

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

[JCMI/APAMI Special Keynote Session 2] Patient Engagement

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[SKS-2-01] Role of Health Informatics for Patient Engagement

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Role of Health Informatics for Patient Engagement

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Abstract

Advancements in health information technology (HIT) and its increasingly ubiquitous nature expand the ability to engage patients in the health care process and motivate health behavior change. We reviewed literatures on patient engagement to identify the key drivers, the state of art, and the areas of patient engagement, and the technologies used for patient engagement. We also reviewed achievements in patient engagement through HIT in four countries of APAMI region, South Korea, Japan, China and Taiwan. We described the state of the art and benefits of patient engagement, six areas of patient engagement, and multiple technologies in use in patient engagement, defined the issues of health literacy, healthcare information technology literacy to achieve quality outcomes and safe healthcare.

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Introduction

Patient engagement is not a new concept. The value of patient engagement has evolved in the healthcare industry last two decades. Institute of Medicine (IOM) formally introduced patient engagement in “Crossing the Quality Chasm: A New Health System for the 21st Century” report in 2001 [1]. This report called for reforms to achieve a “patient-centered” care. IOM has further emphasized the value of patient engagement whereby individuals have the opportunity to access health data, enabling them to be the “source of control” in making healthcare decisions.

Patient engagement is defined as “the process of building the capacity of patients, families, care givers, as well as health care providers, to facilitate and support the active involvement of patients in their own care, in order to enhance safety, quality and people-centeredness of health care service delivery” by WHO [2]. Patients are regarded as partners in care working together with members of their health care team to maintain and improve their own health and wellness. They are well-informed and actively participating in decision making and self-care.

With health information technology (HIT) usage continuing to increase, the technology becomes a powerful and critical tool for patient engagement. HIT is used to engage, educate and empower patients by activating the role of patients in their own healthcare journey. Healthcare providers are adopting

new and innovative approaches to boost patient engagement in their care setting. With HIT, patient engagement can take on many forms, from patients accessing their own health data via patient portals, to discussing their treatment plan with their doctors through secure electronic messaging, to monitoring their own health activities using wearable devices.

Materials and Methods

The authors reviewed literatures on patient engagement to identify the key drivers, the state of art, and the areas of patient engagement, and the technologies used for patient engagement. The authors also reviewed achievements in patient engagement through HIT in four countries of APAMI region, South Korea, Japan, China and Taiwan.

Results

Key drivers of patient engagement

The primary drivers of patient engagement are communication. The growing demand for improved and more efficient communication between healthcare providers and patients has created an impetus to use patient-facing technologies to promote patient engagement [3]. Some of these tools give patients the opportunity to be more responsible for their care by providing them with the ability to access health data, choose care providers, and manage their health care. For example, patient portals allow patients to view, verify, and act on their health data from preferable access points outside of the traditional healthcare settings. Other tools allow patients to communicate directly with their healthcare provider, and interact with other patients with similar health conditions, creating a broader and more connected health care network.

Another big driver of the patient engagement is the government policy such as US federal government's Office of the National Coordinator's (ONC) Merit-Based Incentive Program (MIPS), which includes requirements for very basic patient engagement services [4] and NHS England Patient and Public Participation Policy [5]. ONC's Meaningful Use Stage 2 requires that physicians provide patients the ability to view online, download and transmit their health information, generate and transmit permissible prescriptions electronically, and use secure electronic messaging to communicate with patients on relevant health information.

Along with MU, an equally important driver of the patient engagement trend has been the rise of accountable care models

and payment reforms [6]. Under accountable care models, healthcare providers need to keep the patients well and helping them get better – as opposed to fees for services rendered. As a result, healthcare providers are looking for ways to engage patients in healthcare between visits to the doctor's office.

