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SPONDYLOARTHRITIS (M KHAN, SECTION EDITOR)

"Mobile Health" for the Management of Spondyloarthritis and Its Application in China

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Abstract

Purpose of the Review Spondyloarthritis (SpA) is a group of inflammatory diseases characterized by inflammation in the spine, peripheral joints, and entheses that usually start at the prime of one's life and lead to impaired physical function and reduced quality of life. Ankylosing spondylitis (AS) is prototype of SpA. This article reviews the opportunities and challenges of using mobile health (mHealth) in managing SpA, and report some of our experiences using a mHealth solution for management of SpA patients and performing related research in China.

Recent Findings The recent rapid development of mobile communications and the common use of intelligent electronic devices have led to the increasing application of mHealth for chronic disease management by healthcare providers and patients alike. This is a promising new technology that can help mitigate limitations in time and space for patient management, promote easier communication between patients and their healthcare providers, reduce medical expenses, and optimize medical services. We have developed a smartphone-based mHealth SpA management system (SpAMS) that also helps the patients to monitor, manage, and share information on their disease with their physician at regular intervals.

Summary There is a shift from a paternalistic model of healthcare to more personalized healthcare in which disease management is conducted by the patient together with their healthcare providers. The increasing utility of mHealth is expected to benefit disease management, promote patient–doctor communication, reduce medical expenses, and optimize medical services.

Keywords Disease management · Mobile health · mHealth · Spondyloarthritis · Ankylosing spondylitis · Data management · Healthcare · Real-world research · SpAMS · China

Introduction

Since the 1980s, the world has experienced an unprecedented digital evolution [1•]. Electronic medicine has emerged along with digital technique development, with the consequent innovation in information dissemination being as promising as the invention of printing. The development of electronic medicine is being driven by mobile technologies, including smartphones and other wireless communication devices. In recent years, mobile devices have experienced dramatic innovations, enabling anytime, anywhere, and real-time connectivity and interactions [2]. Now, mobile devices are an essential part of our day-to-day activities [3]. Simultaneously, "mobile health" (mHealth) has rapidly evolved that utilizes those mobile technologies and social media. The World Health Organization defines mHealth as the medical and public health practice supported by the use of various mobile

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devices, such as the mobile phone, as well as more complex functionalities and applications [4]. Currently, mHealth integrates high-tech components such as artificial intelligence processors and sensing technology into medical practice. It leverages the Internet and electronic communications to achieve patient–wearable device interactions, patient–doctor interactions and extend these to medical institutions, thus supporting the evolution of the healthcare industry [5]. It is being introduced in all medical areas, especially in chronic disease management [6]. Chronic diseases generally have a long duration and require lifelong medication and monitoring, demanding high patient compliance and self-management abilities [7]. Health management in patients with chronic diseases is important for preserving an appropriate quality of life and, besides medication, requires patients to follow diet, exercise, and other programs. These long-term monitoring and management activities cannot be efficiently performed using the centralized administration of a hospital. In contrast, mHealth offers a solution for real-time monitoring, regular communication, and professional guidance, and can improve the efficiency and outcomes from the treatment and management of chronic diseases. Spondyloarthritis (SpA) is a group of chronic inflammatory rheumatic disease that can impair physical function and reduce quality of life. This paper discusses the opportunities and challenges associated with mHealth application to manage SpA, and also report the experiences of the authors using a mHealth system for patient management and SpA research in China.

Advantages of mHealth in SpA Management

Among rheumatic diseases, SpA may be the one of the best candidate for mHealth application; a disease that typically strikes young people (approximately 20 to 35 years old) in their prime time of work and family productivity, and is usually a lifelong condition [8]. Usually, patients in this age are able to quickly understand and master such technologies and devices, and are more likely to support and adopt mobile communication technologies [9]. Moreover, people suffering from SpA are highly concerned about its impact during this critical life stage. Without a long-term and high-quality health management, aging and the progression of the disease may undermine work productivity and the quality of life over time, expanding its consequences to social and economic aspects. In addition, although regular exercising can improve the prognosis of SpA, studies have shown that adherence to exercise programs is very low. Still, wearable devices to track physical activity improve the engagement of these patients [10], because they accurately monitor activities in real time and motivate physical activity by retrieving exercise and progress information [11]. Therefore, the disease management and health education are essential to minimize the impacts of SpA.

