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Title

Social Media and Mobile Technology for Cancer Prevention and Treatment.

Permalink

<https://escholarship.org/uc/item/8dn985dm>

Journal

American Society of Clinical Oncology Educational Book, 37(37)

ISSN

1548-8748

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Publication Date

2017

DOI

10.14694/edbk_173841

Peer reviewed

Social Media and Mobile Technology for Cancer Prevention and Treatment

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OVERVIEW

Given the number of lives affected by cancer and the great potential for optimizing well-being via lifestyle changes, patients, providers, health care systems, advocacy groups, and entrepreneurs are looking to digital solutions to enhance patient care and broaden prevention efforts. Thousands of health-oriented mobile websites and apps have been developed, with a majority focused upon lifestyle behaviors (e.g., exercise, diet, smoking). In this review, we consider the use and potential of social media and mHealth technologies for cancer prevention, cancer treatment, and survivorship. We identify key principles in research and practice, summarize prior reviews, and highlight notable case studies and patient resources. Further, with the potential for scaled delivery and broad reach, we consider application of social media and mHealth technologies in low-resource settings. With clear advantages for reach, social media and mHealth technologies offer the ability to scale and engage entire populations at low cost, develop supportive social networks, connect patients and providers, encourage adherence with cancer care, and collect vast quantities of data for advancing cancer research. Development efforts have been rapid and numerous, yet evaluation of intervention effects on behavior change and health outcomes are sorely needed, and regulation around data security issues is notably lacking. Attention to broader audiences is also needed, with targeted development for culturally diverse groups and non-English speakers. Further investment in research to build the evidence base and identify best practices will help delineate and actualize the potential of social media and mHealth technologies for cancer prevention and treatment.

New cancer cases in the United States number nearly 1.7 million annually. With earlier detection and improved treatments, the 5-year cancer survival rate increased from 49% during 1975 to 1977 to 69% during 2005 to 2011. Yet, cancer remains the second leading cause of death in the United States, with a substantial proportion of cancers preventable. Tobacco use alone is estimated to cause 29% of all cancer deaths,¹ and more than one in five cancer diagnoses are related to lifestyle factors of obesity, physical inactivity, alcohol consumption, dietary factors, sexual health, and sun exposure.² Vaccinations and regular cancer screening also are important for cancer prevention and early intervention. Among cancer survivors, quitting smoking and maintaining a healthy body weight through physical activity and healthy nutrition reduces the risk of disease recurrence or progression.

Given the number of lives affected by cancer and the great potential for optimizing well-being via lifestyle changes, patients, providers, health care systems, advocacy groups, and entrepreneurs are looking to digital solutions to enhance patient care and broaden prevention efforts. In this review, we consider the use and potential of social media

and mHealth technologies for cancer prevention and cancer care. Social media are websites and applications (apps) that allow users to create, share, and participate via virtual communities and networks. Social media can provide fellowship with others, because of sharing common attitudes, interests, goals, or experiences, person-to-person, in real time, at low or no cost. mHealth, more broadly, refers to the delivery, facilitation, and communication of health-related information via mobile telecommunication and multimedia technologies (e.g., handheld devices, smartphones, tablets). The boom in mHealth has been made possible by the high penetration of internet access and increased use of smartphones. An estimated 89% of United States adults are now online, with smartphone ownership at 72%.³ As such, social media and mHealth technologies offer the ability to scale and engage entire populations, develop supportive social networks, connect patients and providers, encourage adherence with cancer care, and collect vast quantities of data for advancing cancer research.

Our review attends to the use of social media and mHealth technologies in cancer prevention, cancer treatment, and survivorship. The field is broad and emerging rapidly with

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Disclosures of potential conflicts of interest provided by the authors are available with the online article at asco.org/edbook.

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the need for determination of evidence base and identification of best practices for patient care and data security. Given the breadth of our interest, a comprehensive review is not feasible. Instead, we identify key principles in research and practice, summarize prior reviews, and highlight notable case studies and patient resources. Further, with the potential for scaled delivery and broad reach, we consider application of social media and mHealth technologies in low-resource settings and best practices for dissemination.