Benefits of improved patient engagement

Benefits of patient engagement enabled by the technology include enhanced communication, better care and improved outcomes, increased satisfaction, and lower costs [7]. Patient engagement improves communication between patients and providers. Enhanced communication leads to better care, improved outcomes, and patient satisfaction. When patients are given access to their health data as well as treatment information, they are better able to participate in their care. Patient's participation gives providers more information about the patient's condition and helps them make better decisions. Increased ability to monitor patients' health condition enables early intervention, and possibly lower emergency room visits and hospitalizations. Easy access to their health data and the ability to interact with their healthcare providers give patients a sense of empowerment. This helps to increase their overall satisfaction with the care received and outcomes of such care, which is a major component of value-based payment. Time and money can be saved by scheduling appointments using the patient portal. Appointment reminders not only increase patient satisfaction, but reduce cancellations and no-shows.

Hibbard and Greene reviewed the available evidence of the contribution of patient engagement to health outcomes, and costs [8]. Engaged patients are more likely to take preventative measures like having regular health checkups, screenings, and immunizations. They are also more likely to eat healthy, exercise regularly, and avoid risky behaviors like smoking. This led to fewer illnesses. The highly engaged person living with a chronic illness is more likely to take their medications as prescribed and consistently engage in self-care and self-monitoring behaviors. This led to fewer complications and fewer emergency admissions to the hospital. Even though it was found that highly engaged patients experience fewer hospitalizations and emergency room visits, there is limited evidence to date about the impact on costs.

Baker reviewed case studies of patient engagement for health system improvement across organizations in four different countries [9]. Baker concluded that there is considerable variation in the approaches adopted by healthcare organizations to patient engagement and patient-centered care. However, providing patient-centered care and improving patients' experiences with their care are important goals of healthcare organizations. Patient engagement may be an important catalyst for improving patient outcomes and organizational performance, but additional evidence is needed to understand patients' experiences of the engagement process and whether these outcomes translate into improved quality of care.

State of art in patient engagement

Some of the latest technologies focusing on patient engagement involve managing patient health data, managing communication with healthcare providers, self-care at home, and education. A survey conducted by the New England Journal of Medicine identified five tools to help healthcare providers improve patient engagement: biometric wireless devices, apps for smartphones, SMS appoint reminders, social media as a patient education tool, and medication adherence reminder [10].

Specifically, 85% of respondents reported that biometric wireless devices, such as wireless glucometers that are able to collect patient health data and transfer it to an EHR, offers significant benefit in patient engagement especially in the area of population health. Seventy-five percent of respondents reported that healthcare apps for smartphones could offer a significant benefit in patient engagement. An app could be used to help patients manage their medications which could be particularly useful for patients with chronic conditions. Seventy percent of respondents indicated that SMS-based appointment reminders systems were identified as the most effective tool for patient engagement. Connections through social media can be used as a way to encourage patient engagement and improve health behaviors. Eighty-five percent of respondents indicated that social networks are potentially useful in healthcare delivery, especially for chronic disease management (85% of respondents) and promotion of healthy behaviors such as weight management, physical activity, and healthy eating (78%). Sixty-six percent of the respondents indicated that medication adherence reminders as the applications best suited for patient engagement technology tools.

All of these technologies are useless if the patient does not take an active role in their health. According to a 2018 Survey of US Consumers, about a third of consumers are interested in using apps for identifying symptoms, for health coaching and for recognizing the mood [11]. Many consumers are comfortable using at-home tests, mobile devices, and related technologies to diagnose, monitor, and manage their health problems. For instance, 51% are comfortable using an at-home test to diagnose infections, 45% using an at-home genetic test to identify existing or future health risks, and 44% using an at-home blood test that connects to an app to track overall health trends (for instance, cholesterol, and fasting blood glucose). The use of technology such as websites, smartphone/tablet apps, and personal medical devices to monitor health and measure fitness levels has increased. For instance, the use of technology to measure fitness levels has increased from 17% in 2013 to 42% in 2018 and the use of technology to monitor health issues has increased from 15% in 2013 and 27% in 2018. Sixty percent of the surveyed consumers indicated that they are willing to share personal health data (generated from wearable devices) with their doctor to improve their care.

