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Mobile Health Application and e-Health Literacy: Opportunities and Concerns for Cancer Patients and Caregivers

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Abstract Health literacy is critical for cancer patients as they must understand complex procedures or treatment options. Caregivers' health literacy also plays a crucial role in caring for cancer patients. Low health literacy is associated with low adherence to medications, poor health status, and increased health care costs. There is a growing interest in the use of mobile health applications (apps) to improve health literacy. Mobile health apps can empower underserved cancer patients and their caregivers by providing features or functionalities to enhance interactive patient-provider communication and to understand medical information more readily. Despite the potentiality of improving health literacy through mobile health apps, there exist several related concerns: no equal access to mobile technology, no familiarity or knowledge of using mobile health apps, and privacy and security concerns. These elements should be taken into account for health policy making and mobile apps design and development. Importantly, mobile apps should be developed with the goal of achieving a high range of user access by considering all health literacy level and various cultural and linguistic needs.

Keywords Mobile applications · e-Health literacy · Cancer · Patients · Caregivers · Underserved populations

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Cancer is the second leading cause of death in the USA. It is reported that more than 590,000 people die from cancer and more than 1.5 million cases of invasive cancer occur annually [1]. Cancer pertains to "multiple diseases where abnormal cells divide without control" [2]. Among other chronic diseases, cancer is known as a very costly disease that has major economic ramifications in society. In 2010, for example, the annual total cost of cancer was estimated approximately $1.16 trillion [3]. Although cancer can be monitored and treated, it requires long-term and high-expense care in most cases. Many cancer patients experience severe pain or symptoms attributed to treatment toxicities or the disease itself [4]. Essential to quality care in cancer is patient-tailored treatment and support. Preferably, symptom and treatment assessment should be ongoing, and health information should be promptly shared among patient, caregiver, and provider(s) [4].

There is an increasing interest in the use of mobile health applications (apps) to improve the effectiveness and efficiency of cancer care delivery and outcomes. As computing technologies run on mobile devices that customize people's specific needs, mobile health apps have convenient and efficient designs in which individuals can use them anywhere and anytime with relatively low costs [5]. According to the Pew Internet and American Life Project, more than half of American adults with cell phones own smartphones, and about 20% of them have downloaded a health app [6]. The 2012 estimates showed that there were approximately 13,600 mobile health apps in the iPhone [7]. Among various mobile

health apps, apps related to exercise and weight loss are currently being used most commonly. Medical apps are also available on the smartphone market by offering means that support clinical decision-making for patients and their caregivers, drug reference and interaction checking, and medical vocabulary explanations [8]. Several mobile apps also provide guidelines that patients can access; for instance, the Epocrates app provides the National Comprehensive Cancer Network guidelines for cancer care.

Mobile health apps can empower patients by providing essential health information and access to care in an efficient manner. Particularly, patients with chronic conditions or diseases can utilize mobile health apps to better monitor and report their symptoms or illness [8]. For instance, diabetic patients can use diabetes apps to self-monitor their blood glucose, insulin logs, and medication [9]. As a cost-effective way, mobile health apps provide cancer information and intervention to cancer patients appropriately. Generally, cancer patients need certain information concerning their symptoms and treatment/procedures, as they frequently experience them during the treatment. Especially, those who experience symptoms at home need prompt assistance and care that they need. Mobile health apps can address this issue with various functionalities that facilitate information gathering and intervention customized for cancer patients' need, including audio and video features, text messaging, imaging, touch screen, content/information sharing, internet access, and tracking capabilities [10]. These functionalities help provide cancer patient-tailored care and monitor and manage symptoms or conditions more easily [11]. There are various mobile health apps that tailored cancer patients. The Cancer.Net Mobile app, for example, provides essential cancer information concerning cancer treatment, medications, management of side-effects, and costs of care, approved by numerous oncologists [12]. As a self-management system, WebChoice assists symptom assessment and management for cancer patients, facilitates interaction and communication between providers and patients, and provides reliable and useful links and resources to cancer patients [13].