SOCIAL MEDIA APPLICATIONS TO CANCER PREVENTION AND CANCER CARE

Social media come in several forms with differing audiences and emphases (Table 1). Among United States adults online, 79% use Facebook, 32% Instagram, 31% Pinterest, 29% LinkedIn, and 24% Twitter.⁴ Further, social media use in the United States has become routine, with daily use reported by 76% of Facebook users, 51% of Instagram users, and 42% of Twitter users.

Most health-oriented research has been performed on general social media outlets such as Facebook and Twitter, with relatively little information available on smaller or specialized networks such as Snapchat. Yet, the emphases of specialized networks may make some platforms more optimally suited for specific intervention components. For example, video on YouTube or photos on Instagram may be effective for instruction and role modeling. Smaller and more private social networks may be preferred when discussing sensitive topics such as weight, tobacco, heavy alcohol use, or sexual activity. If using a larger and more general social medium, it may be prudent to consider private invitation-only groups, such as the example presented on use of Twitter to deliver private, peer-to-peer, quit-smoking groups (Sidebar 1). Closed quit-smoking groups targeting young adults also have been tested on Facebook^{5,6} and WhatsApp⁷ with encouraging short-term effects.

KEY POINTS

- **Innovations in mHealth and social media applications are occurring across the cancer spectrum, from primary prevention to screening, early diagnosis, treatment, survivorship, and end-of-life care.**
- **Thousands of health-oriented mobile websites and apps have been developed, with most focused upon lifestyle behaviors (e.g., exercise, diet, stress, smoking).**
- **Advantages of social media and mHealth technologies include low- or no-cost, high scalability, self-tracking and tailored feedback functionalities, use of images and video for enhanced health literacy, broad reach, and data sharing for large-scale analytics.**
- **Although development efforts have been rapid and numerous, evaluation of intervention effects on behavior change and health outcomes are sorely needed, and regulation around data security issues is notably lacking.**
- **Targeted development is also needed for culturally diverse groups and non-English speakers.**

TABLE 1. Categories of Existing Social Media and Popular Examples

Category	Examples
Major general-purpose social media outlets	Facebook; Twitter
Social media with a chronic illness focus	Smartpatients; CaringBridge; PatientsLikeMe
Photo-emphasizing social media	Instagram; Snapchat
Video-emphasizing social media	YouTube; Periscope
Blogs and message board–style networks	Tumblr; Reddit; Medium
Social video game or simulation networks	Xbox Live; Apple GameCenter; Second Life

Social media can provide varying degrees of anonymity, which may be attractive for stigmatized behaviors or medical conditions. When faced with the unknowns of a new diagnosis and a menu of treatment options, each with particular risks and benefits, social media can provide a unique connection with others who have direct personal experience. For example, with a focus on empowering patients, *Patients-LikeMe* is a free website, organized by medical conditions, where people can share health data, track their progress, connect with others, and contribute to big data analytics. *PatientsLikeMe* reports nearly 450,000 registered users and offers communities on nine cancer types.

With a specific focus on cancer survivors, *Springboard Beyond Cancer* addresses more than 20 symptoms and health behaviors. The site promotes skills training and use of strategies for active self-management among cancer survivors with the aim of lessening the impact of disease and treatment side effects and improving quality of life.⁹ The mobile-optimized website draws existing information from Cancer.org, Cancer.gov, and literature related to survivorship and health behavior interventions.

With social media sites that are largely uncurated or expert moderated, patients should be forewarned that negative or inaccurate health information might be posted. For example, user communities may encourage excessive dieting, vaccine avoidance, or use of nonevidence-based treatments (e.g., laser or herbs for quitting smoking). Harassment also can be a problem on more open networks such as Twitter and Reddit. Review of online content on breast cancer identified difficulty finding accurate information because of the lack of regulated sites.¹⁰ Although social media has become an important channel for disseminating findings from medical studies, the problem of fake news, including fake health news, is real, with growing recognition of the need for countermeasures.^{11,12}

KEY PRINCIPLES OF SOCIAL MEDIA TO ENHANCE CANCER PREVENTION AND TREATMENT

At the foundation of social media applications for cancer prevention and control are techniques related to social support, health communication, self-regulation, and motivation enhancement.