Areas for patient engagement

Patient engagement can be applied in myriad healthcare practices and in healthcare education/training for medical personnel. Engaging patients and their families in healthcare is an important endeavor in all parts of the world. However, a large gap persists between its actual implementation and recognition of its importance.

According to the World Health Organization (WHO), patient engagement encompasses the following [2].

- Collection of information about patient experiences and care outcomes
- Healthcare education and training
- Design and development of patient-centered processes and systems
- Patient engagement in policy development
- Patients' access to their own electronic health records
- Educating and empowering people to recognize their health needs and seek healthcare in a timely manner

This section provides examples and explanation additional to the WHO's explanation.

Collection of information about patient experience and care outcome

Collection of information about patient experiences and clinical outcomes often serves as a starting point for developing relationships with patients. Such information can be collected through surveys, informal online feedback, interviews, or focus group discussions. Feedback on patient experiences leads to understanding their needs, preferences, and values, which helps improve the quality and safety of care.

Healthcare education and training

Patient engagement also serves as a means of healthcare education or training. For trainees in healthcare, it is important to listen to actual patients' experiences and thinking. This permits deep knowledge of the patient and maintaining of trust between patient and clinician. These core values are essential for providing care with empathy, at a high level of quality, and with particular regard to safety. Encountering the patient's story during training is a valuable experience and helps the trainee gain greater awareness of safety.

Design and development of patient-centered processes and systems

At the organizational level, it is useful to have patients and their families as advisory committee members, as they often positively impact the design and development of patient-centered processes and systems (Frampton & Patrick, 2008). Even after development and implementation, it is still useful to listen to and accumulate patients' and families' experiences and to feed this input back into the system. These efforts also enhance patient and family engagement.

Patient engagement in policy development

Engaging patients and families in policy development raises their awareness of diseases relevant to them. For example, patients can take part and assist in development and dissemination of medical tools, informational contents, and healthcare materials. Patients and families can also participate in clinical research as data sources or as collaborators in research design, research planning, and implementation.

Patients' access to their own electronic health records

Some developed countries have begun allowing patients access to their electronic medical records. Patients' personal involvement in monitoring or updating dosage or treatment plans may not only increase harmony between the clinicians' and patients' treatment policies, but also impel a review or intervention by the healthcare professional. In the United States, the delivery of personal health record data to patients via the Blue Button system has proven to be an effective strategy.

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

In low-income, resource-poor countries, engaging the patient and family can begin by having them be educated and empowered to understand their health needs and seek healthcare at appropriate timing. It is also important that patients and families ask questions and discuss their concerns. Their involvement in design and development of tools helps deepen their understanding of health and disease, while promoting use of related tools. A finding from a clinical research on health checkups in rural Bangladesh demonstrated that explaining

health checkup results to people who thought obesity was a symbol of family wealth educated them that it is actually a health threat [12].

Patient Engagement Technology

Online Patient Communities

Online Patient Community (OPC) is a type of Online Health Community, for its main users are patients or their relatives, though medical staffs may play the role of counselor or organizer. OPC is the earliest form which Internet involved in individual's health, developed from on-line bulletin board service.

OPC is widely used, according to a survey conducted by the Pew Research Center in the U.S. [13]. Twenty-six percent of adult Internet users in the U.S. have read someone else's health experience in the past 12 months. And 16% of adult Internet users have gone online in the past 12 months to find others who share the same health concerns. Behavior of OPC users can be classified into 5 categories (1) seeking informational support, (2) providing informational support, (3) seeking emotional support, (4) providing emotional support, and (5) companionship [14].