In order to understand and utilize mobile health apps effectively, users need to have certain level of e-health literacy skills. The US Office of Disease Prevention and Health Promotion defines health literacy as "the degree where persons have the capability to obtain, process, and understand basic health information and services required for making appropriate health decisions" [14]. It was reported that in the US, approximately 30 million adults (aged 16 and older) had below basic health literacy [15]. Individuals with low health literacy are less likely to use preventive services [16] and more likely to visit the emergency departments [17]. Notably, patients with limited health literacy have a tendency of having lower adherence to medications, poorer health status, and increased health care costs [18–20]. To appropriately use mobile health apps, patients also need to have functional e-health literacy skills. As compared to health literacy, e-health literacy refers to "the capability to find, understand, and assess health information obtained from electronic means and use the acquired information or knowledge for addressing health issues" [21]. Specifically, e-health literacy compounds both general health literacy and usability/navigation skills central to digital wayfinding [22]. Given the contemporary health care setting where health information is increasingly exchanged through electronic means, e-health literacy is essential not only for patients'/caregivers' care efforts, but also for providers to effectively deliver quality care.

Health Literacy, Cancer, and the Mobile App

Health literacy is critical to cancer patients and their caregivers as they struggle to understand complicated procedures, treatment options, and side effects. Low health literacy among cancer patients can adversely affect their conditions or illness and result in premature mortality [23]. Several studies identified the factors associated with low health literacy among cancer patients. For instance, Halverson and colleagues found that compared with urban cancer patients, rural cancer patients were less likely to understand clinical information and take medication properly, even though the results were weakened after controlling for level of income and education [18]. Kim and colleagues examined how cancer knowledge among prostate cancer patients influenced their health literacy and found that patients with less sufficient cancer knowledge were more likely to have a lower level of literacy [23]. Sparks and Nussbaum investigated age-related barriers among older cancer patients and revealed that older cancer patients were more likely to have age-related communication barriers [24].

In addition to cancer patients' own health literacy, caregivers' health literacy plays a crucial role in caring for cancer patients. Family caregivers of cancer patients tend to seek and receive medical information concerning treatment options or procedures from health care providers and are involved in making clinical decisions for cancer patients [25]. Cancer patients are often too sick to seek necessary medical information and care for themselves [26]. Moreover, cancer patients can be easily overwhelmed by an overage of medical information regarding complex procedures and treatment [26]. Faced with the responsibility of serving as a family caregiver, health literacy is an important and essential element of cancer care, since it can influence caregiving and health outcomes among cancer patients [25]. Significantly, limited health literacy among caregivers can negatively impact communication about patient medical history, shared decision-making, and adherence with health care providers [25].

Health literacy is essential and crucial for both patients and their caregivers, not only to monitor and manage their clinical conditions or symptoms but also to make informed clinical decisions. Studies have recommended strategies to improve health literacy among patients and their caregivers, and one of them is the use of mobile health apps. For instance, Kim and Xie have highlighted the role of mobile health apps to empower underserved patients and their caregivers by having them engage in communication with their health care providers [27]. Their systematic review of the relationship between health literacy and the use of the Internet- and mobile app-based health services finds that touchscreen-based apps helped users with low health literacy to more actively engage in patient-physician communication and to achieve understanding of and education about medical treatments [27]. A thematic analysis by Klasnja and colleagues evaluated the HealthWeaver Mobile app designed to provide information management systems to cancer patients; the study revealed that patients were not only empowered by accessing cancer-related information and monitoring their own care but also were assured and felt more in control about their health information [28].

Although mobile health apps can be utilized to improve health literacy among cancer patients and their caregivers, there are several concerns. First, not all cancer patients and caregivers have equal access to mobile technology, which can increase cancer disparities [29]. Evidence shows that compared with whites, racial/ethnic minorities are less likely to use health information technologies [30]. The 2012 survey results from the Pew Internet and American Project revealed that compared with individuals from middle- and high-income families, those from low-income households had less access to the Internet on their mobile devices [31]. Second, cancer patients and their caregivers may not know how to utilize and navigate mobile devices or application features effectively. In 2015, a study by Bailey et al. investigated how patient health literacy was associated with the use of mobile phones, and found that patients with limited health literacy compared to those with adequate health literacy were less likely to own and suitably use a mobile phone for health-related purposes [29]. Third, there are privacy and security concerns with mobile health apps. It is noted that many smartphone apps are still unregulated despite increased public efforts to address this issue. Given the nature of dealing with individual health data, transmitting or storing private health information in an insecure manner through mobile applications remains problematic [32]. Evidence shows that present health care data do not receive sufficient security support (i.e., Databased Management System security functionalities) [33]. Despite the presence of privacy policies in mobile apps, people often do not read or comprehend them sufficiently and this can result in accepting vendor agreements without having the correct information or content [34].