SIDEBAR 1. *Tweet2Quit* Smoking-Cessation Intervention

Description

In private and by invitation-only 20-person groups, *Tweet2Quit* fostered peer-to-peer support and accountability for maintaining commitment to quit smoking. The Twitter-based intervention encouraged engagement via two scheduled automessages a day: (1) discussion questions based on tobacco treatment clinical practice guidelines and (2) individualized autofeedback based on past-day participation. A customized computer program automatically downloaded the group's tweets daily, analyzed those who tweeted versus not, and sent prewritten and varied messages that praised tweeters for participating and encouraged nontweeters to do so. The groups lasted 100 days.

Study Design

In a two-group randomized controlled trial with 160 tobacco smokers, *Tweet2Quit* was combined with a web guide (smokefree.gov) and nicotine patch. The comparison group received the web guide and nicotine patches without the Twitter support group. Tobacco abstinence was reported at 60 days follow-up.

Examples of Group Tweeting

M1: I've smoked. :(but I hide when I do bc I'm ashamed. :-p

M2: Who you hiding from? YOU are the one that wants to quit...start over and try again!

M3: Its ok to trip u just need to get back on track it sounds like u want to quit maybe u need more patches

M1: I am going to get more and start fresh. Ty!!!

M4: It's ok to stumble. just keep getting back up. you can do it!

M1: When I saw myself failing I stopped tweeting so much. Didnt want to bring the rest of you down. :-/

M2: You need to keep tweeting! Maybe WE can bring you back UP!

M3: Know we r all here to help anytime day or night u want to smoke txt us we r here for u

Study Findings

Tweet2Quit participants reported significantly greater sustained tobacco abstinence compared with control subjects: 40% vs. 20%; $p = .012$. Engagement was high, with participants averaging 57 tweets over an average of 47 days. More tweeting was associated with quitting ($p = .003$).⁸

Study Limitations

The sample was largely non-Hispanic white (88%), and outcomes were self-reported and short term (60 days). A larger randomized controlled trial is underway with an ethnically diverse sample and 6-month bioconfirmed outcomes of tobacco abstinence.

Future Applications

Social media may be leveraged to create support groups to attend to other cancer-related behaviors such as diet, physical inactivity, and excessive alcohol use.

Social Support, Influence, and Norms

Online social networking for fostering social support has a long research history, from online mailing lists and message boards to more modern iterations such as Instagram. Social support is important for behavior change broadly,¹³⁻¹⁵ and ample evidence indicates that existing social media groups can provide informational and emotional support to cancer survivors and caregivers.¹⁶⁻¹⁸ Online communities have been linked to increased empowerment¹⁹ and retention²⁰; engagement with the communities has been linked to behavior change success for weight loss, smoking cessation, and other cancer-related behaviors,^{8,21,22} although some effects are small.²³⁻²⁵ Additionally, structured short message service and text messages to generate forum discussions, provide reminders, or offer tips and strategies have been effective build-ins.²⁶ Ideally, social support is bidirectional, and

attention should be paid to facilitate receipt as well as provision of social support. A recent intervention study found that expressing social support was associated with perceived bonding within the social media group and positive coping strategies, whereas receipt alone of supportive messages was not.²⁷

With a focus on influencing perceived social norms, social media interventions have demonstrated preliminary efficacy for reducing problematic alcohol consumption.^{28,29} Yet, of concern, the literature also finds social networking associated with negative outcomes related to social comparison, such as poor body image and depression.^{13,30} When designing interventions for cancer prevention and survivorship, it is important to consider potential unintended negative consequences and attempt to avoid or ameliorate them. For example, implementing weight-related programming

in photo-sharing media may require private groups, stricter rules, or additional intervention to reduce negative social comparisons to participants with lower weights, “thinspiration” accounts, or slim celebrities.