mHealth to Promote Management of Patients

Although there are environmental and genetic factors associated with the onset of SpA, there is no known cure for it [12•]. As the course of the disease can last decades, patients are required to comply with therapeutic scheduling and disease management, closely followed by doctors and other healthcare professionals. Various mHealth devices are endowed with features for self-monitoring, motivational support, behavioral feedback, health information education, and healthcare decision-making [13]. The portability and connectivity of mHealth can potentially serve as an effective tool in facilitating the long-term follow-up and facilitating the healthcare delivery to reach hard-to-reach populations [14]. In fact, interacting with mHealth devices has been proposed to change health beliefs and behaviors of individuals, build knowledge and skills in health self-management, enhance self-efficacy to treat symptoms, reduce health-risk behaviors, and improve clinical outcomes [6, 15, 16]. Moreover, mHealth can make education resources for SpA patients more abundant and accessible, especially for those living in remote areas far from healthcare facilities [17].

The existing shortage of rheumatologists is expected to worsen over the next decade, whereas simultaneously the demand for rheumatology care is expected to increase [18]. Hence, empowering patients to be active participants in SpA management through mHealth devices may improve medication adherence and symptom management, reduce their disease activity and number of necessary in-person visits [19••], and also provide accessibility at any time and place through their personal devices. Accessibility to information along with measurements from sensors and point-of-care devices increases patients' awareness of their health and disease status, especially for diseases such as AS and related forms of SpA, which are characterized by subjective symptoms in early disease state. Furthermore, massive health- and illness-related information can help doctors, researchers, and policymakers to create better solutions for diagnosis and treatment. Likewise, adopting mHealth for SpA management can be convenient from both individual and social perspectives, as these solutions become easily accessible.

Nowadays, mHealth adoption can be promoted given changes in cultural norms, which accept people carrying mobile devices at all times and using them in public places. In fact, according to one report, 90% of individuals almost never leave their mobile devices [19••]. Therefore, active and passive data collection about SpA symptoms and management strategies can be performed throughout the day by patients using mobile devices. Then, the collected data can help the patients to learn more about their disease and its management, and this information can be shared with their rheumatologists to optimize decision-making during in-person clinical visits.

Opportunities of mHealth for Real-World Research

Besides serving patients, mHealth can also be used to support and enrich real-world research [20]. In principle, the convenience and accessibility provided by mHealth should at least enable healthcare providers and researchers to frequently collect traditional and novel types of health-related data in a more targeted manner [12•]. Currently, real-world research/evidence, especially that related to data integration from a variety of information sources, has been extensively used in academia and is valuable to medical investors and policymakers [21, 22]. A review published in the *New England Journal of Medicine* in 2016 states that real-world evidence comprises information on healthcare that is derived from multiple sources outside typical research settings, including electronic health records, claims and billing data, product and disease records, and data gathered through personal devices and health applications [22, 23]. Real-world research promises to be an important addition to clinical trials for several reasons. For instance, mHealth can provide a more comprehensive and cost-effective assessment of the disease status considering a larger number of patients. In addition, mHealth can be used to track and manage patients through mobile devices and health-related applications.

Preliminary Exploration of mHealth on SpA Management in China

Countries like China with vast territories and large populations, and consequently with heavy burden of diseases, require more cost-effective health management and follow-up solutions [24, 25•]. Fortunately, mHealth can enhance patient–doctor interaction and management of patients with a vast range of illnesses. It is providing a promising forum for patients throughout China and the healthcare administrators, and can also result in making real-world research more feasible, including health economic issues [14].

Development of Rheumatology in China

Despite a very large number of patients with rheumatic diseases, many municipal hospitals do not have rheumatology departments given that rheumatology is a relatively new specialty in China. It was not until the end of the 1970s that rheumatology was set up as a separate department in hospitals in China. The hospitals that do have such a department are often small in size and with limited scope of practice. Moreover, many doctors currently engaged in the treatment and management of rheumatic diseases are from other specialties, such as nephrology, endocrinology, and hematology. In addition, physicians at rheumatology department had been mostly transferred from other departments, and some of them also treat other specialty diseases.