Increasing mHealth Usage Across the Cancer Care Continuum

Cancer patients frequently deal with various physical and emotional symptoms while receiving treatment or procedures. They may also experience side effects resulting from treatment. It is crucial to promptly identify and appropriately manage those side effect symptoms or conditions. In this context, mobile health apps can help provide support and care services to cancer patients and their caregivers in an efficient manner. Mobile health apps are beneficial for cancer patients residing in rural area where health care resources are insufficient, since these technologies are capable of providing remote and integrated care services that may fill the discrepancy in cancer care [35]. There is a growing interest in developing mobile health apps for delivering cancer care and treatment. A 2013 study reported that 295 cancer-related apps were identified and available on Android, iPhone, Nokia, and BlackBerry platforms [36]. Compared with other cancer apps, breast cancer apps were the most common and targeted resource, and numerous apps aimed at increasing cancer awareness and education [36].

Many cancer patients receive treatment in the outpatient setting and are required to self-manage symptoms without provider involvement. Effective self-care helps cancer patients to feel more confident and improve their health outcomes. Various mobile health apps have been developed to support self-management for cancer patients. For instance, the Advanced Symptom Management System (ASyMS) designed to assist cancer patients to monitor and report their symptoms and provides prompt feedback and advice concerning symptoms and care as well as sends alerts to providers in a clinically urgent circumstance [35]. Similarly, a Wireless Health Outcomes Monitoring System (WHOMS) functions to monitor cancer patients' symptoms and health conditions from providers [37]. Additionally, the Connect system that incorporated the principle of patient-centeredness not only helps cancer patients self-manage their symptoms but also facilitates shared decision-making communication among patients, caregivers, and providers [12].

In addition to mobile apps for supporting self-management of cancer-related symptoms, numerous mobile apps for cancer prevention and screening have been developed and are increasingly used. Specifically, Wu and colleagues [38] developed a colorectal cancer screening app for Android mobile phones by using three algorithms and revealed that the app can facilitate identifying individuals at high risk of having colorectal cancer more quickly and efficiently, and promote earlier cancer screening participation. Heo and colleagues [39] developed a mobile health app for breast self-examination (BSE) and examined the effectiveness of the app to improve BSE behavior among females aged 19 and older. They found that overall, the percentage of participants conducting BSE increased from 62.2 to 71.1%, and in a subgroup analysis,

the percentage of those practicing BSE at the appropriate time (7 days after menstruation onset) was substantially improved from 2.2 to 33.3%. In 2017, a content analysis conducted by Ginossar and colleagues [42] investigated the content of cancer care continuum and the availability of mobile health apps related to breast cancer obtainable from the App Store and Google Play, and revealed that nearly 30% of the apps included the content of primary prevention and approximately 45% of the apps provided information concerning breast self-examination or mammography screening.

Implications for e-Health Literacy, Secure Privacy, and Usability

The need to improve e-health literacy has been emphasized and continuously discussed among health literacy experts and health care stakeholders. Numerous health care organizations have highlighted the importance of improving health literacy by identifying related system-level factors. As a capability to function in the health care environment, health literacy not only depends on individuals' ability but also depends on the complexity and accessibility of health care systems [43]. In other words, there are multiple factors associated with individuals' health literacy: health care professionals, health care systems, clinical conditions, and community health beliefs. Mobile health apps can serve as a platform to improve health literate care systems by facilitating interactive patient-physician communication and providing flexible, secure access to patient information. Particularly, mobile apps can be utilized to empower patients and caregivers with low income and racial and ethnic minorities, as they more commonly use smartphones than other health information technologies [34]. Yet, there continues to be disparity in access to the Internet in that minority populations are less likely to have access to the Internet compared with whites, although they are high users of mobile Internet [30].

