

## 12

# ONLINE HEALTH INFORMATION

## Conceptual Challenges and Theoretical Opportunities

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“Tectonic shift”: That is how the architects of the first Health Information National Trends Survey characterized recent changes in the way we seek and consume health information (Hesse et al., 2005). Thanks to the dramatic diffusion of the Internet and widespread availability of health information and services online, the majority of Americans now conduct increasing amounts of their health communication via online channels. The latest Pew survey found that 61% of adults had used the Internet for health information (Hesse et al., 2005, reported 63%), up from 25% in 2000 (Fox & Jones, 2009). The most frequent searches were for a specific disease or medical problem (49%) and a medical treatment or procedure (41%). Searching for exercise and fitness information increased the most from 2002, up to 38%. Quite noteworthy is that two-thirds talk about the results with someone else, typically a spouse or friends, and that just over half of all online inquiries are done for the benefit of someone else. More and more, users are also reading someone else’s experiences (41% via news group, website or blog), rankings of doctors or health care providers, and rankings of hospitals or other medical facilities (both 24%), receiving health or medical updates (19%), or listening to a health or medical issue podcast (13%).

While the digital divide is still a reality, with e-health usage tempered by access issues (e.g., Beckjord et al., 2007), sociodemographic, psychological, and health factors (e.g., McNeill, Puleo, Bennett, & Emmons, 2007; Rice, 2006), the trend toward posting and seeking health information online continues, especially globally. In Europe, 44% of the adult population of Norway, Denmark, Germany, Greece, Poland, Portugal, and Latvia (71% of Internet users in these countries) report going online for health information (Andreassen et al., 2007) in order to read up on medical conditions and prepare for or follow up on doctor visits. Similar patterns have been observed in less developed parts of the world, especially among the younger generation. For example, Borzekowski, Fobil, and Asante (2006) report that two-thirds of the in-school youth and over half (54%) of out-of-school adolescents in Ghana’s capital city of Accra had gone online, with 53% of them seeking health information on the Internet with “great interest” and “high levels of efficacy” (p. 450).

## **An Overview of e-Health**

The increase in and diversification of users are matched only by the tremendous variety and scope of health information and services available online. The landscape of e-Health has become a vast one, with individual and population health technologies that have been deployed in clinical as well as nonclinical areas for a range of stakeholders, with the overall goal of enabling and improving health and health care (Eng, 2001). It includes access to and provision of content (health information, health behavior change, decision making); connectivity (across functions, organizations, actors, providing research results); community (messaging, online support); commerce (products, medical equipment and supplies, medications, insurance); and care (self-care, electronic health records, disease management, telemedicine/tele-Health) (e.g., Eng, 2001; Gibbons, 2007; Wallis & Rice, 2006). See Tables 12.1 and 12.2 for a summary of the advantages and disadvantages of e-Health, as well as facilitators of and barriers to the development of e-Health.

### ***Health Websites***

Websites remain the mainstay of health information on the Internet. Websites are remarkably versatile tools for mass communication of health information and advice. For example, the Dietary Approaches to Stop Hypertension (DASH) program found that sustained use of materials on nutrition education, delivered totally via the Internet, involving no person-to-person contact with health professionals, resulted in significant dietary improvements and lowering of weight and blood pressure after 12 months (Moore et al., 2008). In general, health websites have been shown to be quite effective in promoting self-help (Farvolden, Denisoff, Selby, Bagby, & Rudy, 2005) and preparing patients for doctor appointments (Hartmann et al., 2007).

Health websites are not only repositories of information, but also vibrant forums for discussion. While research on social support has historically examined chat rooms and bulletin boards on health sites, newer studies have focused on Web 2.0 media such as blogs and wikis. As Denecke and Nejdil (2009) note, some medical weblogs and question and answer portals provide rich information on diseases and medications, and some wikis deal with information on anatomy and procedures. Patients and nurses tend to dwell on personal and emotional aspects while doctors fill their blog posts with information. Both of them are picked up by search engines and therefore enter the mainstream of online health information, given that most people tend to start their quest for health information via search engines (e.g., Eysenbach & Kohler, 2002). Despite the free-floating nature of content, studies show that health blogs are seen as credible sources of information. Medical bloggers tend to be highly educated and devoted to sharing practical knowledge and skills (Kovic, Lulic, & Brumini, 2008). Sundar, Edwards, Hu, and Stavrositu (2007) argue that blogs have the real potential to put the public back into public health by allowing patients an active, dynamic space for dealing with their illness and informing as well as influencing others along the way. As part of their coping, patient bloggers not only connect with others in similar situations, but also construct their identity, in an effort to assert agency (Sundar, 2008). In the blogosphere, the receiver is the source of both personal and mass communication. In addition, other receivers also serve as sources through their own blogs or by commenting on others' blogs. In this manner, blog technology operationalizes the concept of "receiver sources" (Sundar & Nass, 2001) at both the individual and collective levels.