Health Communication

Communication campaigns using social media such as Twitter and Facebook are increasingly popular. Both large-scale national and international campaigns as well as smaller campaigns by local organizations and clinics have demonstrated engagement with their target audiences using social media.^{14,15} Role model narratives are effective methods of persuasion with demonstrated positive impacts on cancer prevention behaviors¹⁹⁻²¹ and can easily be delivered using video and photo tools in most popular social media systems. Evaluation of a breast cancer awareness campaign launched on Facebook by the Centers for Disease Control and Prevention found greatest engagement for posts with photos rather than status/links or videos; posts released in the early morning and afternoon (2:00 PM to 6:00 PM) versus other time periods; and posts shared earlier (2014) than later (2016) in the campaign.³¹ Social media also can provide opportunities for truly interactive intervention methods. For example, a study found that participation in cocreating antismoking campaign content on Facebook produced greater information searching and intention to quit than simply viewing the content online.²²

Self-Regulation

Self-regulation techniques, such as goal setting and feedback, are the foundation of many interventions that seek to change health behaviors, both for cancer prevention and adherence with cancer treatment regimens. Social networks are incorporated into some health-related apps and websites to promote self-regulatory skill-building,²⁶ and many general social networks include large subcommunities related to these topics. Some forms of these media may be particularly well suited to promoting self-regulation. For example, video-sharing services can provide highly detailed instruction and rich feedback from peers as well as experts.³²

Motivation Enhancement

Social media shows promise for delivery of general and social rewards. In fact, several scholars have suggested that virtual rewards such as badges may be more effective when implemented within some form of social network, to emphasize personal status, group affiliation, and reputation.^{33,34} Recommendations for gamification emphasize the importance of social engagement, personal reflection, and nurturing game elements for producing long-term motivation,^{35,36} all of which can be facilitated via social media.

Engagement

Inadequate engagement can be a major limitation to cancer-related social media interventions.³⁷ Research consistently has found that posting photos results in a greater amount of engagement than other post types.^{31,38,39} A study

of scientific communication with the public across social media platforms by the European Organization for Nuclear Research found that “wow” photographs (i.e., awe-inspiring photographs) produced the most engagement, especially when posted on the photo-emphasizing platform Instagram.⁴⁰ Another recurring finding is that users may prefer different social media platforms, making formative research and/or use of multiple channels an important consideration.^{7,41}

MHEALTH APPS AND WEARABLE DEVICES FOR CANCER PREVENTION AND CANCER CARE

A full range of mHealth apps are available for download from digital marketplaces (e.g., iTunes, Google Play) for use on smartphones, tablets, and other handheld devices. Thousands of health-oriented apps have been developed, with most focused upon lifestyle behaviors (e.g., exercise, diet, stress, smoking).⁴² Yet, a mere 36 comprise half of the downloads. The focused use is attributed to the very limited functionality of most mHealth apps: just 10% can connect to a device or sensor, only 2% sync with providers' systems, and few incorporate social networking functions.⁴³ Table 2 presents categories and examples of mHealth apps relevant to cancer prevention and cancer care.

Several reviews have been published on mHealth apps. With attention to the prevention, detection, and management of cancer, one review identified 295 mHealth apps available in 2012.⁴⁴ Most common were apps on breast cancer (47%) or cancer in general (29%), apps aimed at raising cancer awareness (32%), providing cancer education (26%), supporting fundraising (13%), assisting in early detection (12%), or promoting a charitable organization (10%). Far fewer were apps designed to support disease management (4%), cancer prevention (2%), or social support (1%). The authors conducted a companion systematic review of the

TABLE 2. Categories of mHealth Apps With a Cancer Focus and Examples

Category	Examples
General health apps	Find a Health Center; Medscape
Health risk assessment apps	BRisk; BCSC; Rotterdam Prostate Cancer Risk Calculator
Quit-smoking apps for patients/providers	ASPIRE; QuitStart; QuitGuide; QuitMed-Kit
Diet and fitness apps	SuperTracker; SWORKIT; Endomondo
Self-regulation apps with social networking	Fitbit; Lose It!; My Fitness Pal; QuitNet
Symptom navigator apps	My PearlPoint Cancer Side Effects Helper
Patient portals	OhMD
Health condition trackers	My Breast Cancer Journey
Screening exam apps	ePrognosis Cancer Screening
Environmental exposure apps	Detox Me, Healthy Living Mobile App
Cancer treatment and survivorship apps	Cancer.Net (ASCO), iCancerHealth; National Comprehensive Cancer Network

health literature (1990–2012) and could not identify a single empirical evaluation of a cancer-focused mHealth app.