Epidemiological data indicate high prevalence of AS and related forms of SpA in China [8, 26]. For example the prevalence of AS in China is approximately 0.3% [26]. Considering the 1.4 billion populations reported by the National Bureau of Statistics of China in 2018, the number of people suffering from AS in China is approximately 4.2 million. Moreover, patients often do not have sufficient knowledge about their rheumatic disease, and many of them are treated by other specialists (i.e., orthopedics, pain management doctors) and do not receive the most appropriate management. A survey of Chinese rheumatologists unveiled the current situation of prevalent rheumatic diseases and the serious shortage of rheumatologists [27]. There are only 4515 rheumatologists (32 rheumatologists per 10 million population), and some doctors have not received standardized training on managing rheumatic diseases [27]. In contrast, a survey in the USA in 2005 by the American College of Rheumatology showed that there were 4969 registered rheumatologists (166.7 rheumatologists per 10 million people) [28]. In addition, there is very uneven distribution of rheumatologists across China. Therefore, besides improving the specialty training and the quality of rheumatology practice in China, it is also urgent to establish digital management systems to increase efficiency, reduce medical expenses, and fulfill the healthcare needs for the majority of patients, especially those in remote areas.

Establishment of Smartphone-Based SpA Management System

Recognizing the importance of managing patients suffering from rheumatic diseases and the need for patient-centered real-world research, a smartphone SpA management system (SpAMS) [29••] has been developed by a collaboration of the rheumatology team of the People's Liberation Army General Hospital, information technology professionals, and SpA patients. The main purpose of the SpAMS is to support chronic disease management and real-world research by constructing a mHealth system based on data collection and analysis. The SpAMS includes a patient terminal, a doctor workstation, and an interactive system. The patient terminal is mainly intended for disease assessment of prior clinical visits, disease management counseling, disease monitoring during follow-up, and return visit reminders. The doctor workstation is mainly used for disease assessment during visits and disease management and providing recommendations based on different conditions. In addition, the SpAMS provides opportunities for rheumatology research management, including creating research topics, specific research cohort management, and other functions to provide raw data for real-world research. According to the regulations regarding internet healthcare information services issued by the National Health Commission of the People's Republic of China (Internet Health Care Information Service Management, http://www.gov.cn/flfg/2009-06/23/content_1347818.htm), the SpAMS only

provides healthcare management and appointments for outpatient clinics based on the disease status, but does not allow healthcare decision-making (online diagnosis and treatment) for patients.

Patient Management and Education

The SpAMS allows patients to collect personal data related to aspects such as daily recording of pain, joint swelling and stiffness, medication administration, laboratory tests, and imaging examinations for assessing the disease progression. The system also allows to communicate with patients via WeChat, the biggest and most influential social media application in China, record follow-up information, and receive feedback from patients. The information can be easily organized, visualized, and shared with physicians to maximize efficiency. The patients with AS receive education about their disease management once a week via WeChat regarding topics such as appropriate exercising, sleeping positions, regular self-monitoring, and medications that may affect those who plan to have children. For instance, we suggest them to perform functional exercise under the guidance of rehabilitation therapists to maintain function of the spine and enhance muscle strength. We also suggest patients to sleep with the appropriate posture on a hard-surface bed to prevent body flexion deformity. Only in the past 30 days, a total of 50,028 users read those management strategies 85,261 times, which has remained stable over the past 6 months. In addition, the patients registered in the SpAMS can perform active self-evaluation according to the disease activity, and then initiate online consultation with physicians. The doctor will recommend the patients a follow-up visit or suggest a local hospital treatment based on the medical history and follow-up survey, which can reduce unnecessary outpatient services in our tertiary referral center, thereby decreasing patients' financial and time expenditures (i.e., fares and hotel expenses, commute time), especially for patients from remote areas, who account for 86.3% of the patients. For example, calculating from the speed and price from China's railroad system, the SpAMS can save at least 5512 h (5.3 h per person) and ¥39,552 (¥327.4 per person) for a total 1037 non-Beijing patients. The cost saved by the SpAMS is equivalent to 16% of the per capita income calculated according to the data from the National Bureau of Statistics of China in 2016 [29••].