Table 12.1 Advantages and Disadvantages of e-Health

<i>Advantages</i>	
<ul style="list-style-type: none"> <li>• allow anonymity and reduced social cues, to increase honest discussions and disclosure, for posting personal health information and problems and less risk in online self-disclosure</li> <li>• allow some who are not comfortable posting messages to “lurk”</li> <li>• awareness and management of one’s own health records</li> <li>• better informed patients for physicians</li> <li>• broader access on demand (more times and places)</li> <li>• broader range of health information</li> <li>• collaborative health decision making</li> <li>• connect patients and health care providers who are geographically or professionally isolated</li> <li>• convenient and efficient learning environments for medical training</li> <li>• cost-containment or cost-reduction strategies</li> <li>• emotional support</li> <li>• encyclopedic breadth of information</li> <li>• expanded choice and autonomy</li> <li>• faster diffusion of medical research and knowledge (i.e., rare conditions)</li> <li>• finding/communicating with/evaluating health providers</li> <li>• foster development of online communities</li> <li>• foster development of social and professional health care networks beyond patients/individuals and beyond system users</li> <li>• greater access to diverse sources of health information</li> <li>• greater communication with others sharing the health problems, and with health professionals</li> <li>• greater provision at lower cost in residential and rural homes</li> <li>• healthier communities</li> <li>• healthier employees</li> <li>• healthier population more capable of self-care</li> <li>• help patients make sense of their medical experience (such as cancer)</li> <li>• improve access to alternative medicine products and information</li> <li>• improve and update dissemination of health information</li> <li>• improve doctor-patient communication (through e-mail, and bringing in printouts of Internet health information)</li> <li>• improve patient empowerment and self-care</li> </ul>	<ul style="list-style-type: none"> <li>• improve self-presentation in discussing medical conditions with others</li> <li>• increase access to emotional and social support from broad range of others who share same experience and concerns</li> <li>• increase access to health information</li> <li>• increase interaction with others dealing with the same problem</li> <li>• increase personalization</li> <li>• increase the capacity of health care providers to promote, treat, monitor, and discuss health conditions</li> <li>• match the modes used to the intervention purposes of the users’ learning styles</li> <li>• message tailoring and stages of readiness assessed through interactive choices</li> <li>• more adherent and satisfied patients</li> <li>• more efficient service</li> <li>• more interactivity</li> <li>• more personalized and customized information and interactions</li> <li>• not just receive but also provide social support or the more broad experience of generalized reciprocity and sharing</li> <li>• provide clinical support (such as medical education, diagnoses, and best practices) to nonphysicians</li> <li>• provide convenient support for peer counseling</li> <li>• provide more health services to underserved populations, reducing health disparities</li> <li>• provide online health insurance applications and registration</li> <li>• reduce costs</li> <li>• reduce errors and delays (such as in prescriptions, medications, obtaining personal medical records)</li> <li>• reduce health care costs</li> <li>• reduce obstacles to interpersonal communication</li> <li>• support groups</li> <li>• sustained use of e-Health products</li> <li>• switch from telephone calls to online information provision</li> <li>• tailor health information</li> <li>• tailoring</li> <li>• therapeutic value of self-disclosure</li> <li>• time, place, and space flexibility in taking online medical education courses</li> <li>• wider access for at-risk groups through online health campaigns and interactive interventions</li> <li>• wider markets for products</li> </ul>

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Table 12.1 Continued

<i>Disadvantages</i>	
<ul style="list-style-type: none"> <li>• access to unregulated drugs and risk of bypassing checks for drug interactions</li> <li>• access to unverified information and alternative medicines or treatments</li> <li>• allow some to “lurk” and “free ride”</li> <li>• altering perceived expertise and authority of physician</li> <li>• applications misuse</li> <li>• barriers to access, worsening digital and cultural divide</li> <li>• benefits require technical expertise, skills and medical knowledge</li> <li>• challenges to physicians by patients with Internet information</li> <li>• commercial biases in health and prescription sites not always identified</li> <li>• complexity and difficulty in understanding online medical information</li> <li>• decrease public trust in health providers and practices</li> <li>• email interaction with patients generates considerable demands on staff and raises liability issues</li> <li>• enormous barriers to access in developing countries</li> <li>• fraud</li> <li>• improper use of personal information</li> </ul>	<ul style="list-style-type: none"> <li>• inaccurate and unknown quality of information (especially through online support groups)</li> <li>• inappropriate access by third parties</li> <li>• may require additional procedures and effort to use a new system</li> <li>• may require important financial investments over time</li> <li>• missing or misleading website links</li> <li>• narrow and self-reinforcing information and interactions</li> <li>• overload, confusion, and even fright, from online health information</li> <li>• overwhelming number of sites and resources</li> <li>• presentation of opinion as fact</li> <li>• pressure on physicians to prescribe Internet-advertised medicines</li> <li>• privacy and confidentiality risks</li> <li>• risk of frauds or severe health damages</li> <li>• search results are difficult to filter</li> <li>• self-diagnosis and prescribing</li> <li>• unknown authorship, lack of source citation</li> <li>• unreliable networks or storage</li> <li>• use of social media to bypass bans or restrictions on advertising</li> </ul>

Sources: Eng (2001), Fox (2006), Freeman & Chapman (2008), Morahan-Martin (2004), Murero & Rice (2006), Neuhauser & Kreps (2003), Vance, Howe, & Dellavalle (2009).

Health websites do, however, vary in their content and features, especially across commercial and nonprofit sites. A content analysis of 20 commercial and 11 government health sites in 1999 (Rice, Peterson, & Christie, 2001) compared 74 specific features in seven major categories: Non-Interactive Substantive Content, e-Commerce, Multimedia Content, Navigation or Assistance, Search Methods, Interactivity, and Policy. Scientific/Medical/Academic materials were slightly more frequent on government sites (especially notices of clinical trials, and medical library databases) than on commercial sites. Alternatively, commercial sites had somewhat more Educational/Journalistic/PR/Publicity features than did government sites, but only in the area of prevention/wellness information. Obviously, commercial sites had far more e-commerce features, especially in the form of advertising banners, sponsors, online pharmacies, and health or life insurance quotes. Commercial sites also used multimedia features more frequently, especially moving icons/animation or pictures/illustrations. Government sites provided more navigation and assistance features, and search methods and tools, especially in the use of topic headings, but with far less use of pull-down or scrolling menus. Commercial sites provided extensive support for interactivity among users compared to government sites, especially chat rooms and news groups, and also for interactivity with the website. Government sites provided noticeably fewer policy features, particularly with respect to copyright (to be expected, as most, but not all, government information is not copyrighted), advertising policy, and disclaimers. On average, commercial sites offered 22.5 of the 74 features compared to 14 by government sites.