With a focus on breast health, a search of breast symptoms and diseases in major app stores identified 185 mHealth apps, of which 139 (75%) focused on breast cancer. Most of the apps (51%) were educational, 16% were self-assessment tools, only 14% were deemed evidence-based, and a mere 13% involved medical professionals in their development. Potential patient safety concerns were identified in 29 (16%) of the apps. Needed are mHealth cancer prevention apps informed by behavior change theory that attend to multiple risk factors and are appropriate for patients with low health and e-health literacy. As an illustrative example, the purposeful design of a breast cancer prevention app is summarized in Sidebar 2.⁴⁵

A recent study conducted with 54 women at elevated risk for breast cancer evaluated, in a randomized controlled design, the combination of a wearable technology to monitor physical activity (Fitbit One) with a smartphone app to monitor diet (My Fitness Pal), and coaching calls from trained counselors. The goal was weight loss. Women randomized to the wearable plus mHealth app plus coaching achieved significantly greater weight loss (4.4 vs. 0.08 kg; $p = .004$) than women randomized to usual care.⁴⁶

With a focus on managing symptoms following breast cancer treatment, The-Optimal-Lymph-Flow health IT system is an mHealth site with an electronic assessment and education on self-care strategies for lymphedema symptom management.⁴⁷ Evaluated over 12 weeks with 355 survivors of breast cancer, 97% reported high satisfaction with ease of use, and participants reported less pain, less soreness, less aching, less tenderness, fewer lymphedema symptoms, and improved symptom distress (all p values $< .05$).

In the area of tobacco control for cancer prevention, a number of apps have been developed with good interest. A 2014 search identified 546 smoking-cessation apps in the Apple Store and Google Play, which were downloaded an estimated 3.2 million times in the United States and 20 million times worldwide.⁴⁸ A review specifically of Android apps for quitting smoking identified 225 apps available between 2013 and 2014.⁴⁹ Most provided simplistic tools (e.g., calculators, trackers). Use of tailoring was limited, though positively related to app popularity and user ratings of quality.

The numbers are anticipated to rise as interest in mHealth apps and wearable health devices continues to grow. The past 2 years (2014–2016) saw a doubling in consumer use. One in three adults now report using an mHealth app and

SIDEBAR 2. Development of the Physical Activity and Your Nutrition for Cancer (PYNC) Prevention App

Objective

To promote healthy diet, nutrition, physical activity, and weight loss among women at risk of breast cancer who have varying levels of health literacy and e-health literacy.

Methods

An eight-step process is being followed to ensure that the intervention materials are appropriate for the intended audience. Development to date has included literature reviews, conceptual design, drafting informational and motivational content, acceptability review with community members, and scientific review by the research team. Remaining steps include prototyping materials, assessment of health literacy level, usability testing with community members, and final modifications.

Framework

The app uses Leventhal's Common Sense Model of Health Behavior, which describes how thoughts and beliefs about health and disease risk influence behavior.

Components

The app draws upon commercially available technology for monitoring physical activity, caloric intake, diet, and nutrition (Fitbit, LoseIt!, and USDA's ChooseMyPlate) while providing evidence-based information about breast cancer and ways that women can reduce their risk of the disease.

Prototype Feedback

Recommendations included use of "more relaxed language" and presentation of information "in a more visual way." Other suggestions included ideas for easy-to-prepare healthy foods, instruction on how to read food labels, and information on environmental contaminants and chemicals that may influence cancer risk, such as cleaning and beauty products.

Future Directions

Next steps are testing the efficacy of the mHealth intervention in increasing physical activity, improving diet and nutrition, and managing weight through a randomized controlled trial.