Personal Health Records

According to the ISO technical report of Health informatics, personal health records (PHR) is defined as a type of health record. The key features of the PHR are that it is under the control of the subject of care and that the information it contains is at least partly entered by the subject [15]. PHR can contain a diverse range of data, including but not limited to (1) personal information, (2) insurance information, (3) medication records (allergies and adverse drug reactions, prescription record, medications and dosing, immunizations and the dates), (4) illnesses and hospitalizations records, (5) X-ray and lab reports, (6) consultation and special treatment reports, and (7) dental and vision records.

Remote Patient Monitoring and Telemedicine

The rapid popularization of medical sensors and wideband network has provided technical possibility to the realization of remote patient monitoring and telemedicine with precise monitoring of physical parameters and stable transition of massive data. Remote patient monitoring is extremely helpful in the care of elder patients with chronic disease. A mattress embedded with piezoelectric sensor and matched with smartphone application can tell the user's sleep quality based on heart rate, respiratory rate and body movement during night [16]. A smart band can warn the nurse for possible fall accident when a sudden and short acceleration change of patient is detected. Telemedicine can allocate medical resource to the area and population which the traditional medicine mode could not do with acceptable cost before.

Hospital-branded Apps

Considering the informational asymmetries between patient and health provider, a visit to hospital could be rather confusing and exhausted. To reduce the time and economic cost during medical service, hundreds of hospital-branded apps have been developed. Basic functions of a typical hospital-branded app usually include (1) helping patients make appointment of health check and meeting with doctor online, (2) navigation to and within the hospital, (3) communication and follow-up between patient and healthcare provider, (4) health education for patient and (5) news of the hospital. Studies have shown that well-designed hospital-branded apps can significantly improve patient-reported convenience scores and satisfaction rate [17].

Moreover, hospital-branded Apps can help patients and caregivers connect with their medical team and community in the treatment of specific diseases. EpiWatch, an Apple Watch app developed by The Johns Hopkins Epilepsy Center, allows adults with epilepsy to track their symptoms, seizures, medication and potential triggers, and send the data to researchers. Researchers at Massachusetts General Hospital's (MGH) have developed the MGH Perinatal Depression Scale, a free iPhone application includes questionnaires about mood, anxiety, sleep and stress at important time periods during and after pregnancy. The questionnaires will identify which specific symptoms are most critical in the diagnosis of PPD in women ages 18 to 45 who are pregnant or up to 12 weeks postpartum [18].

Hospital-branded apps have brought great convenience to their users, medical staffs and the managers of hospital, but special notice should also be given to patients who have difficulty to use the technology, such as the elderly population and the handicapped, in order not to make the barrier of information even higher for them.

Social Media

The spontaneous initiative of patient is crucial in the healthcare of chronic disease because it needs years of persistence, sometime the rest of one's life. Patients with chronic disease have better performance in living healthy life style and higher compliance with treatment when they receive support from group or family [19].

Being different from online patient community, social media is characterized with the immediacy of interaction and strong connection within certain user groups, so it is frequently incorporated into research programs to create a sense of community, group people around shared goals, and offer social and emotional support. When the weight management program and support network has delivered within Facebook group, effects on weight and metabolic syndrome risk factors in overweight and obese adults are obvious than those who received the same program in a booklet [20].

Direct-to-consumer Tools

Direct-to-consumer (DTC) healthcare consists of products and services that a consumer can access without having to go through an intermediary, normally medical professionals or healthcare companies. Personal genetic tests and pharmaceutical market are two major healthcare involved in DTC model. First emerged in 2006, DTC genetic tests allow consumer to send his or her biosample to the lab and get a private individualized analysis report of genetic background, including the possibility to get certain disease, the potential talent on specific field, etc.

DTC pharmaceutical sale make it available for consumer to buy OTC drugs on websites, in some of which consumer can even buy prescription drugs by uploading a valid prescription. Researchers suggested that industry guidance should consider addressing visibility and accessibility of information in the Web environment to help pharmaceutical marketers meet the requirements for DTC promotion and to protect consumers from misleading drug information [21].