One decade later, West and Miller (2009) conducted a rigorous content analysis of the top 44 commercial websites, top 30 nonprofit health websites, and each state's department of public health website. Few commercial sites displayed health information quality certification seals, and generally had low levels of sponsor disclosure, while government sites presented clear disclosure. Accessibility (e.g., color contrasts, text "alt" tags for images, text telephones or telecommunications devices for the deaf tools, navigation tools) was provided by just over half of government sites, but less than 20% of commercial or nonprofit sites. The mean reading grade level of the text on the sites was 11.4 for government, 9.6 for nonprofit, and 8.7 for commercial sites. Commercial and nonprofit sites offered more interactivity (newsletters, e-mail messages, updates, tailoring, mobile devices) than government sites. Security policies were provided by 84% of commercial, 56% of government, and 40% of nonprofit sites, though privacy policies were more abundant (98%, 56%, and 77%, respectively). Although many of the policies were weak or ambiguous, 77% of commercial sites stated they would not share personal information, with 44% of governmental and 60% of nonprofit sites doing so. Information quality (comparing coverage of breast cancer, strokes, and kidney stones) varied widely across these three major categories of sites, and across nations and cultures (Baek & Yu, 2009).

### Health Devices

In addition to web-based technologies, health communication online takes place through a number of devices. Given increasing acceptance of self-service technology and the readiness for medical self-diagnosis (Lanseng & Andreassen, 2007), a suite of online as well as offline applications, using a variety of media from telephones to kiosks, has emerged to provide automated health care. Electronic mail, for example, is proving to be a cost-effective tool, both for directing attention and traffic toward health websites (Woodall et al., 2007) and for reminding users to adopt healthy behaviors. An e-mail intervention called *Alive!*, featuring weekly goal-setting, individualized feedback, tips, reminders, and promotion of social

Table 12.2 Facilitators of and Barriers to e-Health

<i>Facilitators</i>	
<ul style="list-style-type: none"> <li>• appropriate regulation (i.e., Health Insurance Portability and Accountability Act [HIPAA] standards) and reliable web content</li> <li>• broadband infrastructure</li> <li>• collaboration and cooperation among agencies</li> <li>• computer skills and Internet proficiency for nonmedical public and health care providers</li> <li>• cultural and psychological dimensions</li> <li>• facilitating cultural agents and media support</li> <li>• government promotion of access and infrastructures for e-Health</li> <li>• interconnectivity across systems and channels</li> <li>• mobile/wireless devices and interconnections</li> <li>• more familiarity with and use of general Internet resources</li> </ul>	<ul style="list-style-type: none"> <li>• multicultural expertise and teamwork for development of telemedicine projects, including cooperation and coordination among service, infrastructure providers, and health care providers</li> <li>• patients' willingness to be involved in medical decisions</li> <li>• physician recommendations of health sites</li> <li>• positive perceptions of technology and online service attributes</li> <li>• positive attitude reinforcement and satisfaction from previous online experience (word of mouth)</li> <li>• private investments</li> <li>• reimbursement for online time and services (such as e-mail communication, or medical record exchanges)</li> <li>• support by national and international medical associations</li> </ul>

(Continued)

Table 12.2 Continued

<i>Barriers</i>	
<ul style="list-style-type: none"> <li>• access and knowledge</li> <li>• accountability and responsibility</li> <li>• applying technical standards for interoperability and clinical/care protocols</li> <li>• appropriate infrastructure</li> <li>• appropriate usability design</li> <li>• attracting users to a site</li> <li>• computer fears</li> <li>• computer/ICT skills</li> <li>• contention for system usage between administrators and health care providers</li> <li>• cultural divides concerning technology use and social norms toward health behaviors</li> <li>• developing sufficient privacy protections</li> <li>• differences in data conceptualization by physicians (narratives) and administrators (structured data entry)</li> <li>• differences in procedures for reimbursement and health coverage across economic sectors and national boundaries</li> <li>• difficulties in assessing online knowledge acquisition</li> <li>• disparities in Internet (especially broadband) access and knowledge (digital divide), especially for the very groups that need it most</li> <li>• ethical conflicts (private sites promoting products and services by sponsors)</li> <li>• fragmented and conflicting jurisdiction (across federal, state, regulatory agencies, and technical standards)</li> <li>• high costs of technology overwhelm low cost of access and communication</li> <li>• HIPAA regulations</li> <li>• implementation costs</li> <li>• individuals' perceptions of current medical information rights</li> <li>• insufficient and varying levels of health and technology literacy</li> <li>• insufficient bandwidth</li> <li>• insufficient control or awareness of third party access to personal medical records</li> <li>• insufficient health staff</li> </ul>	<ul style="list-style-type: none"> <li>• insuring quality information and care</li> <li>• interoperability (different standards imposed by regulatory agencies)</li> <li>• joint involvement by local service providers/physicians/patients</li> <li>• lack of basic infrastructure</li> <li>• lack of insurance reimbursement codes for online treatment</li> <li>• lack of interconnection</li> <li>• lack of standard evaluation criteria</li> <li>• lack of support for sustainability of online interventions and health projects</li> <li>• large gap between those with Internet access and those with many kinds of chronic health problems (such as HIV/AIDS)</li> <li>• legal issues such as cross-state pharmacy licenses</li> <li>• limited vision by government and health care agencies as to potential applications</li> <li>• low commitment to and engagement with online health material</li> <li>• low interest in learning about health topics</li> <li>• majority of health sites in English language</li> <li>• need for anonymity (especially for stigmatizing or deviant topics)</li> <li>• norms for mediated patient-physician relationships</li> <li>• overcoming people's avoidance of relevant health information</li> <li>• physician resistance/hesitancy</li> <li>• political divisions, with varying motives</li> <li>• poor management of ICT personnel and projects</li> <li>• reimbursement uncertainty</li> <li>• standard codes for practices and protocols</li> <li>• state licensing laws</li> <li>• sustainability (costs, updating, link stability)</li> <li>• time required to learn new systems</li> <li>• usability</li> <li>• varying national and cultural norms and policies</li> </ul>

Sources: Lieberman, Lloyd-Kolkin, Kreuter, Chea, & Benter (2004), Murero & Rice (2006).

support resulted in significant improvements in diet, physical activity, self-efficacy, and quality of life (Block et al., 2007).