21% a wearable device, with use greatest among adults age 18–34. The most popular mHealth app segments are fitness (59%) and diet/nutrition (52%), followed by symptom navigators (36%), patient portals (28%), health condition trackers (25%), medication trackers (12%), and disease-management apps (10%). Most consumers (77%) and doctors (85%) view health wearables as helping to engage patients in their health, and over a third of physicians have recommended mHealth apps to their patients.^{43,50} In the area of cancer care, novel wearable technology concepts include balance sensors for patients with chemotherapy-induced peripheral neuropathy⁵¹ and Google glasses with a fluorescence imaging system for complete resection of tumors in surgical oncology.⁵²

The demonstrated evidence, however, for mHealth apps in promoting and sustaining behavior change is still limited. A 2016 review of 38 articles of mobile phone applications for behavior change, four specific to cancer, was unable to identify a single best practice approach to evaluate mHealth apps, which the authors noted was further complicated by a general lack of regulation.⁵³ Similarly, a systematic review of randomized controlled trials testing the efficacy of mHealth apps for cancer prevention identified only four trials for smoking cessation and two for sun safety and concluded a meta-analysis was premature in this area.⁵⁴

Health apps also have been developed to help consumers reduce exposures to known or suspected carcinogens and other toxicants in work or home environments. App functions include education, scanning of product bar codes at point-of-purchase, and self-tracking. With the same limitations acknowledged above, to date, the environmental health apps have not been tested for acceptability, feasibility, or effectiveness in randomized controlled trials.⁵⁵

PRIVACY AND CONFIDENTIALITY CONCERNS WITH SOCIAL MEDIA AND MHEALTH TECHNOLOGIES

Although technologies such as smartphone mHealth apps and other remote monitoring devices have the potential to transform oncology care,⁵⁶ they also raise new considerations with regard to patient privacy and confidentiality. Apps may support a patient's self-report of symptoms or passively record location and other information using global positioning systems, accelerometers, and physiologic sensors. The ability to collect large amounts of personal data over long periods of time provides clinicians and researchers with insights into disease treatment and progression and also raises unique ethical issues.^{57,58} We consider in this study the privacy and confidentiality concerns of social media and consumer-oriented mHealth technologies; patient safety, data security, and confidentiality of mHealth technologies; and regulatory developments. With direct application to practice, we also consider clinician-patient discussion points regarding the risks and benefits of using mHealth technologies.

Patients who purchase consumer-facing smartphone apps and other mHealth technologies (e.g., apps for weight loss

and wearable devices for monitoring steps, heart rate, and sleep) may not be well informed of privacy practices. Systematic reviews of health and wellness apps available from generic app stores have identified deficiencies in the extent to which data uses are documented and appropriate security measures are implemented.^{59,60} Among the most commonly used apps available for iOS and Android, only 183 of 600 (31%) had privacy policies, and 66% of the privacy policies did not specifically address the app.⁵⁹

Consumers may be unaware that smartphone apps may share sensitive information such as sensor data on location with third parties such as advertisers. Many apps sold direct to consumers send unencrypted data to third party sites for advertising or analytics.⁶¹ The main security risk is unauthorized access to data during collection, transmission, or storage. Unencrypted data (e.g., global positioning system coordinates, telephone numbers, email addresses, health information) transmitted over the internet can be intercepted. Efforts have been made to create secure devices and apps, but many contain serious flaws.⁶²

Security threats also exist for provider-facing mHealth technologies. Ethical and regulatory issues related to mHealth technologies used by providers for patient care relate to patient safety and the security and confidentiality of patient data transmitted and stored in mobile medical apps.⁶³ Hackers and malware pose an increasing threat to the security of mobile medical apps.

REGULATION AND CERTIFICATION OF MEDICAL APPS AND MHEALTH TECHNOLOGIES

In some countries, government agencies have begun to regulate or curate medical apps.⁶³⁻⁶⁵ In 2013, the U.S. Food and Drug Administration (FDA) released guidance for mobile medical apps that draws a distinction between unregulated apps and mobile medical apps that are subject to overt FDA regulation.⁶⁶ Apps that convert a mobile platform such as a smartphone or tablet computers into a medical device are regulated by the FDA.⁶³ The FDA regulates mobile apps that pose a greater risk to patients if they do not function as intended (e.g., apps that perform clinical tests such as blood or urine analysis, apps that display diagnostic images from x-rays and MRI, and apps that remotely display data from bedside monitors). The FDA focuses on technical issues related to patient safety and the security and integrity of information but not patient privacy.⁶² Consumer-oriented apps for general health education are mostly unregulated.⁶⁶ In Europe, an Irish app (ONCOassist) for the iPhone and iPad that contains prognostic tools and calculators for oncologists at the point-of-care, has received Conformite Europeenne certification indicating that it complies with relevant European Union legislation.⁶⁷ The European Medical Device Directive MDD 93/42/EEC mentions software in its definition of a medical device.

