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The Internet and Health Communication

A Framework of Experiences

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Health issues, especially research on health communication and health-related public communication campaigns, are becoming increasingly important for the public agenda. The same is true of new communication technologies, especially the Internet. The intersection of these two highly significant social trends is creating a rich, consequential, and challenging domain for users, health providers, researchers, and policymakers.

The economic stakes are enormous. Health care consumes more than 13% of America's GNP; while much of this will remain in "bricks-and-mortar" and "hands-on" sites such as hospitals and in-home delivery of services, much will also migrate to the Internet. Jupiter Communications reported that the online consumer health care market is expected to grow

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to $1.7 billion by 2003 ("The Doctor Is Online," 1999), up from just $1 million in 1998, driven by prescription drugs, over-the-counter drugs, vitamins, and health-care products sold online. This technology promises to revolutionize the way health care is provided in at least as profound a way as did the movement of the site of health care delivery away from the barbershop. People will be empowered to gain expert insight into their problems and assess the options available to treat them. Diagnosis and cure will be dispensed interactively and electronically. At the same time, there are many opportunities for incorrect, misleading, fraudulent, and dangerous practices. Serious questions also arise about the ability of those with economic, intellectual, or physical limitations to participate effectively in this new environment.

This chapter reviews the primary evidence and issues surrounding the use of the Internet for health communication. The following sections discuss: coverage of the topic in the print media, usage of Web sites, mailing/discussion lists, online communities and newsgroups; medical computing, the health care industry, and community health information systems; patient-physician interaction, physician-physician interaction, patient-patient support, online medicine, online health information credibility, privacy and liability, policy and access; and the use of interactive media for health communication campaigns. The other chapters in this volume consider these issues in greater detail.

COVERAGE AND USAGE OF WEB SITES, MAILING LISTS, COMMUNITIES, AND NEWSGROUPS COVERAGE OF INTERNET AND HEALTH COMMUNICATION IN RECENT PUBLICATIONS

Table 1.1 clearly shows the growing interest in this area, based on very specific keyword searches in five major commercial publication databases. The major growth has occurred in just the past 3 or 4 years.

General Usage

Almost half of Internet users in 1997 reported looking for health information or support (FIND/SVP, 1997, cited in Eng, Maxfield, & Gustafson, 1998). A CyberDialogue/Internet Health Day survey of 2,000 Internet users estimated that more than 24.8 million people sought online health and medical content in 1998, up 44% from the prior year ("Double Mastectomy," 1999). General use of e-health sites grew 176% in 1999, to 10.8 million in December (*Media Metrix,* 2000), much faster than the growth in general Internet usage.

Table 1.1 Growth of Articles Concerned With Internet and Health Communication Retrieved From Business, Professional, Trade, and Technical Publication Databases, 1991-1999, as of January 2000

		ABI/INFORM[b]			
Year	*DowJones News & Business*[a] *(%)*	*Business Abstracts (%)*	*Allied Health (%)*	*Periodical Index (%)*	*Medicine*[c] *(%)*
99	43	18	19	25	16
98	23	37	24	23	41
97	17	32	34	21	16
96	12	05	14	17	10
95	04	08	07	11	13
94	01	—	01	03	03
93	—	—	—	00	—
92	—	—	—	00	—
Total	7,697	415	70	3,481	116

NOTE: Search query (on January 5, 2000): (*Internet*) or (*WWW*) and (*health communication*) or (*medical information*); 1999 figures are underestimates as many items are added to databases several months after their publication date.

a. Dow Jones Interactive News and Business Headlines: 6,000 leading U.S. and international business newspapers, magazines, trade journals, newsletters, television and radio transcripts; searched fulltext.

b. ABI/INFORM: 1,000 U.S. and international professional publications, academic journals, trade magazines; searched abstracts and fulltext.

c. MEDLINE: 3,600 journals covering medicine and health care, communication disorders, population biology, and reproductive biology; searched all fields.

The CyberDialogue/Internet Health Day survey reported that about 52% of users sought out information on diseases; about one third sought out information on diet and nutrition, pharmaceuticals, and fitness; and about 15% sought out information on children's health. About one quarter of the disease-related searchers had joined an online support group (MSNBC, 1999). A recent Harris Poll found that nearly 70% of online users have researched a disease or medical condition, seeking information on, in decreasing frequency, depression (19%), allergies/sinus (16%), cancer

(15%), bipolar disorder (14%), arthritis/rheumatism (10%), high blood pressure (10%), migraine (9%), anxiety disorder (9%), heart disease (8%), and sleep disorders (8%). After the National Library of Medicine provided free Web access to MEDLINE in June 1997, usage jumped 1,000% to 75 million searches per year (Lindberg & Humphreys, 1998).

The Health on the Net Foundation's third annual survey (HON, 1998) reported results based on 1,863 online responses. One of the biggest differences from the prior two surveys was that a majority of respondents were patients, and female. Health is one of the few areas of Internet usage where women outnumber men (53% to 47%) (Goldman-Sachs, 1999). Overall, 93% found Internet medical/health information useful, although 53% felt such information needs to be enhanced. Seventy-three percent of the respondents sought such information from their home. While 22% sought such information for a patient, 29% sought it for themselves. Other beneficiaries included spouse (6%), child (9%), parent (8%), friend (17%), and relative (5%). Sixteen percent strongly agreed that the quality of the information needs to improve, with 37% agreeing, 37% neither agreeing nor disagreeing, 8% disagreeing, and 1% strongly disagreeing. Twenty-five percent strongly agreed that useful medical/health information was easy to find, with 43% agreeing, 17% neither agreeing nor disagreeing, 14% disagreeing, and 2% strongly disagreeing.

Web Sites

A July 1999 study reported in *Nature* found that there were more than 15,000 health information Web sites categorized at the prime tier of both the Yahoo and Netscape directories. In addition, there were at least 44 professional-level Web sites that were dedicated solely to compiling and making available to their visitors other health-related Web sites (the figures reported in the following tables show even greater coverage). These numbers exclude ancillary topics related to health, such as health law and end-of-life processes. Many of these are commercially based, and represent a market capitalization of over $1 billion. In July 1999, drkoop.com was the most popular online health site, as evidenced by nearly 1.5 million hits per day, and retained this distinction until the end of 1999, when the OnHealth Network (http://www.onhealth.com/ch1/index.asp) had more than 3.2 million unique users and nearly 16 million page views (*Media Metrix*, 2000), becoming the 82nd most frequently visited site on the Web. In 1998, the U.S. Department of Health and Human Services site, http://www.healthfinder.gov, received about 4.7 million hits per month from 8,000 people per day. Links to comprehensive general, government, and commercial health sites, especially indexes, can be found at http://www.scils.rutgers.edu/~rrice/healsite.htm. See also this book's Appendix for the rapidly growing list of books that discuss and review online health information resources.