The latest trend, however, is the use of mobile devices. A recent intervention employing a wrist-worn accelerometer, with real-time feedback via the Internet, led to significant increases in, and maintenance of, level of physical activity (Hurling et al., 2007). Another study showed that diary monitoring and behavioral coaching via digital assistance devices were quite feasible and well accepted by migraine sufferers (Sorbi, Mck, Houtveen,

Kleiboer, & van Doornen, 2007). Other studies have explored the feasibility of SMS (short messaging service) on mobile phones for disease management, from submitting asthma diary data (Anhøj & Møldrup, 2004) to recording blood glucose level of diabetics (e.g., Kim & Kim, 2008) to reporting routine pill intake (Cocosila, Archer, Haynes, & Yuan, 2009), with encouraging results. The widespread diffusion of mobile phones among youth has provided prevention scientists with a new channel for reaching their target audiences. Several elaborate multimedia mobile-phone smoking cessation interventions have been launched (e.g., Whittaker et al., 2008), with significant impact on abstinence (Brendryen, Drozd, & Kraft, 2008).

### ***Bundled Interventions***

Of course, the success of such interventions via newer media is contingent upon the characteristics, preferences, and abilities of target groups. There is evidence to suggest that older media centered around printed text are more effective with certain populations, especially when the intervention is purely informational and designed for mass dissemination (e.g., Kroeze, Oenema, Campbell, & Brug, 2008). However, when the technological affordances of newer media are leveraged to provide value-added advantages such as tailoring (discussed below), they can be quite effective, especially when they are deployed in tandem rather than in isolation.

An emerging theme is the importance of supplementing web-based interventions with other technologies that are more personal in their reach. For example, An et al. (2008) found that adding peer e-mail support to smoking cessation messages in an online college-life magazine served to increase abstinence. Even when compared to an interactive control condition, interventions tend to be more successful when bundled with tailored e-mails, journaling activities, and small-group motivational interviewing (Norman, Maley, Li, & Skinner, 2008), thus lending new meaning to the notion of "multi-media." As Zbikowski, Hapgood, Barnwell, and McAfee (2008) found, integrating phone counseling to tailored e-mails and printed *Quit Guides* promoted adherence to their web-based tobacco cessation treatment. Richardson, Brown, Foley, Dial, and Lowery (2005) reported similar success when they enhanced pedometer feedback with tailored nutritional counseling for increasing walking activity among those at high risk for cardiovascular disease. In their weight management intervention, Ware et al. (2008) noted that the "use of monitoring devices to capture and send data to the automated Web-based coaching program may have influenced the high levels of engagement" (p. 1).

One technology often serves as a triage mechanism for health information delivered via another. Nijland, van Gemert-Pijnen, Boer, Steehouder, and Seydel (2008) call for research that focuses on web-based triage mechanisms for medical complaints while simultaneously developing interactive technologies for patients. The key to bundling interventions appears to be effective integration of various online and offline technologies. The Comprehensive Health Enhancement Support System (CHESS) developed by Gustafson et al. (2008) is a good example of integrating information with patient support and analysis as well as decision tools. When compared to control subjects who were given ready access to high-quality breast-cancer websites, CHESS subjects were more likely to log in and access health resources, experienced greater social support, and reported better quality of life and health care competence both during and after the intervention. The value of integration is quite obvious when one considers the multi-dimensional nature of the quality criteria specified by patients and caregivers for Internet interventions. As Kerr, Murray, Stevenson, Gore, and

Nazareth (2006) found out, health care recipients not only have detailed expectations for content (e.g., practical, updated, deep, mention of scientific controversies, accurate, non-commercial) but also for design (e.g., easy access, attractive layout) and functionality (e.g., interactivity, personalization, navigational ease), thereby making the intervention more than merely informational and motivating health communicators to think creatively about leveraging the unique technological capabilities of newer digital media.

### Technological Features

The ability of the interface to interact with the user is perhaps the most important and distinctive feature of online health. Numerous studies have shown that interactive features in health systems are favored by patients, both for keeping track of preventive regimens (Hurling, Fairley, & Dias, 2006) and for making disease-related decisions (e.g., Evans et al., 2007). Technological features of new media have given rise to a number of tools that are associated with pro-health behavioral outcomes (e.g., An et al., 2008).

### Interactivity

The power of interactivity lies in its ability to engage the user. As interventionists know all too well, getting users to pay attention to health messages has been a major challenge for campaigns using traditional media. But, with interactive media, this does not appear to be an issue. Engagement with content has been theorized as a critical outcome of interface interactivity. Several studies have demonstrated the heightened user engagement generated by interactive tools (e.g., Ware et al., 2008). In his model of interactivity effects, Sundar (2007) identifies three species of interactivity corresponding to source, medium, and message, the central elements of all communication. Interactivity as a *source* feature is the ability of the interface to allow the user to serve as creator or source of content. This is particularly evident in Web 2.0 outlets such as social networking sites and blogs, where users contribute health information. It is available to a somewhat lesser degree in web portals and other customizable interfaces where the user is given opportunities to gatekeep and organize health information. Even simpler interfaces, like the CD-ROM program used by Hornung et al. (2000), allow the user to play source by letting them select the order in which three versions of sun-safety behavior episodes are viewed with three variations of cartoon characters. Interactivity as a *medium* feature refers to the various tools available for interaction with an interface, from mouse-overs to downloads to sliders, each serving to enhance the perceptual representation of health content provided by the system. As a *message* feature, interactivity is the degree to which the interface affords users the ability to have a sustained, threaded interaction with some part of the system, be it in a message board or an online tool that calls for back-and-forth interaction from the user. Health-risk assessment tools are a good example of message-based interactivity because their output is contingent upon user input. As Strecher et al. (2008) found, a Web-based cessation program that delivers information sequentially (as user interaction progresses) leads to greater engagement with the intervention.