In the United States, the Health Insurance Portability and Accountability Act (HIPAA) contains the primary set of regulations that guide the privacy and security of health

information.⁶⁸ HIPAA regulations require covered entities and their business associates (e.g., physicians, hospitals, health plans) to protect health information that identifies an individual and that relates to an individual's physical or mental health or health care services provided to the individual.⁶⁹ Developers of mobile apps and sensors must consider whether the software and information technology will be used by a covered entity and whether it will include any protected health information. For example, an app that assists a health care provider with following up patients must be designed to allow the provider to comply with HIPAA.⁶⁹ HIPAA requires that identifiable health information be encrypted so that only those authorized to read it can do so.⁶⁸ In the United Kingdom, the National Health Service established a Health Apps Library that endorses apps considered to be relevant to people in Great Britain and that provide trustworthy information, comply with data storage regulations, and do not pose potential risks if used improperly.⁷⁰ A recent assessment of 79 apps certified as clinically safe and trustworthy by the Health Apps Library found systematic gaps in compliance with data protection principles.⁷⁰ None of the 79 apps encrypted personal information stored locally, 66% (23 of 35) of apps sending identifying information over the internet did not use encryption, and 20% (7 of 35) did not have a privacy policy.⁷⁰ The authors noted that app users cannot see into the inner workings of apps or the services to which they connect; hence, they must trust developers to comply with privacy regulations and security best practices.⁷⁰ Medical information stored on apps or transmitted via the internet or Bluetooth should be secured using encryption.⁷¹

WHAT SHOULD CLINICIANS TELL THEIR PATIENTS ABOUT PRIVACY AND CONFIDENTIALITY?

Clinicians can only provide limited guarantees about privacy protection. Data collected on mobile phones can be subpoenaed as part of legal proceeds in civil or criminal cases.⁵⁷ Because of the potential for hacking of personal data from mHealth apps, the security of data collected via mobile phones cannot be guaranteed.⁵⁷ As stated, many mHealth apps do not use encryption when transferring data.⁷² A further issue is that telecommunication companies record metadata and data transferred over their networks and sell them to third parties.

Patients' trust in their clinicians contributes to treatment adherence and continuity of care and, in turn, plays an important role in the adoption of mHealth technologies.⁶⁸ Clinicians should discuss the risks and benefits of using mHealth technologies as part of patient-centered care.⁶⁸ Providers should be aware of their institutions' privacy and security policies as part of their ethical obligation to ensure patient-physician confidentiality. Before using mHealth technologies, clinicians should obtain informed consent from patients so that they understand the benefits, risks, and potential harms. The rapid pace of development, early efforts at regulation, and the complex nature of the

risks posed by using mHealth technologies raise challenges in communicating risks to patients.⁵⁷ Discussion of the potential risks (e.g., data harvesting, data breaches), benefits (e.g., self-awareness/self-management, attention to adherence and lifestyle behaviors, patient-provider communications), and unknowns (e.g., optimal balance of tech to touch) is warranted.

USING SOCIAL MEDIA AND MHEALTH APPS IN LOW-RESOURCE SETTINGS

Globally, by 2030, the burden of cancer is predicted to worsen significantly in low-income (82% increase in incidence) and lower-middle income (70% increase) countries.⁷³ The rise in mobile phone access worldwide⁷⁴ affords opportunity for delivering social media and mHealth technologies to improve cancer awareness, encourage timely screening, and secure follow-up care.⁷⁵ In the United States, mobile technologies have bridged the digital divide.⁷⁶ By ethnicity, African Americans and English-speaking Hispanics are just as likely as whites to own a mobile phone and use it for a wider range of activities.⁷⁶ In a survey of female public housing residents in Boston, nearly all reported mobile phone use for calls (97%) and texts (84%); recent use (past day) of the internet was 65%, social media 59%, and email 28%; 70% had a Facebook account and 12% a Twitter account.⁷⁷ Social media users were more likely to be Hispanic and Spanish speaking.