Some sites offer particularly intriguing content, such as a live broadcast of a double-mastectomy (http://www.thehealthnetwork.com). The patient felt that potential breast-cancer patients might benefit from this experience, and others supported this increased sharing of health information and medical procedures, but others criticized the media hype associated with the event, as well as the possibilities for distractions and possible liabilities for the doctors involved ("Double Mastectomy," 1999). An early astounding site is the Visible Human Project, providing detailed views of a human body at 1-millimeter cross-sectional intervals (http://www.nlm.nih.gov/research/visible/visible_human.html). The Web site of the Office of Alternative Medicine in the National Institutes of Health provides links to sites on acupuncture, aromatherapy, herbology, macrobiotics, naturopathic medicine, and yoga, among others (Slobodien, 1998). The National Library of Medicine has just opened an Internet-based registry of all ongoing clinical trials looking for participants (http://clinicaltrials.gov).

Mailing Lists

There are many specialized online support groups, such as for cancer (see Landro, 1999). A search on Liszt.com provided 278 health-related mailing lists. Table 1.2 lists the major categories, with number of lists within each. Topics of these lists ranged from ethnicity-specific health issues, managed health care, and women athletes, to hypnosis and past lives, occupational health, distance health education, and holistic and natural health care. Liszt.com also found nearly 400 commercial lists (ads, press releases, announcements) in 28 categories ranging from allergy supplies, aromatherapy, and how to stop smoking, to natural healing, stress management, and vitamins and minerals.

Meta-List.net, a search engine for nearly a quarter-million online newsletters and discussion lists, returned 501 results for the term "health com-

Table 1.2 **Health-Related Categories, and Numbers of Online Mailing Lists Within Each, Found by Listz.com, as of October 1999**

ADD 5
AIDS 9
Acupuncture 2
Addictions recovery 7
African American 1
Allergy 6
Alzheimer's 4
Arthritis 4
Autism 4
Blindness 7
Cancer 18
Children 8
Chronic fatigue 6
Dentistry 11
Depression 7
Diabetes 4
Disabilities 23
Diseases 49
Drug abuse 2
Eating disorders 5
Epilepsy 1
Exercise 7
Food 22
General 18
Hair 1
Health 5
Health professionals 21
Hearing loss 5
Holistic 6
Homehealth 1
Hospice 2
Kids 4
Leukemia 3
Long-term care 2
Massage 1
Medicine 48
Men 1
Mental health 32
Midwifery 2
Nursing 20
Occupational therapy 5
Organ transplants 2
Pain 6
Pregnancy 20
Prostate 4
Psychiatry 6
Safety 20
Skin 2
Stroke 1
Student 2
Support 74
Syndromes 18
Toxins 1
Twelve steps 9
Unclassifiable 1
Weight loss 29
Wellness 9
Women 35

munication" (such as a list for health-promotion and disease prevention researchers) and 126 for the term "medical information" (such as the medicine and developmental disabilities list). The E-Zine-List (http://www.meer.net/~johnl/e-zine-list) shows that of the 80 most frequent keywords used to index and retrieve online newsletters and e-zines, "health" was 18th, with 180 e-zines. Of course, there are many other lists that may not be included in Listz.com's or Meta-List.net's search processes. For example, askdrweil.com, which specializes in holistic and herbal medicine, lists more than 280 message boards.

Table 1.3 **Online Health-Related DejaCommunities Found by DejaNews.com as of October 1999**

Australia's healthy investment, Baby boomers and aging, Bay Area older women, Bionutrition, Clubhouse (mental health), Darkaventure magnetic health products, Diagnosis: breast cancer, Esj nutritional products, For your good health, Geritarics 1001, Health and fitness, Health and lifestyle, Health bracelets, Health wealth and you, Healthcare IT careers, Healthshack.com, Herbalchest, HerbaLife, HIV the cure is there, Humans of the earth, Israel mental health, Jenny Craig support group, Life quest herbs, Living the holistic lifestyle, Managed care health professionals, Medweb India, Nursing homes—don't do it, Nutrition and immune support, Practice management options, RSD disability, Sexual health, Smokers survey, Spiritual, Su ko ming gung fu, Tai chi chuan, Toddler health, Wheel council storytelling for prevention, Wolfsong herbs, www.allpets.com

Communities

DejaCommunities is a new free service that lets people with common interests get together online. Interactions include ongoing discussions, chatrooms, Web site recommendations, group event promotion, polling, project collaboration, and announcements. The service also allows users to create their own public or private communities. Already, there are 50 communities relating to health, shown in Table 1.3. There were four communities identified by the term "health communication": Health care-human resources; mentally maimed families; Chinese medicine; and military medical student association. The 29 "medical information" communities included topics ranging from diving medicine, avoidant personality disorder, and a military medical student association to hyperbaric oxygenation therapy and AA alopecia areata.

Newsgroups

In 1995, the last time individual newsgroup readership figures were provided (see news.lists), half of the top 10 Usenet newsgroups (each with from 8,000 to 22,000 readers monthly) were concerned with health topics. In decreasing order, they were: depression, diet, cancer, eating-disorder, and arthritis (Walther & Boyd, in press). More recently, DejaNews.com listed 17 main categories of "health & fitness" newsgroups, from Addiction to Mental to Surgery, with 107 subcategories, as shown in Table 1.4. A Listz.com search of newsgroups that had the word *health* in either the list

Table 1.4 **Categories of Health and Fitness NewsGroups Listed by DejaNews.com as of March 2000**

Addiction (Cigarettes); Alternative (Naturopathy); Industry (Education, Insurance, Networks); Media (Books, Health Web Sites, Magazines, Newsletters, TV); Men's (Hair Loss, Impotence); Mental (Depression); Nutrition (Diet Aids, Diets, Supplements, Vitamins); Physical Conditions (Arthritis, Asthma, Cancer, Dental, Dermatological, Diabetes, Disability, Gastrointestinal, HIV and AIDS, Injuries); Women's (Abortion, Anemia, Birth Control, Chronic Fatigue, Gynecology, Infertility, Maternity, Menopause, Menstrual, Osteoporosis)

name or its short description found 70 groups. Eight had FAQS (frequently asked questions sections) and 21 were moderated. Topics ranged from "really old medicine from India," biofeedback therapy, and chronic fatigue syndrome, to oxygen and ozone therapy, and Russian health documents.

Specialized Health Web Sites

There are now so many Web sites about any given topic that specialist meta-search engines and gateways are emerging to help provide evaluations and guidance. As Table 1.5 shows, Invisible Web (http://www.invisibleweb.com), which is a meta-search engine that returns specialized rather than general lists or sites, provided 26 "health" subcategories pointing to 640 sites, while Yahoo! provided 43 "health" subcategories pointing to more than 19,000 sites. The Johns Hopkins reproductive health and population page has links to over 400 approved sites in 50 categories (jhuyccp.org/netlinks), and the Argus Clearinghouse provides detailed evaluations of its approved member health sites (clearinghouse.net). There are also many medical journals online (http://www.yahoo.com/Health/Medicine/journals), with a growing number of them full-text and peer-reviewed.