Real-World Research Opportunities

As mentioned above, the SpAMS provides a clinic data platform to perform real-world research. A formal process in the SpAMS has been implemented to propose, refine, and execute research by leveraging the infrastructure that maximizes interactions among researchers, patients, and patient advocates. During registration, patients are greeted with the latest opportunities to engage in research projects tailored to their health condition, medication, and other characteristics. Therefore, specific opportunities are offered according to patient eligibility. For example, female SpA patients in childbearing age and treated with certain SpA medications may be invited to participate in fertility-related research that, depending on eligibility criteria, will obviously not be offered to other patients, preventing unnecessary communications. Therefore, the SpAMS can provide valuable tools to collect and facilitate research, ultimately benefiting patients and clinicians by providing real-time monitoring and indicating potential treatment pathways.

Technology Reserves

Emerging sources of data from various devices can be routinely generated, collected, and analyzed. These high-volume, high-velocity, and high-variety digital healthcare data include location, exercise and sleep patterns, and daily routine information [30]. As the amount of data is said to double every 2 years with falling prices of data generation and storage [1•], leveraging data explosion in medicine can provide a myriad of benefits. Data processing is associated with the available resources at a given point in time, and the need for analyzing and utilizing information is fostering the development of analytical techniques. As data are accumulated over time through mobile medical devices, pieces of information including patient history and imaging may become the basis of emerging methods such as artificial intelligence, predictive analytics, and cognitive computing. Note that without massive datasets, there are neither big data solutions nor intelligent data, and researchers cannot wait until analytical techniques become mature before accumulating data.

Challenges for mHealth Development

Similar to the contrast between the periods before and after the industrial revolution, no emerging technology has been established without difficulty. In this sense, the sensitive nature of healthcare and personal information imposes unique challenges to mHealth.

Data Security

In general, the ease with which mHealth tools can be used is incompatible with information confidentiality. Data security has become a major concern and the level of trust between patients and physicians influences implementation of mHealth. Security breaches of server data are the usual target of cybercriminals [31]. The usual clinical practice of de-identifying sensitive personal information before wide

dissemination carries the risk of correct re-identification of individual records [1•]. In addition, private access to personal health information by authorized individuals is also an important aspect, as it can result in malfeasance. In some countries and regions, strict security regulations for patient information in traditional healthcare network severely limits information access, hindering the development and generalization of mHealth solutions. Currently, the lack of clear and definite laws and regulations on emerging technology limits the assessment and standardization of rights and responsibilities related to mHealth.

Data Analysis

Unlike big data applications in other industries, the digital healthcare data serves not only to assess the associations between information sources but also to uncover any potential causality from these correlations. In fact, analyzing such associations allows to determine epidemiological trends, but it is difficult to unveil definitive conclusions on the causes of diseases in clinical practice. Accumulation of big data can generally cause quality issues, and missing or erroneous data in healthcare can substantially invalidate analysis results. Given the special characteristics of healthcare data, it is necessary to devise robust methods and promote extensive medical knowledge and acquisition of computer skills. It is difficult for people without medical knowledge to mine healthcare data, and few experts have the necessary knowledge of these two areas. There are still problems in transformation of all activities in the clinical practice into digitized data to begin with, and any subsequent extraction of valuable information from these data. Moreover, data extraction and analysis need to be further developed to fully leverage the potential of healthcare data and increase its availability.

Summary

mHealth is a promising technology that can mitigate limitations in time and space for patient management, promote patient–doctor communication, reduce medical expenses, and optimize medical services. There is a growing market for mHealth for management of chronic diseases, such as SpA, and the current limitations in its implementation will be overcome via technological advances. Scientific evaluation of mHealth solutions is required to assess the effectiveness and feasibility of this revolution in healthcare.

Compliance with Ethical Standards

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