### Tailoring

The contingency of user-system interaction is best realized when an online health system *actively* tailors content based on each individual user's needs and preferences. Tailoring, as

discussed by Parrott and Kreuter in this volume, targets the individual based on characteristics salient in a health situation and has the potential to provide personalized care in a manner that is more feasible and efficient than face-to-face health communication. Tailored systems provide messages appropriate for specific individuals depending on their responses (Hartmann et al., 2007; Huang et al., 2009; Lieberman, Lloyd-Kolkin, Kreuter, Chea, & Benter, 2004). According to Hawkins, Kreuter, Resnicow, Fishbein, and Dijkstra (2008, p. 454), "tailoring involves either or both of two classes of goals (enhancing cognitive preconditions for message processing and enhancing message impact through modifying behavioral determinants of goal outcomes) and employs strategies of personalization, feedback and content matching" leading to a  $2 \times 3$  matrix in which some strategies and their component tactics match better to some goals than to others. This framework has led to different kinds of tailoring (e.g., Kreuter et al., 2004) such as Behavioral Construct Tailoring (BCT) and Culturally Relevant Tailoring (CRT). Widely deployed for promoting a variety of health behaviors (Oenema, Brug, Dijkstra, de Weerd, & Vries, 2008), tailoring is found to be generally more effective than generic messages (Neuhauser & Kreps, 2003). Rimal and Adkins (2003) reviewed studies showing the positive outcomes (exposure, attention, use, recall, credibility, behavior change) of campaigns using tailored messages in general, and online or digital media-based tailored messages in particular. These positive outcomes seem to be due largely to increased relevance, self-monitoring, perceived risk, self-efficacy, and even the process of entering one's own data, all enhanced through feedback, in some cases fostered through regular prompts. Computer-based interactivity, narrowcasting, and tailoring are good matches with the transtheoretical (stages of change) model (Prochaska & Velicer, 1997) as the system can ask questions that identify the user's stage of change (and thus potential motivators such as intention, attitude, self-efficacy, subjective norms, etc.), and then provide appropriate information and activities (see Huang et al., 2009).

### **Use Patterns of Online Health**

A principal attribute of online health technologies is that their content is intrinsically related to user behavior. Both the design and effectiveness of online health information strategies depend heavily on a clear understanding of users and their use patterns. In general, research has focused on three broad uses—information seeking, patient-to-patient (p2p) communication, and patient-physician dialogue.

#### ***Information Seeking***

Most individuals begin most of their health information-seeking online by entering keywords into search engines such as Google and Yahoo (Eysenbach & Köhler, 2002; Fox, 2006), and it takes high Internet self-efficacy to persevere in this task and locate relevant health information (Hong, 2006). As Lau and Coiera (2008) note, although searching across a variety of quality sites can improve consumers' accuracy in answering health questions, their confidence in an answer is not a good indicator of its accuracy. Studies have shown that people, especially students, take away predominantly incorrect information about medical topics when they search online (e.g., Kortum, Edwards, & Richards-Kortum, 2008).

That said, they seek health information online all the time, from looking up symptoms to checking if they qualify for a clinical trial (Atkinson et al., 2007). Perceived and behavioral outcomes of online health information seeking are receiving more research attention, with somewhat contradictory results (e.g., Baker, Wagner, Singer, & Bundorf, 2003; Harris

Interactive, 2003; Morahan-Martin, 2004; Pastore, 2000). Half or more of the 61% of online health information seekers in a Pew 2008 survey said that online health information has affected their health treatment decision (60%) or their overall approach to maintaining their own or others' health (56%), prompted them to ask their doctor new questions or obtain a second opinion (53%), or changed their thinking about diet, exercise, or stress management (59%). Just under 40% reported it influenced whether they saw a doctor or not, or how they coped with a chronic condition or pain (Fox & Jones, 2009).

Rice (2006) summarized various outcomes identified in seven Pew surveys from 2000 to 2002. In 2000, 91% said they had learned something new, 55% improved how they got medical and health info, 48% indicated that online advice had improved the way they take care of themselves, and 47% who had looked for health information for themselves during their last Internet search said it affected decisions about care and treatments. In 2001, 16% said it had a major impact and 52% a minor impact on their own health care routine or way they helped care for someone else, and 80% found most or all of what they were looking for online. In 2002, 73% said the Internet improved the health and medical information and services they received, and a quarter of Internet users who helped another person deal with a major illness, or who dealt with a major illness themselves, said the Internet played a crucial or important role. Rice's (2006) analyses concluded that across those surveys, the primary influences on reported outcomes were the extent of health information seeking, the number of such searches, the extent of engagement in other Internet activities, and time since first going online. Other influences included participating in online support groups, perceived credibility of the information, difficulties in gaining access to a doctor, being non-white or Asian, looking for sensitive topics that are difficult to talk about, and making one's own diagnoses.

Wantland, Portillo, Holzemer, Slaughter, and McGhee (2004) provided one of the first meta-analyses that compared behavioral change outcomes of web-based vs. non-web-based interventions. Twenty-two articles, involving nearly 12,000 participants, reported effect sizes from -.01 to .75. Outcomes involved exercise time, nutritional status knowledge, asthma treatment knowledge, health care participation, reduced decline in health, perception of body shape, and maintenance of weight loss. Rains and Young (2009) provided a very rigorous meta-analysis of 28 studies (involving over 4,000 participants and 12 health conditions) of health-related outcomes related to formal computer-mediated support group interventions (online sites that provide both an educational and a group interaction aspect, with membership registration, a limited duration, and moderating or expert leadership). Positive outcomes, across the studies, from participating included increased social support (average effect size  $r = .16$ ), decreased depression (.23), increased quality of life (.14), and increased self-efficacy in managing one's health condition (.15). Other reviews of online/digital media interventions are provided by Griffiths, Lindenmeyer, Powell, Lowe, and Thorgood (2006), Neuhauser and Kreps (2003), and Rice and Atkin (2009).

