information system of specific institutions such as the provider's electronic medical record (EMR) or insurance company. Individuals can access their health records via Web portals*; (3) integrated or interconnected PHRs* have the ability to connect, exchange, and share information with a variety of information resources. In this type of PHRs, data can be gathered from a variety of sources, including providers' information systems, e.g. electronic health record (EHR), insurance companies, pharmacies, and patients themselves.[18-22]

PHRs potentially support data coordination and access, improve patient-physician cooperation, strengthen patient self-management, and promote health outcomes. Providing personal healthcare information to patients and families through PHR is an opportunity to motivate them to improve their own health.[23]

In review studies conducted on PHRs in different countries, only some specific aspects such as datasets[24], PHR usage for the elderly[25,26], and PHR benefits for various diseases[27], have been considered, have been considered, whereas they are no study on the four major groups of chronic diseases. Therefore, the present study aimed to identify the functions and outcomes of PHR for patients belonging to the four major groups of chronic diseases, i.e. cardiovascular diseases,

cancers, diabetes, and chronic respiratory diseases.

Materials and Methods

Search strategy*:* This systematic review was conducted based on PRISMA [28] guideline. In order to find relevant studies, PubMed, Scopus, Web of Science, and Embase databases were searched using English keywords. Expressions similar to the main keyword, "Personal Health Record", were selected according to the MeSH terms, previous studies, and the authors' knowledge. Finally, the search was performed using the following keywords:

(Personal health record* OR personal healthcare record* OR personal health information OR personal medical record* OR personal electronic medical record* OR personal electronic health record* OR personal electronic healthcare record* OR personally controlled electronic health record* OR personally controlled electronic medical record* OR personal computerized patient record* OR portable computerized patient record* OR portable health record* OR portable medical record* OR my health record* OR patient portal OR portable electronic health record* OR portable electronic medical record*).

Inclusion criteria: Inclusion criteria were: studies in English and without time limitation until the end of August 2018. This research looked for studies on the four main groups of chronic diseases as well as evidence for the use of PHR by the patients.

Exclusion criteria: Some studies were excluded in our research because, although PHR was employed by patients, the study did not measure outcomes. Moreover, studies whose full text was inaccessible, were not original, or were not in English were excluded.

Study selection*:* Selection of related articles was performed in three stages after the initial removal of duplicates. In the first stage, the remaining articles were evaluated based on the title and abstracts of the articles. In the second stage, the remaining articles were evaluated on the basis of their full texts. Finally, articles meeting the inclusion criteria were selected for data extraction.

Data extraction: Data from the selected studies were entered into a data extraction form designed according to the research objectives. Two authors independently reviewed the full text and extracted all critical data from the studies. The extracted information included general information (author's name, year of study, and location of study), method (study type, study duration, and the number of patients), features of PHR (the type of PHR, chronic disease type, and functions of PHR), and the outcomes of using PHR (see **Table 1**).

Data analysis: Data were analyzed via content analysis, and the results were summarized and reported based on research objectives.

Results

In total, 3742 studies were initially retrieved from the mentioned databases. After removing

duplicates and overlapping cases (1523 studies), the titles and abstracts of the remaining 2219 studies were reviewed and screened, and 171 articles were selected for full-text examination. Finally, the full texts of the remaining articles were reviewed based on the purpose of this systematic research and, consequently, 35 articles met the eligibility criteria. The literature review and article selection process is illustrated in detail in the following PRISMA flow diagram (see **Figure 1**).

From among the 35 studies, there were five randomized control trials, and the rest were quasi-experimental or observational studies. In addition, 18 (51.4%) studies were conducted in the United States. The distribution of articles by country is given in **Table 2**.

In accordance with the research objectives, we identified the type of PHR, chronic disease type, and the functions and features of PHRs.

Chronic disease type: In terms of the type of chronic diseases, results demonstrated that 24 studies were on diabetes, nine on cancers, three on cardiovascular diseases, and two on chronic respiratory diseases. Also, Woolf et al. conducted a study on patients with breast, colorectal, and prostate cancer, and Guy et al. performed a study on patients with diabetes and prostate cancer (see **Table 2**).