PRECURSORS TO INTERNET HEALTH SYSTEMS: MEDICAL COMPUTING, HEALTH CARE INDUSTRY, CHINS, AND OTHER MEDIATED HEALTH INFORMATION SYSTEMS

Recent Developments in Medical Computing

The rise of the Internet for health communication is just one subcomponent of ongoing developments in medical computing and information

Table 1.5 **Health Subcategories, and Number of Sites Within Each, Provided by Invisible Web (http://www. invisibleweb.com) and Yahoo! (http://www.yahoo.com), as of March 2000**

InvisibleWeb Health Categories

Alternative medicine 17
Children's health 12
Conferences 2
Diet and nutrition 23
Discussions 48
Diseases 90
Drugs 12
Find a doctor 48
Find a magazine or journal 1
Find answers to health questions 14
Fitness and exercise 8
Health care 5
Laws and regulations 7
Medical news 16
Medicine 174
Men's health 2
Mental health 3
Nursing 1
Parenting 13
Patient information 3
Publications 19
Reproductive health 3
Research 53
Sexual health 2
Statistics and demographics 56
Women's health 8

Yahoo! Health Categories

Alternative medicine 564
Chats and forums 40
Children's health 150
Companies@
Conferences 19
Death and dying@
Dentistry@
Disabilities@
Diseases and conditions 7,265
Education 40
Emergency services 233
Employment 108
Environmental health 194
First aid 16
Fitness 161
General health 73
Health administration 63
Health care 360
Health sciences 26
Hospitals and medical centers 38
Institutes 33
Long-term care 114
Medicine 4,871
Men's health 26
Mental health 641
Midwifery 59
News and media 196
Nursing 424
Nutrition 206
Organizations 21
Pharmacy 1,054
Procedures and therapies 278
Public health and safety 179
Reference 92
Reproductive health 651
Senior health 78
Sexuality@
Traditional medicine 178
Travel health and medicine 15
Web directories 47
Weight issues 75
Women's health 151
Workplace 69

@: These are pointers to categories that are cross-listed in other categories, pointing to more subcategories within them. Thus, this first-level listing underestimates the total number of Yahoo! sites that could be considered to be health related.

systems, large-scale changes in the health care industry (such as managed care/health maintenance organizations, and integrated delivery systems), and new kinds of health information users (such as medical suppliers, pharmaceutical companies, and health information system service providers; (Armoni, 1999; Eder, 2000; Committee, 1997, chap. 1; U.S. Congress, 1993, chap. 3; Winkler & Silberg, 1998).

These new information and computing technologies are being considered, and implemented, to improve a wide range of health processes and outcomes, such as clinical information flow and care coordination among participants, ability to deliver care at the appropriate location of the client and provider, comprehensive capture and storage of clinical information, resource allocation and management, clinical management, patient management, clinical teaching and research, access by general practitioners, and productivity of clinicians and providers. Recent developments in medicine computing include online collections of data from controlled experiments, integration into the health curriculum, health history collection and diagnosis, Web-based clinical systems that access patient data from a variety of sources and display it in a variety of formats (what McDonald et al., 1998, call "canopy computing"), global monitoring of the epidemiology of various diseases (Flahault, Dias-Ferrao, & Lavanchy, 1998), and so on.

These systems may involve the Internet for access and transmission structure, but the heart of their significance lies in connecting dispersed systems and databases (Forslund & Kilman, 2000). For example, the Australian "Doctor's Desktop" plan suggests bringing together four major application groupings: practice administration, practice scheduling (including capabilities to support preventative medicine), pharmaceutical services, and clinical services (More & Clarke, 1999), while other Web-based systems support the diffusion of practice guidelines (Anderson, Casebeer, Kristofoco, Carillo, & Smith, 2000). Coiera (1997) provides a comprehensive review and analysis of medical informatics, medical information systems, medical computing, the Internet, and telemedicine; Bashshur, Sanders, and Shannon (1997) provide a similarly broad coverage of developments in telemedicine systems; and Kissinger and Borchardt (1996) describe and analyze integrated health systems. Armoni (1999) and Eder (2000) consider other developments in health care information systems.

A related development is the use of networked retrieval systems to diffuse medical information among doctors, clinicians, and researchers (Detmer & Shortliffe, 1997). However, in spite of the comprehensive National Library of Medicine's MEDLINE system, which provides access to 30 years of medical literature and 9 million records, many doctors are unaware of recent relevant information or have limited time and expertise to use such systems. More accessible and widely used Web-based online health information databases and search tools include: (a) Internet Grateful Med (http://www.igm.nlm.nih.gov), the free Web-based interface to the MEDLINE database, which has specialized features such as the ability to convert common query terms into specific NLM medical thesaurus terms, and general and detailed displays of results; (b) PubMed (http://www.ncbi.nlm.nih.gov/pubmed), which provides a simpler interface to MEDLINE, though it does offer a "see Related Articles" (based on similarity of content) link, and a special specialized filter for clinical queries; and (c) the Medical World Search (http://www.mwsearch.com), which allows searching of thousands of medical sites using the NLM thesaurus (Rampil, 1998). The Johns Hopkins Center for Communication Programs offers online searchable databases on research, project, poster images, and full text publications (http://www.jhuccp.org).

Detmer and Shortliffe (1997) describe several systems that have been designed using information science principles and techniques to improve the retrieval, credibility, use, and diagnostic decision support of medical information, including their MedWeaver system, designed as an interface that integrates a variety of specialized databases. One of the most sophisticated health-oriented search approaches is the MARVIN project (Baujard, Baujard, Aurel, Boyer, & Appel, 1998), which was first applied by the Health on the Net Foundation, to facilitate better access to valid medical information, in its MedHunt search engine, which uses a vector-based approach, translates among eight languages, and has both high recall and high precision.

One Internet-based association, the Global Health Net (LaPorte, 1997; http://www.pitt.edu/HOME/GHNet/GHNet/html) integrates "health and telecommunication professionals [from academia, government, industry, and international agencies] who aim to develop an infrastructure to network everyone around the globe involved in public health and prevention efforts." Its underlying principle is that prevention investments and activities are far more cost-effective than medical treatment efforts.