Broad reach, low or no cost, and high scalability make social media and mHealth apps particularly well suited for application in resource-poor settings. Social media can be used across platforms (i.e., Android, iOS, and personal computers) and can connect individuals over long distances, which can be valuable to individuals in rural areas with rare cancers who do not have peers or role models readily available otherwise. Even for those with more common cancers, online social media allows social interaction without the burden of travel to clinics or support group locations. Research indicates barriers to engaging in care among some low-income groups, such as residents in public housing.⁷⁸ Social media and mHealth technologies may aid outreach efforts with appropriate messaging and support for cancer prevention efforts.

Needed and worthy of evaluation is the extent to which people with lower levels of health literacy or numeracy find cancer-related use of social media and mHealth apps to be helpful or practical and whether apps are effective in helping culturally diverse groups to reduce their risk of cancer. Emphasized is the thoughtful development and use of mHealth applications to solve health disparities, not widen them.

To inform development of a social media smoking-cessation intervention, focus groups were conducted with 33 Hispanic, Spanish-speaking, current and former smokers in the San Francisco Bay area.⁷⁹ Most participants owned a smartphone (84%), and the majority of cell phone owners reported daily texting (81%) and Facebook use (69%). The participants valued the communal aspect of social media

and suggested strategically tailoring groups based on key features (e.g., age, gender, language preference). Participants reported preferring visual, educational, and motivational messages connected with existing services.

Development of social media and mHealth programs for diverse settings and communities can be achieved with limited investment by drawing upon existing resources. Content analyses of various social media groups (e.g., Facebook groups, individuals using the same Twitter hashtag) have identified several types of social support provided,^{16,80} and numerous interventions have shown that behavior change techniques can be effectively delivered via existing social media tools.^{7,23,81} Hence, expending resources to create new cancer-focused mobile apps or websites may not be necessary to deliver effective prevention and treatment interventions. Even if the long-term goal is to create an entirely new system, existing tools can provide a method for prototype testing. For example, combinations of personal emails and group sessions via social media can be used to test out the potential effects of face-to-face or app-based delivery of these techniques. An example of effective low-cost leveraging of mobile technologies comes from work in Ambanja, Madagascar, where smartphones were used to take and transmit high-definition images for the detection of cervical intraepithelial neoplasia of grade 2 or worse as an adjunct to standard on-site examination.⁸²

CONCLUSION

Exciting innovations in mHealth and social media applications are occurring across the cancer spectrum, from primary prevention to screening, early diagnosis, treatment, survivorship, and end-of-life care. These new platforms and technologies avail social engagement and support as well as personalized data points for patients and providers to inform care decisions. Cancer-prevention applications include

attention to tobacco use, diet, physical activity, and sleep; there are screening apps and cancer risk calculators to raise awareness; and links to patient communities or providers for symptom management. Advantages of social media and mHealth technologies include low or no cost, high scalability, self-tracking and tailored feedback functionalities, use of images and video for enhanced health literacy, broad reach, and data sharing for large-scale analytics. Although development efforts have been rapid and numerous, frameworks and investigations of efficacy for achieving and sustaining behavioral change and positive health outcomes are sorely needed, and regulation concerning data security issues is notably lacking. Targeted development is also needed for culturally diverse groups and for non-English speakers. Further investment in research to build the evidence base and identify best practices will help delineate and actualize the potential of social media and mHealth technologies for cancer prevention and treatment.

ACKNOWLEDGMENT

J. J. Prochaska's research is funded by the National Cancer Institute (R01-CA-204356), the National Heart, Lung and Blood Institute (R01-HL-117736), the State of California's Tobacco-Related Disease Research Program (24RT-0035 and 25IR-0032), and an intramural grant from the Stanford Cancer Institute. J. J. Prochaska is on the advisory board for Carrot Sense, a digital health company. S. S. Coughlin's research is funded by the Office of the Assistant Secretary of Defense for Health Affairs under award no. W81XWH-16-1-0774 and by intramural support provided by the Augusta University College of Allied Health Sciences. E. J. Lyons is supported by a Mentored Research Scholar Grant in Applied and Clinical Research (MRSR-14-165-01-CPPB) from the American Cancer Society and the Claude D. Pepper Older Americans Independence Center (P30-AG-024832).

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