### ***P2P Communication***

The rising importance of "patient expertise" (Tuckett, Boulton, Olson, & Williams, 1985) has benefited from online media, which offer a variety of tools for peer interactions about health topics. Sites such as patientslikeme.com help users share their symptoms, find similar others, and learn from each others' experiences (Frost & Massagli, 2008). Online peer communication involves four dimensions of health behavior influence (Ancker et al., 2009): information, emotional support, instrumental support, and peer modeling. A

rigorous analysis of participants on a Taiwanese Post-Traumatic Therapy (PTT) psychosis support bulletin board found that the most exchanged types of support were information and specific linkages (threaded responses) (Chang, 2009). Social media websites, such as YouTube, Facebook, MySpace, Twitter, and Second Life are increasingly popular sources of health information, especially for teens and young adults (Vance, Howe, & Dellavalle, 2009). Social media may be especially appropriate for support groups (Ancker et al., 2009), as they provide ways for individuals to describe their identities, conditions, concerns, and interests, which in turn allows others and groups to connect with each other based on those entries, and to develop multiple networks. Features such as tags, comments, initiating connections, links to other sites and services, and privacy controls, offer both a sense of community and control. Many non-contributing "participants" can benefit, and postings and threads are archived for later users, allowing both extended access as well as, unfortunately, persistence of outdated information. The English Wikipedia is a prominent source of online health information compared to the other online health information providers studied (Laurent & Vicker, 2009). RSS feeds are already being used in campaigns such as the Johns Hopkins Bloomberg School of Public Health's Center for Communication Programs to distribute up-to-date changes and new entries about health information. Blogs allow users with similar health information needs and concerns to share their views and experiences. Podcasts are another, portable means of providing relevant audio or video information to target audiences at their convenience, while wikis (or collaboratively created online documents) support collaboration among project members (Haylock & Rabi, 2007).

While information and advice are sought significantly more than emotional or esteem support, for issues involving spiritual or partner matters, patients express greater interest in communicating with others who share their values even if they are not particularly knowledgeable (Bunde, Suls, Martin, & Barnett, 2006). They obtain valuable advice on a number of intangible issues, including how to communicate with health care providers (Meier, Lyons, Frydman, Forlenza, & Rimer, 2007). In general, as Barak, Boniel-Nissim, and Suler (2008) note, patients derive a host of benefits by way of social interactions and improved feelings—all non-specific but psychologically important in that they lead to personal empowerment, which can be useful for dealing with certain health conditions. They also point out that participation has potential costs, such as dependence, distancing from physical contacts, and exposure to unpleasant experiences typical of social engagement online.

### ***Patient-Physician Dialogue***

A growing number of online health seekers have approached their physicians specifically because of, or to mention, information they found on the Internet (Rice & Katz, 2006). Available statistics indicate relevant numbers at anywhere from 8 to 24% of patients (e.g., Murray, Lo, Pollack, Donelan Catania, White, et al., 2003). Murray, Lo, Pollack, Donelan Catania, Lee, et al. (2003) found that 85% of a national random sample of physicians reported that patients had brought Internet information to an office visit. If physicians felt that the quality of information the patient brought was accurate and relevant, they judged it to be beneficial. Even early on, from the physician's perspective, 93% said that they want their patients to discuss Internet information with them, and 62% even said it is a good idea for the physicians to explore the Internet in order to familiarize themselves with the information patients find (Hollander & Lanier, 2001). Sixty-two percent of patients believed that the doctor should recommend specific websites to patients so that they could learn more, yet

only 3% reported that a doctor had done this in the past 6 months (Diaz, Sciamanna, Evangelou, Stamp, & Ferguson, 2005). In general, research overwhelmingly indicates that the increased patient health-seeking behavior does not necessarily lead to patients desiring to replace or challenge their physician, nor to decreased telephone contacts with or visits to physicians (e.g., Baker et al., 2003). However, Murray, Lo, Pollack, Donelan, Catania, Lee, et al. (2003) reported that inaccurate or irrelevant information was judged to harm health outcomes and the physician-patient relationship. The most consistent predictor of a perceived deterioration in the physician-patient relationship, the quality of health care, or in the health outcome, was physicians' feeling that patients were challenging their authority. A substantial number of physicians (38%) believed that the patient bringing in information made the visit less time efficient, particularly if the patient wanted something that the physician considered inappropriate.

Rice and Katz (2006) analyzed responses from the same national random sample of 2000 physicians providing at least 20 hours a week of direct patient care, stratified by medical specialty, about their patients' bringing Internet health information to the appointment with the doctor. Their integrated model reported on levels and predictors of influences on physicians' perceptions of, and reactions to, their patients' discussing Internet health information, and of their own and patients' perceptions of the outcomes associated with those discussions. For example, they were more likely to assess this information as relevant to the patient's disease or condition if they had more positive assessments of the effects of Internet health information, felt that public health information was more accurate, and spent fewer hours per week on patient-related care. Overall, the strongest influences on outcomes were physicians' use of e-mail to communicate with their patients, their evaluations of the accuracy and relevance of the online health information about which their patients talk, and how good their patients are at assessing health websites.

Patient-health care provider communication through the Internet is still infrequent. Less than 4% of people in 2005 had used online systems to interact with health care providers, though most indicated they would like to, for activities such as using e-mail to schedule or receive reminders for appointments, communicating with their doctors, receiving test results, managing one's medical record, and sending self-monitoring results to doctors (PR Newswire, 2006). Another study observed that there were fewer than 1 in 10 outpatient visits in 2001 (9.2%) to physicians who reported doing Internet or e-mail consults, and this did not increase in 2002 (5.8%) or 2003 (5.5%) (Sciamanna, Rogers, Shenassa, & Houston, 2007). Overall, most studies have found positive outcomes from online mediated health care provider-patient relations (Miller, 2001), including reductions in visits to the doctor's office (Bergmo, Kummevold, Gammon, & Dahl, 2005).

### **Conceptual Challenges and Theoretical Opportunities**

As the influence of online health information continues to rise, medical practitioners and health communicators alike are asking questions that require greater scientific understanding of the nature, uses, and effects of online health media. Traditional communication concepts such as "source" and "credibility" are undergoing revision in light of the new technologies introduced by online media, thereby challenging researchers to formulate new theories of health communication that take into account the importance of emergent technological affordances. In particular, the following discussion considers issues of sources, sourcing, and source-layering, agency and customization, and credibility.