In order to enhance interactive communication and provide understandable health information to people of all health literacy levels, mobile health apps should be developed by incorporating usability and evidence-based health literacy strategies. Evidence-based health literacy strategies, or practices measured as successful, for designing mobile health apps have been suggested in the literature. For instance, the myfamily app as part of the healthfinder.gov, incorporate six evidence-based strategies: (1) *learn about your users*; (2) *write actionable content*; (3) *display content clearly*; (4) *organize and simplify*; (5) *engage users*; and (6) *evaluate and revise your site* [42]. Specifically, these strategies highlight the importance of receiving and applying users' feedback, using plain language and simplification that enable users to find and understand information easily, avoiding the use of medical or technical jargons, engaging users with customizable information like quizzes, and evaluating and revising apps from repeated feedback on usability [41].

There is growing attention placed on designing and developing mobile apps meant to be useful for those with low health literacy [41]. Chaudry and colleagues discussed two studies conducted on individuals with chronic conditions and low literacy skills and technical familiarity, and suggested the design of mobile health apps that can empower low health literacy populations [40]. That is, mobile health apps should have larger widgets that can be easily visualized, incorporate scrollbars and a review mechanism, and utilize a hybrid navigation structure [40]. Mobile health apps should also be designed and developed in consideration of cultural and linguistic factors such as cultural beliefs, languages, and health literacy skills, particularly for individuals with low income and racial/ethnic minorities. Specifically, the National Standards on Culturally and Linguistically Appropriate Services (CLAS) are recommended for adoption in the design and execution of mobile apps [44]. Effective mobile health apps may provide culturally and cognitively adequate health education, especially patient and caregiver health education that can strengthen their health literacy and improve health outcomes.

As caregivers often provide constant cancer support and care, they benefit from receiving and processing cancer- or health-related information accurately and efficiently. While designing interactive mobile health apps, developers should consider versions of the mHealth apps designed for caregivers. Family caregivers generally have several challenges such as psychological and physical burdens associated with caregiving, and time constraints for providing continuous support and care [45]. Accordingly, researchers and designers should expect and know that caregivers are largely consuming the resource, in addition to the patient. Some research even suggests that a less exhaustive or extensive cancer patient app could be an alternative to a caregiver version [11, 42, 45]. Patients with chronic diseases like cancer can get overwhelmed by the in-depth granularity of information, which can lead to a detrimental effect of their physical and mental health [11, 28]. In this regard, "easy-to-learn and use" and "evidence-based health literacy strategies" should be incorporated in the design and development of mobile health apps, particularly for underserved cancer patients and their caregivers. Specifically, they include the use of larger widgets that enables users to interact with them, incorporation of both back button and home button, and inclusion of a review mechanism [40].

The health care mobile app accessed through multiple platforms and operating systems can present more security vulnerabilities in terms of being hacked. This raises a significant concern in consideration of the nature of patients' medical information, specifically for cancer patients. Significantly, mobile health apps should be designed by critically reviewing privacy and security aspects, and provide secure access to patient information. Currently, in the US, there is legislation

that protects the privacy of computerized health information, called the Health Insurance Portability and Accountability Act (HIPAA). It is essential that this law is effectively applied to mobile health, and must be appropriately updated or revised in consideration of current information technologies. In addition, more robust access control and authentication (i.e., frequent verification of the mobile device owner and more complex password) should be provided by mobile health apps to ensure that the user and owner are identical [32]. It is also important for app developers to identify and incorporate users' preferences on privacy and protect the content related to users' privacy (e.g., activities and location) [32]. Additionally, individual health information and data should be managed in a secure and protected space in mobile devices.

Beyond the matter of security, e-health literacy as a researchable concept faces the same challenges of health literacy—balancing the individual's abilities with those of the system and stakeholders in health. But additional dimensions of e-health literacy will include new work addressing wayfinding, usability, accessibility, and equity, and is sure to bring new evidence and challenges to the context of cancer care. The role of the caregiver remains quintessential and must be privileged in the work ahead on health literacy as well as e-health literacy. Future research areas must include user analytics and artificial intelligence in providing enhanced, individual care and aggregate level analysis for policy making and strategizing.

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