eHEALTH: CURRENT EVIDENCE, PROMISES, PERILS AND FUTURE DIRECTIONS

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eHEALTH: CURRENT EVIDENCE, PROMISES, PERILS AND FUTURE DIRECTIONS

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INTRODUCTION: PROMISES AND PERILS OF eHEALTH

Timothy M. Hale, Wen-Ying Sylvia Chou, Shelia R. Cotten and Aneka Khilnani

The rapid diffusion of the Internet and the development of a wide variety of digital technologies have created tremendous opportunities to improve health communication and public health, while also raising challenges in the emerging field of eHealth. The term eHealth is used to refer to the use of information and communication technologies for health and healthcare delivery services (Hale, 2014). Jeff Goldsmith (2000) and Shelia Cotten (2001) published seminal papers that outlined key opportunities and challenges. They identified the potential for technology to transform (1) how people seek and share information about their health and medical conditions; (2) the patient provider relationship and empowerment of patients with the knowledge needed to take an active and informed role in making decisions about their medical care; (3) how people build and maintain health-related communities and garner social support; (4) how people access healthcare services; (5) the organization of healthcare institutions and care team management; and (6) methods of data collection for use in remote monitoring and care management. They also identified several challenges, including (1) the digital divide and disparities in access to technology; (2) privacy and security concerns that

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may pose a barrier to adoption; and (3) the quality and sometimes contradictory information available online.

Researchers have explored many of the promises and challenges identified by Goldsmith and Cotten during the last 15 years. For example, health behavior interventions disseminated via social networking sites have shown a positive effect on behaviors (Laranjo et al., 2015). A remote monitoring program for patients with heart failure (HF) can improve medical care and patient self-management, lowering rates of hospitalization and mortality post HF-related hospitalization (Agboola, Jethwani, Khateeb, Moore, & Kvedar, 2015). However, challenges associated with new eHealth services have emerged. For example, social disparities in access and use of eHealth technologies continue to limit the potential of eHealth to improve the care and health outcomes of the socially disadvantaged, who are most at risk of chronic diseases and poor or limited health care. Another emerging challenge concerns the growing quantification of behaviors and biometrics enabled by wearable sensor-based technologies. While the available comprehensive quantitative data may aid health care, these technologies also pose ethical, privacy, regulatory, and methodological challenges.

This volume presents a selection of cutting-edge studies on the role and impact of the Internet and other technologies in health communication across a broad range of contexts. Contributions generally fit into three major categories with overlapping themes: (1) Communication research testing conceptual models or taking a critical theoretical perspective to examine emerging trends. Works include analysis of the digital divide (Neter et al., Chapter 6), the role of personality traits in determining who benefits from online support (Ren and Xiaojing, Chapter 7), and how online health information resources can help people understand their medical conditions and treatment options, thus potentially taking more control of their health care (Seckin et al., Chapter 8). Authors also explore the social and cultural implications of electronic medical records (EMRs) and new communication technologies (Wang, Chapter 4) and self-quantification technologies such as activity trackers and mobile health apps (Ross, Chapter 5). (2) Descriptive studies examining sociodemographic factors associated with eHealth use and preferences. A study examines how people assess the credibility of eHealth information (Klawitter and Hargittai, Chapter 1), while an analysis of a national survey evaluated the public's level of trust in health information channels (Thai et al., Chapter 2), and finally, another study assesses eHealth communication in a specific community, namely deaf adults (Kushalnagar and Kushalngar, Chapter 3). (3) eHealth intervention studies both in public health and the clinical care context. Contributions *Introduction* 3

are limited in this area, and two studies examine tobacco cessation interventions (Peterson et al., Chapter 9 and Sanders-Jackson et al., Chapter 10).

Many of the chapters discuss social and healthcare implications of eHealth services and activities. One major theme that emerges is the continuing relevance of the digital divide and moving beyond a conceptualization of the divide as simply access inequities to a more nuanced examination of how technology may contribute to and even exacerbate social and healthcare inequalities. For example, Neter et al. (Chapter 6) examine the association between various types of Internet use (i.e., Web 1.0 consumption activities and Web 2.0 production activities) and healthrelated benefits. They find that Web 1.0 consumption activities are positively associated with healthcare services utilization and perceived health benefits from seeking health information online, but not with self-rated health. Interestingly, Web 2.0 activities were not found to be associated with health-related outcomes after controlling for sociodemographic characteristics in the multivariate statistical models. Ren and Xiaojing (Chapter 7) examine how individuals' psychological traits moderate the effect of participation in an online cancer support group on people's mental well-being following a cancer diagnosis. They find that personality characteristics are related to who benefits most from online support group participation and argue that a patient's personality characteristics should be taken into account before recommending online communities to improve survivors' coping with cancer.