Type of PHRs: The results revealed that, in 32 (91.4%) studies, PHRs designed for patients were tethered PHRs. Furthermore, 28 (87.5%) studies using tethered PHRs reported benefits.

Functions and features of PHRs: **Table 3** highlights the types of PHR functions and features divided by the disease type. Thirteen features and functions were identified in the PHRs designed for patients. The function of "viewing and reading medical records and personal health information" was provided for three groups of chronic diseases in 25 (71.4%) studies (three studies for cardiovascular diseases, 17 for diabetes, and five for cancers). The function of "reviewing billing and insurance information" was provided only in two studies for patients with diabetes, and the function of "reviewing and checking drug interaction" was provided for the patients with diabetes and cancer.

Outcomes of used PHRs: There were 15 outcomes in terms of using PHRs as reported in **Table 4**. Ten (28.6%) studies improved the management and control of chronic diseases for diabetes, cancers, and chronic respiratory diseases, seven (20%) improved self-care and self-management for diabetes, and seven (20%) enhanced activation and empowerment in three groups of chronic diseases (four studies on diabetes, two on cancers, and one on chronic respiratory diseases).

However, the results of four studies[29-32] showed no changes in the life and health condition of patients following access to the PHR.

Discussion

The PHR is an electronic health (eHealth) tool introduced as a practical intervention to support self-management in chronic diseases.[33] The results indicate that most PHRs were designed and

employed in the United States. The study by Price et al.[27] illustrated that most PHRs are used by patients in the US. Because of the patient-centric nature of PHRs, in which the patient is motivated to be an informed and active member of the health care team, this country designed PHRs for chronic disease management.[34] Given the increasing prevalence of the four groups of chronic diseases in the world, counties can improve the management of chronic diseases by designing and applying PHRs.

Chronic disease type: In association with the four groups of chronic diseases, our results showed that the majority of the studies focused on the use of PHR for diabetes. According to the statistical data released by the WHO in May 2018, the cause of mortality for 15.2 million deaths out of 56.9 million cases in 2016 was cardiovascular diseases and heart attacks, introduced as the main global killers. These have also been the main cause of mortality in the last 15 years. The chronic obstructive pulmonary disease was also registered as the cause of 3 million deaths, cancers were the cause of 9 million deaths (1.7 million deaths from lung cancer along with tracheal and bronchial cancers), and diabetes was responsible for 1.6 million deaths.[5,6] The results of the study by Gee et al. indicated that the PHR plays a supportive role in the self-management of chronic diseases, and can be very effective in the establishment of a good relationship between the patient and the healthcare team.[35] Thus, it is advisable that PHRs be designed and utilized for three other groups of chronic diseases.

Type of PHRs: According to the evidence found in this systematic review, no PHR designed for chronic diseases or used by these patients was of the integrated type. Tethered PHRs were either in the form of patient portal or Web-based, or fully connected to the EMR or the institutional EHR. Like the study by Price et al., most reviewed PHRs were of the tethered type.[27] The obvious restriction associated with this type of PHR is that it does not provide comprehensive information or a full image of the patients' health condition[36], whereas an *integrated* PHR is a record connected to other systems with capability of capturing data from different sources such as EHRs, insurance claims, pharmacy data and home-based monitoring devices. Whereas an integrated PHR is a record connected to other systems with the capability of capturing data from different sources such as EHRs, insurance claims, pharmacy data, and home-based monitoring devices. Also, the integrated PHR is capable of connecting to and data exchange and sharing with various types of data sources. In general, this type of PHR has more advantages than the other two, as it provides consumer access to provider-based records and a potentially comprehensive viewpoint of the patient's health. The other advantages of this type of PHR include a reduction of medical errors, elimination of duplicate services, quality improvement, efficiency enhancement, and easy handling of the online transaction tools.[18,19,35-37] Therefore, given the results of the present and the mentioned studies, it seems that necessary infrastructures must be provided for developing and implementing integrated PHR in different countries.