The Health Care Industry

Significant recent changes in the health care industry include pressure to reduce cost, penetration of managed care, rapid consolidation, intense competition, need to demonstrate improved quality, increased government influence, increasing demands from large employer groups and benefit consultants, differentiation of products, complexity of managing information as people integrate across services, and the ongoing need to gain a competitive advantage through growth (Ernst & Young, 1997). With respect to technology, managed care is intensifying information requirements: information must be used from a variety of sources, information must be delivered at the point of service, the health care model is shifting from an "illness" model to a "wellness" model, and decision making is being moved into real time rather than retrospective. Relevant legislation includes the 1996 Health Insurance Portability and Accountability Act, which provides standards for electronic transmission of health care information, the Fair Health Information Act of 1995-1996, and the Telecommunications Act of 1996 and its associated Universal Service Fund designed to provide some subsidies for public Internet connections.

Community Health Information Networks (CHINs)

DEFINITION OF CHINs

Community health information networks (CHINs) are a transaction system, a data repository, and an organization, as well as a social movement that began in the early 1990s and spread across the nation (Rubin & Aukema, 1997). The functions of CHINs include clinically oriented information systems development, shifting of economic risk, expanding managed care, and permitting of greater governmental involvement and monitoring (Dowling, 1997). Nearly 90% of CHINs have a single provider or provider associations as members, 85% have physicians, 55% have payer or medical service organizations as participants, while the government is a participant in less than 20% and purchasers in only 13%. Computer networking has fundamentally changed the way many cities have organized their drug abuse treatment systems (Moberg et al., 1997). Where drug abuse treatment facilities once competed for patients and seldom shared data about patients' prior treatment, now their efforts are coordinated by a central intake facility. Since patient data are readily available through a computer network, patients can be quickly referred to the most appropriate treatments. Information networks have the potential to impact the community-wide approach to many other health issues. Pemble (1997) basically argues that CHINs are integration engines for the flow of health care information within a given community. She sketches out the endemic issues of a complex health care information system that includes topics of ownership, integrity, availability, utility, source control, errors/omissions, and leakage. Overcoming technical incompatibilities and lack of collaboration among systems and organizations will be a major challenge (Bysinger, 1997).

As an example, the Wisconsin Health Information Network (WHIN; http://www.whin.net), established in 1992 as a joint venture between Ameritech and Aurora Healthcare of Milwaukee, includes a wide range of hospitals, health insurers, ancillary service providers, physicians, ambulance services, nursing homes, community clinics, and home health agencies. WHIN provides, from a single workstation, access to patient demographics and search, medical record abstract display, medication profiles, utilization review, outpatient scheduling, patient eligibility checking, insurance claim management, results reporting, patient referral, report transmission, e-mail, and so on. Imminent services include: transmitting X rays to the clinician, library search, transmitting prescriptions to the pharmacy, and electronic signatures. An external evaluation found that there was a faster response to requests, a decrease in the length of patient stays, and an increase in the recovery of previously lost charges (due to procedures missed in the billing process or because late submissions missed program filing deadlines; Pemble, 1997). Another example CHIN is the Community Health and Information Technology Alliance (http://www.chita.org), a member-driven alliance of health care and technology organizations (including Microsoft, the Washington State Health Department, GTE Network Services, and University of Washington Medical Centre), operating as a not-for-profit foundation. It plans to implement a secure Intranet (CARENet) to link its care centers and primary care providers to optimize care coordination. Other integrated health services include the Massachusetts Health Data Consortium (http://www.mahealthdata.org), working with a range of technology partners including IBM, Hewlett Packard, CSC, and EDS; and the Minnesota Health Data Institute. Networks like CDC WONDER, INPHO, and SCARCNET have enabled public health workers to coordinate their responses to many problems, ranging from natural disasters to teenage smoking (Brownstein et al., 1997).

SOCIAL DIMENSION OF CHINS

Moore (1997) and Puskin, Mintzer, and Wasem (1997) recommend that the design of CHINs arise from the information needs and practice styles of clinical care providers, and not from technical capabilities of computer networks. They envision a telecommunications village within which telecommunication health services (health promotion community wellness programs), as well as telemedicine practices, improve the lives of people everywhere, including remote rural areas. The ultimate value of a CHIN, Kahn (1997) argues, is less in the management of health care of an individual than in its ability to exploit databases for analysis and systemic improvement. Based on her experiences as a clinical nurse moderator for a special computer network service, the ComputerLink, Moore (1997) discusses challenges such as relationship development and the establishment of group norms (moderator leadership style, managing confidentiality, acceptable topics, response to dangerous or inaccurate advice, acceptable level of typos, and messages warning of decreased participation near the end of projects). However, recommendations for successful CHINs are sometimes impossible to put into practice, due to problems such as the inability of a CHIN to know even what is care-/cost-effective, let alone what provider does it best (Rubin & Aukema, 1997).

Kahn (1997) provides a case study of the consolidation of entities including the Barnes-Jewish and Christian Health Service located in Missouri and southern Illinois. The mission of this CHIN was to acquire the capacity to measure the current health and changes in the health of the people and communities it serves as well as to acquire the capacity to relate these changes to a particular intervention of the CHIN. He specifies the various problems that were encountered; most notable was the difficulty the organizations faced in making various data sets compatible.

Other Mediated Health Information Systems

Health information systems do not necessarily have to be implemented on a large community-based computer network. Boberg et al. (1997) and Hawkins et al. (1997) describe CHESS (the Comprehensive Health Enhancement Support System), initially a DOS-based system but now available at chess.chsra.wisc.edu, that allows a variety of modules to be networked to the advantage of individual users. Among the modules are "question and answer" sections to address a range of issues people may

have in dealing with a health crisis, a tutorial on getting help and support, comprehensive referral directories, a variety of personal stories (written by professional journalists), a comprehensive dictionary, and finally, a life-style assessment inventory. There is also a module that helps guide people through difficult decision making. Another section provides an action plan to deal with health issues. It also includes an "ask an expert" section, allowing questions to be asked anonymously of physicians. Finally, there are discussion groups allowing participation at any time. Particular modules include topics of sexual assault, breast cancer, and an AIDS module. Evaluations show that CHESS is widely accepted, heavily used, and can have a significant positive impact on health service utilization and lifestyle.

Alemi and Stephens (1997) advocate using the telephone as a comfortable, convenient way to receive health care information and alter behavior. In analyzing a phone-talk bulletin board, they found that the system was used by an undereducated, poor, and drug-using group of patients. This, of course, is a population that is extremely hard to reach by traditional or computer-based means. They also positively assess the prospects for remote management of patients via the telephone.

MAJOR COMMUNICATION ISSUES

Health care requires accurate, accessible information (education, self-care, treatment, medical office management, cost and quality of care management) and timely and effective communication (patients with health care providers, physicians with other health care providers and technicians and insurers, patients with patients and significant others, payers with providers, manufacturers and distributors with providers, and health promoters and campaign designers with at-risk or otherwise salient populations; Goldman-Sachs, 1999). The following sections summarize some of the major issues, and describe current usage, with respect to these flows of information and communication.