Power, in terms of the ability for individuals to take action and have effective control over their lives or as embedded in social norms and established institutions, emerges as another important concept in this volume. The Internet has long been conceptualized as a system that democratizes the dissemination of information (DiMaggio, Hargittai, Neuman, & Robinson, 2001) providing a means for empowering individuals to access health information that was previously guarded by gatekeepers such as healthcare institutions (Hale, Goldner, Stern, Drentea, & Cotten, 2014; Hardey, 1999, 2001). Seçkin et al. (Chapter 8) explore the relationships between online health information seeking and positive health perceptions. They find that seeking health information online contributed to a greater sense of competence to communicate with their provider and, in turn, a greater sense of empowerment to manage their health, better self-care, increased quality of life, and better self-rated health.

Taking a critical theory approach to consider sociocultural implications of eHealth, Chapters 4 and 5 examine how eHealth technologies are embedded in institutions and practices that perpetuate existing power inequalities. Wang (Chapter 4) examines how the use of EMRs and mobile technologies

(i.e., cell phones and pagers) are incorporated into clinical workflows with the intention of enabling healthcare workers to better manage their work time and non-work time. However, she finds that although these technologies did enable better time management for healthcare workers those of higher status in the institutional hierarchy are better able to control how these technologies are used, and benefit the most in terms of time and autonomy, as compared to those in lower status positions. Ross (Chapter 5) examines tools for self-quantification such as activity trackers and mobile health apps. Although these tools are often described as providing new opportunities to conceptualize health and gain power and control over one's body, Ross argues that they also facilitate social control and perpetuate existing gendered social norms of the body and health; and, in effect, they may reproduce and reinforce gender disparities in power and control in behavioral norms.

Another major theme centers on the trust and credibility of sources and channels of health communication. Examining data from the Health Information National Trends Survey (HINTS) from 2005 and 2013, Thai et al. (Chapter 2) examine trends and predictors of the level of trust people have in various health information channels. They find a decline in the trust of traditional mass media and relatively stable levels of trust in the Internet, with trust of physicians remaining high. Trust of the Internet was greatest among those with higher levels of education and income. Klawitter and Hargittai (Chapter 1) examine the cognitive processes involved as people assess the credibility of online health information resources, including search engine results, branding, perceived legitimacy based on site name, and the source of the page/site content. They find that individuals assess credibility largely based on the information presented on the search results page, followed by evaluation of the site and the source of the information provided. Interestingly, the authors find that less savvy searchers believed user-generated content would be curated and that inaccurate information would be removed. whereas more savvy searchers are more skeptical of user-generated content.

The contributions to this volume span diverse populations and types of research methods. Several chapters focus on understudied and marginalized communities and identify potential needs to guide future intervention efforts. These descriptive studies are critical in informing intervention development, with the goal of creating and disseminating effective and equitable technologies and care. For example, Sanders-Jackson et al. (Chapter 10) use semi-structured interview data from lesbian, gay, and bisexual (LGB) young adults to explore interest in the use of social media for smoking cessation. Peterson et al. (Chapter 9) collect data from focus groups with adult Chinese-born men to determine what message themes and images to use in a graphic text

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messaging smoking cessation program aimed at this population. In another example, Kushalnagar and Kushalnagar (Chapter 3) conduct one of the first studies among deaf adults to identify sociodemographic characteristics associated with health-related Internet use in order to inform the design of accessible eHealth systems that meet the needs of deaf users.

With regards to research methods, contributions reflect a wide range of approaches, from a cross-disciplinary literature review, qualitative analyses, mixed methods, and regression modeling for cross-sectional populationbased surveys. For example, Ross (Chapter 5) takes a cross-disciplinary approach, drawing upon literature from psychology, social theory, and new media to outline trends in self-quantification and the gendered objectification of the body and health. A variety of qualitative methods are also employed, including semi-structured interviews (Sanders-Jackson et al., Chapter 10, and Wang, Chapter 4) and focus groups (Peterson et al., Chapter 9). Klawitter and Hargittai (Chapter 1) employ a mixed-methods approach – using surveys, interviews, and observations – to examine how a sample of Chicago adults evaluates the credibility of online health information. To collect cross-sectional data on health communication from deaf adults in the US, Kushalnagar and Kushalnagar (Chapter 3) test innovative online survey modalities, including the use of videophones, and modifying the HINTS to facilitate data gathering from deaf individuals. Ren and Xiaojing (Chapter 7) use an online questionnaire to collect data from visitors to the two largest Chinese online leukemia communities. Finally, authors of three chapters use a variety of statistical techniques to test their models using data from nationally representative samples. Thai et al. (Chapter 2) use regression modeling to analyze a nationally representative sample, while Seckin et al. (Chapter 8) use structural equation modeling and a national probability-based online sample. Finally, Neter et al. (Chapter 6) use linear regression models and data representative of Israeli adults collected using random-digit-dial telephone administered surveys.

As technology continues to evolve rapidly, there are several emerging areas that remain understudied to date. While a growing body of research studies has attempted to capitalize on the promise of eHealth technologies to improve healthcare delivery and provide patients with greater access to medical knowledge and data on their health, concerns of potentially negative health consequences of the growing use of eHealth are beginning to surface. However, many discussions are anecdotal and evaluations are limited in scope and systematic rigor.