Wearables and Mobile Devices

Wearable devices and mobile apps now have been integrated with telemedicine and telehealth efficiently, to structure the medical Internet of Things (IoT). A study conducted in three Norwegian municipalities require pilot users to wear the mobile safety alarm while performing their daily activities. It shows increased safety to users, their relatives and caregivers

and increased activity and mobility indicating improved social and physical health [22]. Although not yet widely used, insulin management applications, wearable blood glucose meters, automated text messages, health diaries, virtual health coaching and other mobile health (mHealth) tools have enhanced diabetes management and prevention and are likely to play an increasing role with the growth of smartphone ownership and medical device innovations [23].

Further development of wearables and mobile technologies is requested not only to meet user needs, but also to bring challenges in terms of privacy. It represents a huge potential for efficiency and innovation in integrated care, but new tools are still required for efficient collaboration and operation for large-scale implementations.

Internet of Things

The Internet of Things (IoT) has been defined as a global infrastructure for the information society, enabling advanced services by interconnecting (physical and virtual) things based on existing and evolving interoperable information and communication technologies. IoT is the extension of Internet connectivity into physical devices and everyday objects. A total of 25 billion devices (things or physical objects) are already connected to the Internet, and this number is expected to grow to 50 billion by 2020. The Internet of Medical Things (also called the internet of health things) is one of the important fields of IoT.

The greatest concern for Internet of Health Things comes from its security. A successful attack to an implantable cardioverter defibrillator can alter the device's parameters to induce unnecessary therapy or prevent required therapy. Marin et al found a widely used insulin pump and its peripherals has no standard cryptographic mechanisms and hence the system is completely vulnerable to replay and message injection attacks. Furthermore, sensitive patient health-related information is sent unencrypted over the wireless channel [24]. Hence, the information security guideline for the body-area network including implantable/wearable medical devices, is necessary.

Barriers to patient engagement

Health and Health Information Technology (HIT) Literacy

The first barrier to patient engagement often concerns health literacy and HIT literacy. If this remains an impediment, patient engagement never progresses smoothly, and can even yield poor results.

Health literacy and HIT literacy refer not only to the abilities of individuals but also to health-related systems and information providers within those systems, and to local areas or workplaces. The issue also includes whether patients receive support from these, and whether patients and families can participate in activities to change systems and circumstances. These issues should be considered not only by individuals but also by the entire local society and/or workplaces. Increasingly, health literacy and HIT literacy are recognized as a determinant of health—one that is closely related to social determinants of health such as literacy, education, income, and culture.

Health Literacy

Canadian activities in public health have been noted for their inter-sectional approach for improving health literacy [25]. The approach's framework consists of the following [26]:

- To identify priorities and organize them into a comprehensive framework for improving health literacy
- To recommend a set of actions that could be taken at the national, and local levels for the purpose of increasing health literacy
- To facilitate conversations amongst practitioners, researchers and policy makers about health literacy and encourage cross-sectoral work around health literacy initiatives.

To be health literate is to be able to access and understand the information required to manage one's health on a day-to-day basis. Ideally, a health-literate individual is able to seek and assess the health information required to:

1. understand and carry out instructions for self-care, including the administering of complex daily medical regimens,
2. plan and achieve the lifestyle adjustments required for improved health,
3. make informed positive health-related decisions,
4. know how and when to access health care when necessary,
5. share health promoting activities with others,
6. address health issues in the community and society

Points 1–4 above are personal activities, but social activities such as in points 5 and 6 are also included. Public Health Association of British Columbia [25] also presents fundamental components to improve health literacy.

A list of objectives has been developed for each component, and these have been used to establish a compendium of relevant and effective possible actions for each of the settings.