Patient-Physician Communication

Online information could have potentially substantial benefits in reduced patient anxiety and decreased time and cost in obtaining health information, in better evaluations of potential doctors, and in better-informed patients who can then engage in deeper discussions with their physicians and be more likely to follow recommended treatments. Online communication may improve interaction among other health care providers, increase interaction and intimacy between doctors and patients, enable the discussion of sensitive topics, provide easy access to quick opinions, avoid telephone tag, improve patient compliance with treatments, and increase patient health knowledge (Hodge, Gostin, & Jacobson, 1999; Lemaire, 2000; Spielberg, 1998; Turner, 2000; Weinberg et al., 2000).

Certainly the current status of patient-physician communication has room to improve. Harris and Associates (1997) reported a large-scale survey of patients (*n* = 1,008) and physicians (*n* = 230), exploring the principle that open and honest physician-patient communication has a "tremendous impact on the quality of health care" (p. 1). Ninety-three percent of the physicians believed that many serious problems could be avoided with more discussion, yet 61% felt that they didn't receive adequate communication training in their medical schools. Patients say that physicians don't listen well and provide difficult-to-understand explanations. Consequences of these problems include patients' avoiding seeing their doctors. Thirty-one percent of patients recently postponed seeking medical advice; 26% of patients were reluctant to talk to or seek advice from doctors, due to embarrassment (25%), feeling they would be wasting the doctor's time (8%), feeling their symptoms weren't important enough (11%), fearing bad news (8%), and being scared of treatment options (7%). On the other hand, physicians say that patients withhold important information, don't follow medical directions, and so on. Forty-eight percent of the physicians thought that not having enough time to go to a doctor's office was a "very" or "somewhat" major reason that patients don't ask questions or talk about health problems, while 67% said that not having enough time to spend with patients was a "very" or "somewhat" serious problem in their practices. Indeed, reasons that patients turned to other sources for health care information included easier accessibility/quicker (52%), not wanting to "waste" the doctor's time (14%), and feeling more comfortable (11%). These differed according to age and gender. A 1995 survey of users of AOL's Better Health & Medical Network reported that 6% said they were able to avoid a visit to the emergency room because of information from the site, and 26% said it saved them from at least one doctor visit (Lowes, 1997).

The Internet is beginning to challenge, redefine, and even increase these communication problems. Davis and Miller (1999) reported that more and more patients are showing up with Internet printouts, becoming more informed about a particular topic than their doctors. While some doctors resist patients who come in with Internet research (Kahin & Keller, 1995), which may be incomplete, misinterpreted, or outright quackery, other physicians know that well-informed patients are better patients. Thus recommendations include providing good review and summary sites for patients, providing them accurate search terms, requesting copies of materials be sent to them before the scheduled appointment, and indicating how much extra charge for consultation will be involved (Lowes, 1997). In a 1998 survey of more than 1,000 California residents, those with Internet access were less likely than were those without access to report consulting their physicians and health care providers for information about medical conditions (Pennbridge, Moya, & Rodrigues, 1999). While more than 75% of all respondents ranked physicians and health care providers as the most trusted sources, those with Internet access ranked the Internet as the third most trusted source (those without access ranked it fifth). Intriguingly, regardless of access, the respondents also ranked the Internet as the fourth (out of eight) most *distrusted* source, behind newspaper/magazine/journal articles, family member/friend, and telephone advice line.

However, because all physician-patient communication must be guaranteed to be confidential, and online communication is not considered secure, most doctors (as well as therapists, lawyers, and financial advisors) will usually not communicate any possibly confidential information with clients via e-mail, cordless or cellular phones, or fax. On the other hand, doctors who do facilitate such interaction are likely to take patients away from those who do not, over and above the business advantages of interconnecting one's practice through the Internet with suppliers, insurance companies, and banks (Eder & Darter, 1998). And online clinics are providing information and diagnosis to thousands of medical consumers (Stroh, 1999). They find that online patients are less passive, although in some cases the virtual waiting room has a backlog of online patients lasting 2 or more hours! Such clinics attempt to avoid liability issues by warning that the online doctors will not "enter into a physician-patient relationship" or "engage in any conduct that involves the practice of medicine" (p. 2), facilitated by enforced anonymity. However, it is possible that physicians may be held legally responsible for not becoming aware of relevant medical information that would be easily obtained through the Internet or other medical information systems (Hodge et al., 1999).

Borowitz and Wyatt (1998) report on the development, content, and effort associated with providing e-mail physician-patient consultation. They reviewed nearly 3 years of e-mail consultation requests (*N* = 1,239) sent to one division at the University of Virginia Children's Medical Center. Nearly 40 were received each month, with 81% sent by parents, relatives, or guardians; 10% by physicians; and 9% by other health care professionals. Nine percent of the requests were seeking a second opinion, implying one interesting use of online resources—avoiding questioning doctors face to face—while 22% requested general information. Reading and responding took about 4 minutes per message. The authors conclude that "e-mail provides a means for parents, guardians, and health care professionals to obtain patient and disease-specific information from selected medical consultants in a timely manner" (p. 1321). Hodge et al. (1999) review other studies of physician-patient e-mail interaction.

Considering the perspective of the physician, Eysenbach and Diepgen (1998) surveyed 58 physicians and Web masters (found on Web sites for dermatological information retrieved through search engines) concerning their attitudes toward unsolicited patient e-mail requests for medical advice, stimulated by a fictitious acute skin problem described in an e-mail sent out by the researchers. Half of the physicians responded to the request. Although 31% would not provide advice without seeing the patient's skin, 93% recommended that the person see a physician, and 59% actually referred to the correct "diagnosis." The study concluded that approaches to handling unsolicited e-mail, as well as the kinds of responses to medical requests, vary widely, representing "a striking lack of consensus . . . on the theoretical and practical handling of unsolicited patient e-mail messages and their judgment of this topic" (p. 1334). Thus standards are needed to protect both physicians and patients. The American Medical Informatics Association (AMIA) has recently developed guidelines for patient-physician e-mail that emphasize privacy concerns (Kane & Sands, 1998).

Spielberg (1998) notes that most physicians use e-mail for reference and physician-to-physician communication rather than communication with patients. However, early physician e-mail users note a variety of advantages, such as a better medical record (indeed, to avoid liability, such messages must be stored as part of the patient's record, rather than treated as casual, ephemeral conversation), more considered response, reduction of media costs, increased service provision through Web site e-mail addresses, the use of online forms for patient information collection, and hypertext links to online resources.