### Sources, Sourcing, and Source-Layering

The sender or source is the originator of communication and therefore quite central to any consideration of user reception of mediated information. While the source is quite obvious when we receive information via traditional media, it is quite murky in online media (Sundar & Nass, 2001). In addition to the “original source” (i.e., the person providing new information), there are various “selecting sources” that edit and disseminate information via the Internet. Let us suppose that a doctor commented about certain new risks of skin cancer on a blog run by a medical organization, but you got to read it as a Facebook entry posted by one of your friends who picked it from delicious.com, a social bookmarking site, based on the number of tweets it received there. Who or what is the source here? Some would argue that it is the doctor (original source) while others would say that it came from Facebook (selecting source). In their typology of online selecting sources, Sundar and Nass (2001) distinguish between *visible sources* (those that are visually seen as delivering the information—doctor or medical organization in the example provided above); *technological sources* (medium or media that the user psychologically perceives as source, such as Facebook or delicious.com or even the Internet); and *receiver sources* (users themselves either individually or collectively—your friend who posted this on Facebook, in this case, or an online support group via a bulletin board). Depending on which of these sources is salient during the course of communication, online users are likely to perceive the content differently because they apply different decision rules (or heuristics) when they encounter different sources. A doctor or journalist may trigger the “expertise heuristic,” whereas reminding consumers that other users of the health website rated this as the most important item may lead to application of a “bandwagon heuristic” (Sundar, 2008).

In confirmation of such distinctions, Hu and Sundar (2010) found that an identical piece of health information was more likely to lead to behavioral outcomes if it was sourced to a website or a bulletin board than to a blog, homepage, or Internet in general. This effect was mediated by perceptions of gatekeeping. Study participants perceived information on websites as being controlled by editors and that on bulletin boards as being monitored by moderators. This, in addition to perception of information completeness (influenced by expertise and related heuristics), seems to reassure users sufficiently to motivate healthy behaviors. Based on these findings, the authors proposed a new typology of online health sources (see Figure 12.1).

While each source can be aligned along any one dimension (e.g., level of professional gatekeeping; medical expertise) in an ordinal fashion, multiple sources pose a particular challenge to researchers, given their widespread prevalence online. As Sundar and Nass (2001) noted, we receive information through a chain of sources, with an implicit hierarchy, but often varying sequence (Stephens, Sørnes, Rice, & Browning, 2008), among them. While each source can individually have effects on user perceptions and actions, “source layering” of multiple online sources can lead to combination effects. For example, Hu and Sundar (2010) found that a health message from a doctor was rated as more credible when it appeared on a website than on a homepage; whereas the same message attributed to a layperson was considered more credible when it appeared on a homepage than on a website. Therefore, appropriate combinations of sources are critical for fostering credibility of online health information. Given the multiplicity of sources online, it is imperative that scholars theorize about ways in which sources come together to influence users.

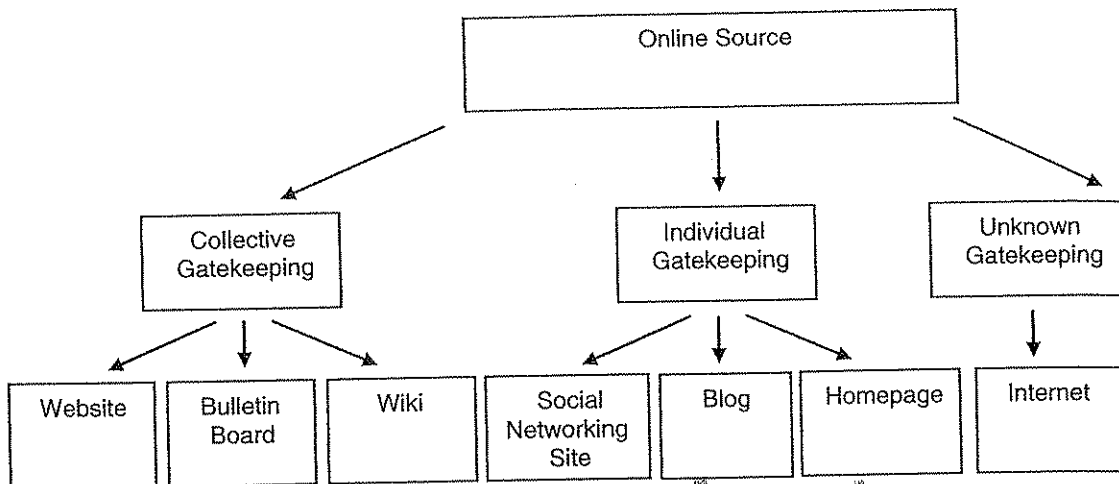


Figure 12.1 Online health source typology proposed by Hu & Sundar (2010).

### *Agency and Customization*

One of the key innovations of online media, especially Web 2.0 media, is that receivers are now able to act as sources, creators, and producers of information. In the health domain, this has dramatically transformed the role of the user, making the patient more proactive about his/her health care and putting the “public” back in “public health.” In proposing their experiential health information processing model, O’Grady, Witteman, and Wathen (2008) stress the importance of collaboration and shared understanding of health issues. Several scholars have noted the sense of community built by social media such as blogs because of participation by other users. At an individual level, these technologies can be quite powerful in building a sense of agency by producing such metrics as number of site visits. Both sense of community and sense of agency are associated with psychological empowerment (Stavrositu & Sundar, 2008). As the next section notes, however, user sources also create considerable challenges to online health information accuracy and credibility.

Even without contributing to a public forum, modern-day patients can become empowered by participating in interactive programs related to their personal health. As Lai, Larson, Rockor, and Bakken (2008) found out, even the simple act of generating a self-care plan is quite empowering for persons living with HIV and AIDS. When patients enter their own data, they feel agentic as evidenced by positive attitudinal and behavioral outcomes. For example, when Anhøj and Møldrup (2004) asked asthma patients to enter their daily information through SMS, rates of compliance with their medicines and treatment went up. When the system pushes users toward entering information for obtaining tailored services, the results tend to be positive (e.g., van Straten, Cuijpers, & Smits, 2008).

However, as Sundar, Marathe, and Kang (2009) argue, simply providing tailored communication does not appear to be sufficient for breeding a strong sense of agency among health users. When the system tailors information for users, the locus of control is located in the system, not the user, therefore making him/her a somewhat passive receiver of health information (though more active than with traditional mass media sources or even some physicians) instead of an active consumer. Given that the information is not expressly solicited by the user, it may be relevant to the user (as determined by the profile), but not quite relevant to his/her needs at the time. Therefore, in order to feel truly agentic, the user, not the system, should perform the tailoring, as argued by the agency model

of customization (Sundar, 2008). Applications of the transtheoretical (stages of change) model to interactive interventions have served to increase the convergence between system content and user agency (Prochaska & Velicer, 1997; Rice & Atkin, 2009).