- *Component 1. Develop Knowledge:* Develop and facilitate an extensive knowledge base that provides access to research and practice-based evidence on effective ways to improve health literacy.
- *Component 2. Raise Awareness and Build Capacity:* Develop and provide learning opportunities that enhance the knowledge, understanding and abilities of the public and private sector workforce, professionals and community members in their efforts to support and promote integrated health literacy. Develop, implement and foster communication strategies that attract the attention of key stakeholders and convey the importance of health literacy.
- *Component 3. Build Infrastructure and Partnerships:* Allocate sufficient fiscal, human, organizational and physical resources to support and sustain a coordinated effort to build the partnerships and implement the activities outlined in the Approach.

This social activity includes not only all citizens but all sectors as partners of citizens. We must establish a society with various sectors that accept and support people with low health literacy (i.e., those who have low health literacy because they lack health literacy education).

HIT Literacy

Aging society has become a prominent issue in some developed countries. For all the stakeholders to actively use patient engagement, it is suggested that the relevant older people amid

this condition have sufficient HIT literacy. Improving HIT literacy is therefore a priority. However, there are limitations on older people acquiring HIT literacy. It is therefore necessary to develop devices and applications that older people can easily use.

Additionally, there is a need to consider means of easily obtaining the cooperation of many stakeholders involved with older people, such as family and care providers. Improving HIT literacy of family members and surrounding businesses is therefore also important. The HIT literacy the older people have already acquired is sometimes gradually lost over time, and older people's responsibilities and work often shift to other parties around them. Despite this reality, the limitations must be overcome.

All of society, including remote areas, isolated islands, and small-scale local governments, must consider what applications or services will help them in advancing HIT literacy. This may necessitate telemedical communication systems using the latest telecommunications technology, at low cost, and that are easy to operate.

Quality and safety issues

In strengthening patient engagement, we should pay attention to the possibility of patients having medical accident, or their becoming unduly anxious or confused after being exposed to unsubstantiated information. Alert systems are increasingly being looked at for securing medical safety. Such systems are also useful for improving the quality of medical care and promoting patient engagement.

Alert Systems

A typical and practical way of establishing an alert system is to predetermine each patient's thresholds and notify the patient or their family when these are exceeded. In Japan, such alert values for diabetes, hypertension, dyslipidemia, and chronic kidney disease are determined by six clinical societies (Japan Diabetes Society, Japan Association for Medical Informatics, Japanese Society of Hypertension, Japan Atherosclerosis Society, Japanese Society of Nephrology, and Japanese Society of Laboratory Medicine) [27].

Healthix in New York provides an alert notifying a person designated by the patient, such as a family member, by an e-mail if a clinical event occurs during hospitalization. The notification contains the patient's name and a link to a portal site where the designated person can view the notification details. This immediate understanding of the situation by a family member or other relevant person can reduce the patient's anxiety and confusion. It also enables deeper understanding of the patient's situation, and possible intervention in the care. Additionally, the family doctor of a patient transported to an emergency room can receive an alert and immediately notify the attending emergency doctor of information needed for treating the patient. This enables more appropriate care to be provided.

Patient-reported outcome

Alert systems are mainly for sending information from the care provider to those dealing with the patient, whereas patient-reported outcome (PRO) is subjective information created on the patient's side. While PRO has advanced in the field of clinical trials, it notably plays a major role in acquiring patient experience, and not only is an important component of patient engagement, but also helps in averting medical accidents and inappropriate medical care.

PRO includes aspects such as degree of satisfaction with treatment, degree of symptoms and functioning, health related quality of life, and compliance with treatment. It is important to measure it by an appropriate method that can ensure reliability and validity. For this purpose, in addition to development of scientifically reliable indicators, it is essential to understand how to conduct training for patients, families, and medical personnel. Paper-based PRO has also been promoted, but digitalized PRO combined with PHR in smartphone should be effective for reporting PRO on daily basis and for data collection.

Compliance with Ethical Standards

This manuscript is part of a chapter titled “Consumer Patient Engagement and Connectivity in Patients with Chronic Disease in the Community and at Home” the authors submitted for Essentials of Nursing Informatics (6th Edition).

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