Nevertheless, there are several legal and ethical issues still under debate. Encryption will increase a sense of confidentiality but can never

guarantee it, which is still a physician's responsibility, subject to legal statues and regulations, including the Electronic Communications Privacy Act, which protects against eavesdropping on most phone and digital communications. Even encrypted messages, if sent to a patient at the employer's e-mail address, are legally susceptible to monitoring and search by the employer. E-mail privacy against governmental searches is not protected unless both the sender and receiver can show they had exclusive access to their messages, which is typically unlikely. A related issue is the need for informed consent associated with e-mail communication, as supported by the American Medical Informatics Association (Spielberg, 1998, p. 1356). And the actual identity of either patient or physician is currently difficult to guarantee via e-mail. As with standard medical practice, practice norms will develop around e-mail communication, such as response time and completeness of response. Two related thorny issues are jurisdiction in cross-state e-mail communication, and whether medical software and hardware are subject to FDA approval. Links to other Web sites may be problematic, as they may be interpreted as endorsement or as antitrust practices among a limited set of providers. Spielberg's analysis identifies a range of new expectations, practice standards, and potential liabilities that are associated with new communication technologies for health communication. Good practice will involve awareness that e-mail communication may become part of the patient's medical record, discussion with the patient about implications of electronic communication, and mechanisms to ensure confidentiality.

Physician-Physician Communication

There is great potential for improving the communication and service provision among the 650,000 physicians, 2 million nurses, tens of thousands of medical researchers, and 1 million administrative health care professionals in the United States (Goldman-Sachs, 1999). The Healtheon Corporation survey noted above reported that 85% of the 10,000 surveyed physicians were using the Internet (Stroh, 1999).

Eder and Darter's (1998) survey of 86 members of a northeast chapter of the AMA found that although half were using the Internet to obtain professional medical information, only 14% indicated they would recommend it as a medical information resource for patients. About one quarter of the respondents said they had, or were planning to have within the year, a Web site. A study of more than 500 physicians with and without Internet access found that while there were no differences in access or usage between obstetricians and family physicians, or even between urban and rural physicians, urban physicians participated more frequently in user groups and exchanged information with other medical professionals (Eitel, Yankowitz, & Ely, 1998). Physicians with Internet access, and younger physicians, were more likely to consider the Internet a valuable clinical resource. A recent survey by the AMA of over 1,000 office-based U.S. physicians found that usage of the WWW (World Wide Web) by doctors rose from 20% in 1997 to 37% in 1999, with 58% of physicians having a computer but not currently having WWW access planning on doing so within the next half year (AMA, 1999). As of October 1999, up to 80% of all U.S. physicians were online (Credit Suisse First Boston, 1999), though Goldman-Sachs (1999) suggests the use of the Internet and the Web is more likely 30% to 40%, with the rest being regular e-mail.

As a Goldman-Sachs (1999) report concludes, the "paper-intensive health care industry is ripe for electronic data interchange through connectivity vendors" (p. 1). Many sites, such as Australia's http://www.medeserv.com.au and http://www.hcn.net.au, provide extensive online services and resources for health professionals, such as evidence-based research databases, tutorial, textbooks, news, Web site indexes, pharmaceutical databases, full-text, world health sites, discussion forums, and so on. Many companies are beginning to offer full-service Web-based support for enrollment, eligibility, and claims processes, such as MedOffice. Medscape.com, Claimsnet.com, and Healtheon/WebMd (for coverage of such e-health issues, see http://www.wrhco.com/research/coverage/ehealth/index.html). The American Medical Association has developed a 30-city physician continuing medical education course on advanced Internet applications for health care, an extension of its more basic Physicians Accessing Internet program (AMA-Internet Health Road Show, 1999).

One study of a physician/researcher discussion list (the anesthesiology discussion group; Worth & Patrick, 1997), based on a content analysis of 635 consecutive messages in 1 month and surveys from 28 participants, found that the practitioners rated the overall quality of responses to clinical questions at 7.1 (from 1, poor, to 10, superb), and their likelihood of using the list again for such questions at 8.7. Practitioners in solo or small group practices were more likely to use the discussion list for consultation and rated the quality of information higher than those in large practices.

A survey of 83 academic and 43 industry drug information centers found that their professionals used the Internet daily, though as of the end of 1997, fewer than 25% of the centers had a homepage (Johnson & Wordell, 1998). Forty percent of industry, and 24% of academic, centers accepted inquiries about drug information via e-mail (though these were less than 3% of all their inquiries), while more than 75% of both types of centers used e-mail to communicate with other drug information professionals. More than 65% of the centers use the WWW as part of their practice. Other than inquiries about current medical news (reported by around 80% of the centers), the most frequent types of information sought by drug information specialists on the Web were, for academics, drug availability, product information, regulatory, and therapeutic uses, and, for industry, regulatory, therapeutic, news groups, and recreation. Academic sites provided links to other WWW sites, a newsletter, and formulary, while industry sites also provided package inserts and product advertisements. Both academic (82%) and industry (69%) representatives agreed that the FDA should regulate industry-based drug information Internet sites.

Patient-Patient Support Communication

One of the most discussed uses of the Internet for patient communication is online support groups. A recent study by Walther and Boyd (in press) identified four primary dimensions of reasons for, and benefits from, online support groups: The social distance provided greater expertise, management of potential stigma, and candor; anonymity helped protect their personal identity concerning sensitive topics; characteristics of the medium allowed users to manage their interactions with respect to expressiveness, stigma, and obligations; and access was available any time and any place.

As of 1998, there were over 50 anesthesia-related discussion groups alone (http://www.eur.nl/cgi-bin/wgt4.pl; Rampil, 1998)! Goggins et al. (1998) summarize an evaluation of the Johns Hopkins Pancreatic Cancer Web site (http://www.pathology.jhu.edu/pancreas). They report very large numbers of accesses to the site, and messages posted to the discussion board, far exceeding what might be expected from the number of patients diagnosed with pancreatic cancer annually, indicating considerable unmet medical information and care needs. More than three quarters of the discussion board posters were female, and nearly 90% were relatives of patients, indicating a powerful emotional and cognitive support resource. In

February 1998, 14.5% of the messages requested information, 12.8% requested or acknowledged support, 34.1% provided information, and 33.6% provided emotional support. The site also generated a number of referrals to the Johns Hopkins hospital. The authors propose that sites dedicated to diseases for which the providers have specialist expertise, such as from university health centers, help guarantee quality information and stimulate usage.

Brennan and Fink (1997) review research showing that computer networks can help to provide "key social support necessary to increase individuals' engagement in health promoting lifestyles" (p. 180). They studied one week's use of ComputerLink, a system providing information, decision-making utilities, and communication and online support for persons with Alzheimer's disease. Participants posted messages to share information, express their feelings, and offer support. In particular, messages provided evidence of social support in the form of affect (liking and admiration), affirmation (acknowledging appropriateness), advice, and information. Social support is positively associated in general with overall health lifestyle patterns (p. 167).