A key concern centers around the "echo chambers" and information silos perpetuated by the Internet and social media (Pariser, 2011; Rainie & Anderson, 2017; Rainie, Anderson, & Albright, 2017). Echo chamber is a

metaphorical description of a situation wherein people's sharing of similar opinions, ideas, and beliefs are amplified or reinforced inside communication channel silos and extends beyond political viewpoints to many other domains, including health topics. For example, there are well-documented online communities centered around skepticism toward vaccination (e.g., "anti-vaxxers") – they frequently share conspiracy theories against government agencies, scientific authorities, and the industry, and disseminate myths and misinformation about the dangers of vaccine (Kata, 2012; Tangherlini et al., 2016). Fear appeal is also a commonly utilized communication strategy in promoting mistrust in scientific authorities (Tannenbaum et al., 2015). The negative health consequences of these online communities are gradually emerging, with evidence that anti-vaccine movements are facilitated by social media and the recent rise of infectious diseases (such as measles and pertussis) are linked to these anti-vaccine movements (Gangarosa et al., 1998; Omer, Salmon, Orenstein, deHart, & Halsey, 2009; van Panhuis et al., 2013). The need to better understand online communication processes and echo chambers is heightened following the 2016 US Presidential election and growing concerns over "fake news" and misinformation circulated in social media (Allcott & Gentzkow, 2017). Future research should examine, through descriptive and experimental methods, the effect of echo chambers across a number of polarized or politicized health topics, such as cancer treatment options, e-cigarette use/vaping, and nutritional/dietary recommendations not supported by science.

Another area that warrants systematic inquiries is the effect of smartphones, mobile technologies, social media, and emerging technology use on the psychosocial well-being of various segments of the population. A substantial body of work finds that social media can enable people to connect across geographical and other boundaries, improving their access to social support that has a positive influence on psychosocial well-being. For example, a large retrospective study of older adults found that Internet use was associated with lower odds of depression classification (Cotten, Ford, Ford, & Hale, 2012, 2014). In another study, the number of Facebook friends that college students have was associated with greater perceived social support, less physical illness, and better mental well-being (Nabi, Prestin, & So. 2013). The positive benefits of social media use on psychosocial well-being are particularly strong for marginalized groups, such as LGB teens who gain a sense of group membership and reduced stigma from participation in online LGB groups (Chong, Zhang, Mak, & Pang, 2015). However, as Cotten, Goldner, Hale, and Drentea (2011) noted, the benefits vary by types, timing, and amount of use people make of these technologies – sometimes with negative Introduction 7

impacts on psychosocial well-being. For example, a systematic review found both positive and negative impacts of social media on adolescents' health (Best, Manktelow, & Taylor, 2014). Additionally, technology use often introduces unintended consequences on psychosocial well-being and health, such as putting adolescents at increased risk of cyberbullying or contact with online predators (Livingstone & Smith, 2014) and increased risk of car accidents or falling while using a mobile phone (Nasar & Troyer, 2013; World Health Organization, 2011).

Finally, there are a growing number of new ethical, social, and legal considerations for health data collection and surveillance in the era of eHealth. New challenges emerge from the gathering of user-generated data through online panels and websites (e.g., Amazon's Mechanical Turk) to privacy and confidentiality protection of research subjects and personally identifiable data and "accidental" data gathering of sensitive information in social media interactions. One example of the challenges ahead is the National Institutes of Health, Precision Medicine Initiative, or All of Us Cohort, launched in 2015 (Collins & Varmus 2015; National Institutes of Health, 2017). This ambitious research program aims to create a cohort of 1 million Americans and collect data including biospecimens and whole-genome sequencing data, EMRs, and data gathered by surveys and personal health technology such as wearable sensors (National Institutes of Health, 2017). To ensure that data are kept safely and securely and in accordance with the participants' wishes, technical solutions for data security are enormous and require a substantial effort to understand and protect privacy and confidentiality. The experience and expertise of eHealth researchers need to be leveraged in participant recruitment, data collection processes, and the management and dissemination of cohort data.

On the frontier of emerging technologies and eHealth, one challenge is implantable devices. For example, an implantable cardioverter defibrillator offers the promise of a more personalized and improved care, but with the trade-off that the data from these devices are most often viewed as the property of the device manufacturer and not made available to the patient (Campos, 2015). In addition, connected implantable devices, as part of an expanding Internet of Things, are vulnerable to hackers and pose a new security risk (Larson, 2017; Newman, 2017).

In summary, eHealth is a rapidly growing and dynamic area of research. Its multidisciplinary nature and the rapid pace of technological developments and changes make doing research challenging and yet exciting. This volume presents works that illustrate both evolving areas of research and emerging topics. While there are few, if any, broad conclusions that can be drawn from research

in this diverse field, one thing is certain – it will only increase in importance as a topic of health communication research in the years ahead.

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