
Special Lecture | JCMI/APAMI Special Keynote Session | Patient Engagement

[JCMI/APAMI Special Keynote Session 2] Patient Engagement

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[SKS-2-02] Patient Engagement and Personal Health Record

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Keywords: Patient Engagement, Personal Health Record (PHR), Smartphone, COVID-19

Patient engagement (PE) is an essential part of patient-medical professional relationships and a significant element of safe, high-quality, and cost-effective healthcare/medical services. Recent advances in information and communications technology (ICT), especially the Internet, smartphones, and decision support systems (including e-commerce and obtaining of informed consent), have promoted PE well. Additionally, a breakthrough development of PE in the corona virus disease 2019 (COVID-19) era is expected because installation of more ICT in medical services is needed. The World Health Organization (WHO) has explained that PE encompasses six essential elements:

1. Design and development of patient-centered processes and systems
2. Patients' access to their own electronic health records (EHRs)
3. PE in policy development
4. Collection of information about patient experiences and care outcomes
5. Healthcare education and training
6. Educating and empowering people to recognize their health needs and seek healthcare in a timely manner

The Personal Health Record (PHR), a smartphone application, can contribute in enhancing all six elements of PE and education/training for medical professionals.

However, we should establish the standard and interoperability of PHR data, including transfer protocol (e.g., HL7 FHIR), standard code of data items, and minimum data set in each clinical use case according to the standard clinical guideline before the PHR is diffused.

Patient Engagement and Personal Health Record

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Abstract

Patient engagement (PE) is an essential part of patient-medical professional relationships and a significant element of safe, high-quality, and cost-effective healthcare/medical services. Recent advances in Information and Communications Technology (ICT), especially the Internet, smartphones, and decision support systems (including e-commerce and obtaining of informed consent), have promoted PE well. Additionally, a breakthrough development of PE in the corona virus disease 2019 (COVID-19) era is expected because installation of more ICT in medical services is needed. The World Health Organization (WHO) has explained that PE encompasses six essential elements:

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Introduction

The worldwide spread of "Internet, smartphone, and e-commerce" has created and expanded "customer engagement (CE)" strategy represented by Amazon, Alibaba, etc. CE became one of the leading roles of digital transformation.

Recently, patient engagement (PE) has become the medical version of CE, based on the Internet, smartphones, and decision support systems (including e-commerce and obtaining of informed consent). According to the World Health Organization (WHO), PE is an essential part of patient-medical professional relationships and a significant element of safe, high-quality, and cost-effective healthcare/medical services [1].

For a healthcare/medical service provider, PE promotion strengthens relationships with patients and medical professionals, and enables the proper allocation of medical resources. Contrarily, if the healthcare/medical service provider does not have a trusting relationship with patients, the safety and service process would overload and resources would be unevenly allocated.

PE could be achieved without ICT, although it could be much stronger and faster with ICT supports. However, the corona virus disease 2019 (COVID-19) pandemic in 2020 has changed the situation. Hospitals/clinics have avoided face-to-face communication as much as possible, even with patients or family members, although it may just be temporary. As a result, the use of Web conferencing system has dramatically increased in the medical/healthcare field. Similar phenomena are also seen in electronic payments, which seem delayed in Japan. It is presumed that the widespread use of smartphones has accelerated because their merit has increased in the daily life (e.g., using cashless payment to avoid human contacts and sense contact with a COVID-19-positive person by the "COCOA" application in Japan) [2]. Promoting the installation ICT may be the positive aspect of the COVID-19 pandemic. In other words, COVID-19 may have contributed to the promotion of PE through ICT diffusion in the healthcare/medical field.

In this article, I would like to consider particularly the relationship between Personal Health Record (PHR) and PE in the COVID-19 era.