Scheerhorn (1997) reports on the HIGHnet messaging system for hemophiliacs. Hemophiliacs, like groups of people with other medical conditions, have particular needs, categorized by good medicine, good physician, good information, good education, peer support, and economic support. Their analysis of 2,259 messages over 18 weeks among 58 members indicated that training was a potent influence on system usage. Messages concerned six themes: education, outreach, advocacy, improved psychological and physical health, business, and cost savings. Smyth, Feinstein, and Kacerek (1997) report on a Cleveland-based computer mediated Alzheimer's support group, noting factors that influence adoption and diffusion, including issues of perceived social presence of mediated interactions.

Preece and Ghozati (Chapter 11, this volume; see also Preece, 1998) report on their analysis of 100 textual communities, indicating that empathy is present to some extent in most Internet communities. Preece (2000) expands this concern with online support communities to describe comprehensively how to design "thriving" online communities (emphasizing usability, sociability, and purpose). Note that online support community members apparently do not have to be active "posters" to gain benefits. Nonnecke and Preece (1999) found, through a rigorous analysis of health and software support distribution lists (DLs) and other very large DLs, that lurkers (subscribed members who posted no messages over a 12-week period) ranged from 0 to 99% on 77 health support groups (with a mean of 45.5% of the members lurking), compared to 50% to 98% (mean, 82% of the members) of nonhealth groups. Lurking was not associated with number of DL subscribers, while lurking was negatively correlated with number of messages posted per day for DLs with more than 500 members, but essentially uncorrelated with smaller DLs, indicating that lurkers tend to avoid high-traffic sites. But even when actual people are on the "other end" and participate, such as in an online support group, there's no guarantee the person has the illness they are discussing or even is the person he or she claims to be, as some people use support groups to play out "sick roles" and exhibit "factitious disorders" (Stephenson, 1998).

Culver, Gerr, and Frumkin (1997) analyzed 1,658 consecutive messages from 313 authors during 5 months in 1994 from an online discussion group concerning painful hand and arm conditions (http://www.sorehand@ucsfvm.ucsf.edu). Seventy-two percent of the messages were posted by an affected person, and only 0.3% by a physician, with 67.6% of the messages providing information and 21.4% requesting information. Of the 55.9% messages addressing a medical topic, 79% provided medical information, with 89.3% of those by users without professional medical training! Nearly one third of this information was coded as being inconsistent with generally agreed medical practice. Sources of evidence were as follows, for nonprofessionals and then professionals: personal experience (61% vs. 13.5%), no source (29.8%, 67.6%), and published source (9.2%, 18.9%). There was very little challenging of advice, information, or conclusions drawn from experiences, though 10% of the messages expressed frustration or complaints about medical care.

Patterson, Shaw, and Masys (1997) warn that "online self-help groups are a fragile meritocracy of written fact and opinion, in which each reader must decide what is true and what is merely unsubstantiated belief" (p. 238). Culver et al. (1997) conclude that medical discussion groups are a mixture of "snake oil" and "self help"; "appropriate diagnosis and treatment may elude participants in such electronic bulletin board discussions, on a scale that is unprecedented" (p. 470).

Interactive Media and Communication Campaigns

The aspect of communication and information technology with the greatest implications for health promotion is interactivity, related both to interacting with a system or data and to interacting with other people (Brennan & Fink, 1997; Rimal & Flora, 1997; Street & Rimal, 1997). Street and Rimal (1997) argue that the defining dimensions of interactivity are *user control* (the extent to which a user can modify the content or form of the mediation) and *responsiveness* (or extent to which a response takes into account a prior action). Interactive media can improve health promotion because of increased learning, information seeking, information processing, and individualized knowledge by current or potential patients or interested parties. Computer networks increase the potential of interactive systems by making available a wide variety of resources, participants, and applications through one system. Street and Rimal's review of past research on interactive health systems reveals considerable confounding among treatments, media features, and content, so that it is hard to draw definitive conclusions as to benefits of interactivity. They integrate this research with the concept of interactivity by proposing a three-stage model of health promotion using interactive technology: *implementation and use* (influenced by institutional, technological, and user factors), the *user-media-message interaction*, and *health outcomes* (intermediate attitude and cognitive outcomes, and longer-term health and prevention outcomes) influenced by psychosocial factors.

Rimal and Flora (1997) consider the distinctions among media features that may be best associated with specific *health domain attributes* (such as addictiveness, skills, and heredity) and *individual attributes* (such as demographics, psychographics, and sociocultural aspects). These distinctions include (a) multimodality, (b) networkability, (c) temporal flexibility (asynchronicity), (d) segmentation capability, (e) interactivity, (f) sensory vividness, (g) modifiability, (h) availability, (i) cost, and (j) ease of use. For example, temporal flexibility, modifiability, and interactivity foster cognitive rehearsal of the desired behavior, increasing the likelihood that the behavior will be applied in actual situations. Or, individuals with low involvement may well benefit from less-interactive media, such as videos, than interactive Web pages. Segmentability of the content, such as through using Web "cookies" (short lines of data stored in a user's browser directory, depending on the user's acceptance of them, that indicate the prior use of a specific Web page or service) to tailor Web content to prior searching behavior, would increase the matching of information to one's readiness for change.

Skinner and Kreuter (1997) summarize theoretical foundations for identifying the kind of health behaviors (asymptomatic screening, lifestyle modifications, cessation of addictive behaviors, medical regimen compliance, precaution adoption) that would respond to particular interactive media interventions. Reviewing the health belief model, efficacy theory, attribution theory, the theory of reasoned action, and the transtheoretical model, they show what specific behaviors and interventions would be motivated by each theory, using different kinds of new media to enable, reinforce, and predispose. For example, an interactive program can identify salient health beliefs and then provide simulations or information geared to those assumptions. Alternatively, a system that has diagnosed the efficacy level of a patient can help focus the person on internal or external causes for a particular unhealthy behavior. The theory of reasoned behavior would propose that individuals be connected to influential or knowledgeable others, say in a support group, to increase the persuasability of suggested health behaviors.

Many communication campaigns are beginning to integrate interactive Web sites into overall communication strategies, such as the REACT Web site for reducing delay in responding to heart attacks (Finnegan et al., Chapter 7, this volume; Simons-Morton et al., 1998). Indeed, information systems can be used to help develop and tailor health messages and campaigns based on the needs, interests, and concerns of specific groups or individuals (Kreuter, Farrell, Olevitch, Brennan, & Rimer, 2000). Other developments include interactive CD-ROMs for campaign planning and country/city analysis, such as the SCOPE CD by the Johns Hopkins Center for Communication Programs (Piotrow & Kincaid, 2001) and the CDCynergy CD by the Centers for Disease Control (Parvanta & Freimuth, 2000). Both of these combine comprehensive census, media usage, and epidemiology databases with simulations of stage-by-stage campaign development and implementation.