Results across the health literature lend support to this notion by emphasizing the strong motivational component underlying the success of tailoring interventions (e.g., Stoddard, Augustson, & Moser, 2008). In general, motivated patients are most likely to benefit from tailoring systems because they tend to put more of their personal information into it. Theoretically, this would suggest the incorporation of motivational mechanisms in inferring the effects of online health information. One strategy would be to identify drivers of intrinsic motivation and accordingly target users who are likely to score high on autonomy, competence, and relatedness, the three predictors of self-determination. As Resnicow et al. (2008) determined, the impact of tailored messages was higher for those who prefer an autonomy-supportive style of communication. A different strategy would be to creatively deploy the tools of online technology to build motivation among users. Several studies have shown that the use of e-mail and other forms of mediated communications to reach patients tend to increase their motivation to adhere to health regimens (e.g., Napolitano et al., 2003). The next step is to theorize which aspects of technology can systematically influence which predictors of self-determination en route to building intrinsic motivation among users. Customization tools can be used to imbue a sense of autonomy whereas navigational aids on the interface can build competence and interactivity tools can promote relatedness, thus offering rich potential for proposing theory-based approaches to deploying online technologies for promoting health-related motivations, which appear to be critical for changing behaviors.

### ***Credibility***

A consistent topic of concern about online health information is the accuracy and quality of the content (see Rice [2001], for a review of health information credibility assessments and experiments; see also Morahan-Martin [2004]; for an extensive program of research on web credibility, see Flanagin & Metzger [2007]; Metzger [2007]). An analysis of 79 studies involving nearly 6000 health websites and over 1300 health web pages concerning users' credibility criteria found that users emphasized accuracy, completeness, readability, design, disclosures, and references, with completeness of content being the most important (Eysenbach, Powell, Kuss, & Sa, 2002). Nearly three-quarters (70%) of the studies concluded that information quality was a problem, with only 9% reporting a positive evaluation. Despite this focus and concern about credibility, most users have reported that they would use the retrieved information or felt the information was helpful; and most had positive evaluations, found what they were searching for, and believed the information was trustworthy, helpful, valuable, and accurate (e.g., Murero, D'Ancona, & Karamanoukian, 2001; Zeng, Kogan, Plovnick, Crowell, Lacroix, & Greenes, 2004). Some hope comes from a LaurusHealth.com survey (Pastore, 2000), which indicated that users felt the most credible health websites are those recommended by users' physicians (67%) or a local hospital (56%), while the least credible are those sponsored by a company that sells products or surveys on that site (9%); even those recommended by friends were perceived as not very credible (32%). Some users, however, do tend to feel that the online health information search process is complex and unsuccessful, leading to overload and confusion; they report having limited search and evaluation skills, ignore credibility indicators, and do not compare across sites (e.g., Morahan-Martin, 2004; Murero et al., 2001).

A key challenge for researchers is to understand how users evaluate credibility of online messages, and leverage this information for designing interventions as well as launching media literacy campaigns. While credibility cues abound in the content of health communication, Sundar (2008) suggests that non-content attributes of the interface can influence credibility as well. He posits that four classes of "affordances" (or action possibilities) in digital media—modality, agency, interactivity, and navigability—could cue cognitive heuristics about the perceived quality and credibility of online health information. This means websites and interventions can be strategic about the design of interface tools, especially in terms of triggering specific heuristics. Theoretically, this argues for greater elaboration of dual-process models in social psychology for examining the effects of technology on perceived credibility of online health information. Researchers have long noted that Internet users do not methodically undertake the information-verification steps recommended by credibility checklists (e.g., Metzger, 2007), preferring instead to let design and other surface features affect their trust in online content. The Elaboration Likelihood Model and related theoretical approaches (Petty & Cacioppo, 1986; Chen & Chaiken, 1999) can be effectively applied to leverage this tendency to rely on interface features. We could segment audiences for tailoring as well as design interfaces for the express purpose of motivating greater audience involvement in health content.

## **Conclusion**

By featuring an increasingly diverse array of digital and online technologies, the Internet has not only changed assumptions about the role of individuals in their health care, but also vastly expanded the domain of health information, health services, and health communication research. Even a partial coverage of issues related to e-Health in this chapter has revealed a broad range of technologies, characteristics of health websites, the development of (especially mobile) health devices, bundled interventions (combined as well as sequential), technological features (source, medium and message interactivity, and tailoring), usage patterns (information seeking and patient-physician dialogue), and conceptual challenges (relating to interactions of sources, agency and customization, and accuracy and credibility), foregrounding the numerous theoretical, empirical, social, economic, and technological challenges that lie ahead as we find ways and means to use new media technologies for improving health throughout society. The Internet has become the preferred source of health information, yet we find a lot of variability across various venues on the Internet, with different sources exerting different kinds of influence, based in part on their differential technical abilities and the affordances that they offer to users. While interactivity has vastly aided health communication on a number of levels, it has served to highlight the importance of user agency in realizing the rich potential of the Internet. Therefore, future theorizing ought to consider the interactive nature of technological features and psychological factors in influencing the nature, uses, and effects of health communication online. This would imply a variable-centered approach to studying technology (Nass & Mason, 1990) by including different levels of a given affordance (e.g., low, medium, and high levels of interactivity) rather than simply comparing online with offline means of communicating a particular piece of health communication. The vast majority of studies in online health communication do not systematically vary technological factors such as interactivity or tailoring. They simply compare the existence of some interactivity against a control condition that has no interactivity, with the former being administered online and the latter through offline means, thus introducing confounds and precluding a clear

understanding of technology's impact on health communication. Future research can rectify this by minimizing the tendency to compare across media and taking seriously the individual affordances of technology that are offered to different degrees by different media. Furthermore, it ought to explore how specific psychological variables related to motivations, attitudes, and social cognition are both influenced by and interact with technological factors en route to predicting behavioral outcomes of online health communication.

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