Six Elements of PE and PHR

According to the WHO, PE encompasses the following [1]:

1. Design and development of patient-centered processes and systems
2. Patients' access to their own Electronic Health Records (EHRs)
3. PE in policy development
4. Collection of information about patient experiences and care outcomes
5. Healthcare education and training
6. Educating and empowering people to recognize their health needs and seek healthcare in a timely manner

Among these six items, close and mutual communication between the medical staff and patient is most significant. Of course, face-to-face communication is still possible; however, using ICT is more realistic considering that engaging with medical professionals is time-consuming and costly. Therefore, to promote PE, the aforementioned three elements, "Internet,

smartphones, and decision support systems (including e-commerce and obtaining of informed consent),” should be essential.

In particular, personal health data that are accessible through healthcare/medical smartphone applications is generally called PHR. Therefore, PHR are an excellent tool to strongly promote all six elements as smartphones are already commonly used as mutual communication tools by the general population, including the healthy people (Figure 1). Recent smartphones have provided better user interface for aged persons, with larger letters, a cartoon, etc.

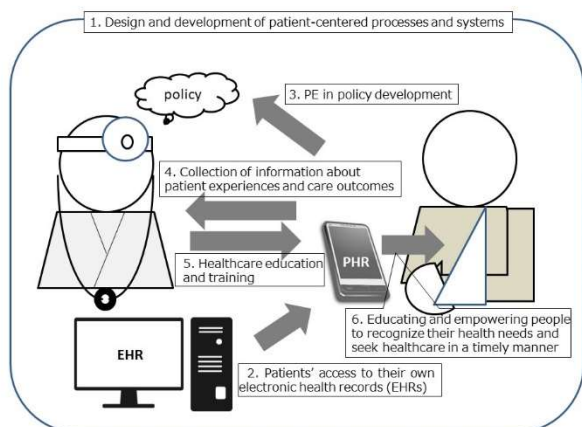


Figure 1- Six essential elements of PE and PHR

Design and development of patient-centered processes and systems

PHR installation in the healthcare/medical information platform enables a patient-centered process. In designing a patient-centered system, such as the PHR, the need of using HL7 FHIR [3], a comprehensive and flexible standard protocol, increases.

Patients' access to their own EHR

As a basic function, the PHR enables access to EHR, especially the diagnosis, results of blood/urine test, and prescription in medical institutes. In addition, access to information of dispensing pharmacies can be possible. The PHR will be linked to the “MYNA Portal” by the Ministry of Health, Labour and Welfare in Japan within a couple of years. Furthermore, daily physical and behavioral data generated on the patient side are collected by the Internet of Things (IoT) and sent to the healthcare/medical information platform via the PHR to be shared among patients and medical professionals.

PE in policy development

A doctor's diagnosis and treatment policy explanation to a patient and his/her family is mainly provided face-to-face at a hospital/clinic. However, depending on the patient condition, his/her family residence, etc., it is not efficiently conducted. The Web conferencing system can also be used on a smartphone, increasing opportunities for communication with the patient and his/her family. Additionally, the doctor can invite them to join the discussion about policy decision.

Furthermore, informed consent/assent can be implemented not necessarily by Web conferencing but by a consent-obtaining system called “dynamic consent,” which is useful not only for one-time consent but also for continuous explanation and confirmation of consent or for obtaining detailed consent such as partial consent. After the revision of the Act on the Protection of Personal Information in 2017 in Japan, individual opt-in consent has been required for the provision of “the

special care-required personal information,” which includes health/medical information, to a third party. Dynamic consent is useful for this kind of secondary data used by researchers and industries.

Collection of information about patient experiences and care outcomes

The PHR also contributes in collecting patient's experience in a medical institute (detailed patient satisfaction surveillance), which is useful not only for improving the quality of medical care but also for solving problems in hospital management.

The subjective evaluation by a patient during/after medical treatment can be used in all medical fields by installing the Patient-Reported Outcome (PRO) in the PHR, which is currently diffused only in the clinical trial of cancer chemotherapy. So far, patient evaluation has been insufficient in a conventional medical process; therefore, this is a great advancement for PE and medical informatics.