Functions and features of PHRs: Another issue studied in the present research was the functions of

PHRs. In several other[18,27,38-41], the functions of accessing to health information, including "entering personal health information", "viewing and reading medical records and personal health information," and "editing and updating personal health information" were identified as important functions for PHRs. In our study, these functions were considered for the PHRs destined for patients with chronic diseases. Like the other nine articles[18,23,27,38-42], the feature of "sending and receiving secure messages to communicate with healthcare providers" was provided for the PHRs of three groups of patients. This function allows patients and providers to better communicate and interact with the healthcare team.

Another function was "scheduling medical appointments". Detmer et al.[18] and three other studies [40-42] reported that this feature improves scheduling efficiency in the PHRs. The function and feature of "requesting medication refill or renew" reduces healthcare costs by limiting visits and telephone calls to the doctor's office.[43-45] The next function was "receiving personal care plan" that was considered for patients with diabetes. Price et al.[27] and Johnston et al. [42] reported that this function sets personal tasks and goals proactively related to healthcare and allows patients to improve adherence to care plans. Moreover, Kaelber et al.[38] stated that the function of "linking to self-management tools and decision support" allows patients to better manage their own health/healthcare. In our review, this function was provided to four groups of patients. Like the other four studies[18,23,41,42], access to educational materials was considered for 15 PHRs. Increasing patients' awareness of health and helping them to be better-educated consumers of healthcare become possible through this function. In two studies, "reviewing billing and insurance information" was provided for patients with diabetes, and three other articles[18,41,42], reported this function and feature.

Another function was "receiving preventive care reminders". Detmer et al.[18] and three other studies[40-42], reported this feature in the designed PHRs. Gerard et al.[46] stated that patients with chronic disease need more preventive care reminder to be encouraged to participate in healthcare management. Our review showed that the function of "reviewing and checking medication interaction" was provided only in two articles, while Detmer et al.,[18] Wagner et al.,[23] and three other studies[40-42] stated that this function is an important function and feature of PHRs. Drug errors and potential harms to patients are decreased through reviewing and checking medication interaction. Furthermore, only four studies reported the feature and function of "sharing health/medical records with healthcare providers" for patients with diabetes, cancers, and chronic respiratory diseases. Finally, Kaelber et al. stated that this function allows patients to share their health information with others.[38]

Outcomes of used PHRs: In terms of the outcomes of PHRs, the study by Vance et al. revealed that

the PHRs' features and functions affect the outcomes and benefits of their use.[47] For example, authorizing the patients to review, confirm, and monitor their health data and providing them with scheduled preventive health reminders can facilitate their self-management.[7,35,36,43,45,48,49] More improved relationships between care providers and patients can also be achieved through patients' ability to exchange e-messages with doctors' offices to refill prescriptions or schedule appointments[7,19,35,36,43,48-50]; increased patient safety can be obtained by a review of drug interactions, access to care plans, and early access to the results of important lab tests [7,35,36,43,45,48]; higher care quality is possible through the provision of coordinated, comprehensive, and continuous care [7,35,43,48]; and more effective care can be achieved through easier access to patients' health history and prevention of duplicate tests and unnecessary services.[48,49] In the present study, we found that a number of these outcomes were achieved by the designed PHRs, but no PHR supported all of the identified features and functions.

Limitations

This study was not free from limitations. For instance, the language of the search was limited to English, so there may have been other articles which were not included. Furthermore, there was also no access to the full text of some articles.

Conclusions

Results of this systematic review demonstrated that PHRs should cover all the discovered functions in order to take advantage of more benefits and outcomes by patients with chronic diseases. For instance, the patients' healthcare knowledge can be improved by providing more educational materials, and easier access to complete healthcare information can be provided for healthcare providers and patients by designing integrated PHRs. Therefore, it is suggested that future PHRs be integrated with all the features and functions discussed in this study, so that they would be able to meet the needs of patients with chronic diseases for self-management. It is also recommended that future studies focus on the design requirements of integrated PHRs.

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There are no comments yet.