Healthcare education and training

e-Learning is expected as a method via the patient PHR. In addition, medication counseling by a pharmacist, dietary guidance by a nutritionist, and exercise guidance/rehabilitation by a physical therapist can also be applied as education/training methods using the video conference system.

Educating and empowering people to recognize their health needs and seek healthcare in a timely manner

In addition to ordinary supply of education, the PHR enables and empowers the patient to recognize the need for strengthening self-management or medical care in a timely manner by the implementation of clinical guidelines with alerts and reminding function. It is also possible to support patients in detecting symptoms of a disease and/or complication at an early stage.

Application to Medical Practice and Education/Training for Healthcare Professionals

Listening to the experiences, opinions, and ideas of actual patients is significant for medical trainees and young medical professionals. This provides in-depth knowledge of the patient and maintains trust between the patient and medical professionals. Most importantly, it provides safe and high-quality medical services with sympathy. For example, during rehabilitation, a physical therapist asks the patient, “Why is walking training difficult for you?” Then, the patient provides information such as “I am upset because it takes a long time for the effect to appear” or “My left ankle really hurts.” Depending on these answers, responses will be completely different. The PHR, including patient experience and PRO function, enhances this kind of communication.

Importance of Standardization and Interoperability

The PHR certainly promotes PE, but the current concern is ensuring standardization and interoperability. To create better and costless PHR applications to improve the health of citizens, we need a healthy competitive market by wholesome PHR providers. If interoperability is neglected by PHR providers, users (citizens/patients) cannot change PHR providers to utilize better applications and will lose all of the collected PHR data when their PHR providers reach bankruptcy.

To ensure interoperability, HL7 FHIR [3], standard codes such as ICD10, and standardization among PHR and IoT

communication are highly expected. In addition, data item standardization for each clinical use case should be essential. These sets of items should be decided by medical professionals in compliance of clinical guidelines. For example, the “recommended PHR configuration” for self-management of four noncommunicable diseases, namely, diabetes, hypertension, dyslipidemia, and chronic kidney disease, was decided by six Japanese clinical societies. In this configuration, 41 items have been selected as the minimum PHR items for these noncommunicable diseases [4]. If each PHR provider complies with the configuration settings, data portability, interoperability, and preservation should be guaranteed within this item range. Therefore, deciding to standardize the sets of PHR item and authorize them for each clinical use case before the PHR is diffused is significant.

In addition, data items, which are useful for clinical guideline support and secondary data use, are often not installed by structured items on the EHR system in Japan. The absence of the item “blood pressure” is a typical example. Even in the EHR for hypertensive patients, blood pressure data are just written in free-text documents. Therefore, by defining the items necessary for each use case in the EHR, the template function supports the inputted structured data during medical consultation. Furthermore, data input can be supported by data sharing with the PHR, by manual or IoT data input. These are indispensable for the effective functions expected in both EHR and PHR, such as clinical guideline support and secondary data use. Contrarily, if data item standardization in each use case is neglected in the early stage of PHR diffusion, the PHR will fall into a simple EHR viewer mainly written by free text and with insufficient effectiveness, usability, and interoperability.

Epilogue

Since ancient times, medical services have been led by doctors. Even now, in the era of “patient-centered medicine,” doctors are still responsible for several of these decisions. PE is a paradigm shift and is a major change in the medical service itself. Using artificial intelligence (AI) to medical service must be a big change, but as long as AI supports doctors’ decision, it cannot be said to be as a big change as PE does.

ICT promotes PE, a paradigm shift. In other words, it can be said that medical informatics plays the most significant role in the promotion of PE in the history. COVID-19 is pushing ahead. It is time to seriously consider how to efficiently introduce appropriate PE into medical services and make patients and medical staff satisfied.

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