MAJOR INDUSTRY AND POLICY ISSUES

Online Medicine

Online medical advertising is growing rapidly, from $58 million in 1999 to a projected $265 million in 2002, still small compared to the total medical advertising and promotion spent in the United States of $8 billion in 1998 (Goldman-Sachs, 1999). Online pharmaceutical sites are generating considerable revenue. In May 1999 they took in nearly $1 billion for prescription drugs, $300 million for over-the-counter drugs, $434 million for vitamins and supplements, and $700 million for personal care products. Users are still wary of commercial health Web sites, however, indicating they are more likely to go to nonprofit, hospital, patient advocacy, other, and pharmaceutical Web sites first (Goldman-Sachs, 1999).

Online sales of medications have generated considerable controversy. Cross-border commerce via the Internet can escape regulatory evaluation, so some products are promoted for symptoms that do not correspond to their intended use; also, quality, manufacturing, purity, safety, efficacy, and enforcement cannot be guaranteed. The purchase of medical products via the Internet allows patients to avoid medical advice and treatment, including an understanding of drug interactions and side effects ("General Policy Issues," 1998).

Online pharmacies per se are "just another channel of distribution" as long as a physician-patient relationship exists (Cohen, 1999). While it is not strictly illegal to do so, providing prescriptions to patients that a doctor has not physically examined is considered unethical by the AMA, unacceptable by the National Association of Boards of Pharmacy, and likely to be fined by medical quality assurance commissions (Stolberg, 1999a, 1999b). A recent study, however, found that of 77 Web sites offering online purchase and direct delivery of Viagra, 52 required users to release the company from liability, only 42 required users to complete an online medical history questionnaire that could have provided information on whether Viagra would be safe and effective for the patient, and only 27 of those indicated that a doctor would review the information (Armstrong, Schwartz, & Asch, 1999). One of the problems is that jurisdiction is widely and partially scattered among federal regulators, FDA, FTC, and state agencies (Cohen, 1999; see also Chapter 17, this volume).

However, the National Association of Boards of Pharmacy has begun to develop a process to certify legitimate Internet drugstores (Cohen, 1999). This association requires online pharmacies to be licensed in all the states to which they ship drugs; upon verification, they are allowed to display the Verified Internet Pharmacy Practice Sites (VIPPS) icon. Some services, such as Cyberdocs, avoid many of these problems by being insured for malpractice, having doctors provide advice only in their areas of expertise, and dealing only with patients from states where the doctors are licensed. The World Health Organization has proposed a range of recommendations for discussion, including review legislation of cross-border activities, establish informational Web sites, develop voluntary codes of conduct, consider cooperative licensing, report problem cases to WHO and Member States, and so on ("General Policy Issues," 1998). President Clinton's 2001 federal budget will request authorization for the Federal Drug Administration to verify the quality of Internet-based pharmacies that fill online prescriptions, and to expand their investigation of Web sites (*New York Times*, 1999).

The growth of this practice is not only fueled by the obvious e-commerce benefits, but also social and cultural trends, such as the rapid adoption of "lifestyle drugs" (such as impotence, hair loss, and diet pills), the attraction of anonymity when requesting certain kinds of medications, the ability to obtain drugs not approved in the United States from foreign sites, and online drug interaction analyses. As an indication of this anticipated usage, one survey found that almost half of the respondents (18% often, and 31% most likely) indicated that they would use the Internet to order prescription refills and make doctor's appointments (Pennbridge et al., 1999).

An obvious negative consequence is the ability of consumers to self-prescribe drugs and to obtain drugs that have not been approved by the FDA.

Credibility of Online Health Information

As with some of the studies of online support groups, analysis of Web pages raises significant questions about the relevance, coverage, and legitimacy of much Internet health information. Hersh, Gorman, and Sacherek (1998) analyzed 629 pages retrieved from Metacrawler based on 50 questions selected from a database of clinical questions. They were judged to be "neither clinically applicable nor of high quality" (p. 1307); 89% were not even applicable to the search question, and most pages had no more than one "quality" measure (such as site affiliation). Rose, Bruce, and Maffulli (1998) identified the 25 most frequently used terms obtained from 100 orthopedic patients as best describing their medical condition, and entered them as search terms into five search engines. (As an aside, 20% of the terms had been misspelled by patients, implying that regular users may not find relevant Internet results for a good proportion of their searches because of unfamiliarity with the appropriate terms!) Of the 5,947 retrieved pages, 20% contained patient information, 19% professional information, 9% commercial information, 2% sports news, 8% unavailable, and 41% other (non-English pages, chat rooms, etc.). The primary result was that only 7% of the pages they retrieved (in this case about fever in young children) were actually relevant to the patients' conditions. Impicciatore, Pandolfini, Casella, and Bonati's (1997) study similarly found that relatively few of the pages provided complete and accurate information. Biermann, Golladay, and Baker (1999) searched for Web sites concerning a specific form of cancer, Ewing's sarcoma. Based on 400 of the 27,000 resulting sites using four search engines, only half actually contained information on this topic, and, of those, only 60% had peer-reviewed information. The authors noted that in addition to the time-consuming and cumbersome search process, users may end up with incorrect and harmful information. McClung, Murray, and Heitlinger (1998) arrived at a similar conclusion from their study of 60 articles from the first 300 hits on a search for information about childhood diarrhea. They reported that only 20% conformed to the current diagnosis and treatment guidelines of the American Academy of Pediatrics; so 80% had inaccurate or out-of-date information. They concluded, "Patients must be warned about the voluminous misinformation available on medical subjects on the Net."

Many have argued that professional medical organizations need to inform and educate not only patients but also doctors about reliable Internet health sites (Henson, 1999). Because of the consequentiality of health information, there are several initiatives to develop credibility and accuracy standards for online information. These include the Health On the Net Foundation's HON label (HON, 1998); the Australian Department of Health and Aged Care's site (http://www.healthinsite.gov.au, which emphasizes reliable and relevant health information, based on a contracted "information Partnership" between the site and accredited/evaluated organizations, which then receive the HealthInsite Web page icon); the New York Online Access to Health (NOAH, http://www.noah. cuny.edu; Voge, 1998); Rees's consumer health information source book (Rees, 1998); the Health Summit Working Group (1998); the Argus Clearinghouse (http://www.clearinghouse.net); the Johns Hopkins reproductive health and population Web page (http://jhuccp.org/netlinks); and other approaches (Jadad & Gagliardi, 1998). In June of 1999, the Federal Trade Commission initiated a program to fight false and deceptive health claims for products advertised or sold via the Internet, including applying existing legislation. The E-Health Ethics Summit, sponsored by the Internet Healthcare Coalition (including actors such as America Online, drkoop.com, Healthwise, Medscape, Healtheon, and WebMD.com), has recently proposed a voluntary code of conduct for Web sites' collection and use of personal information (Woody, 1999). Standards include informed consent, editorial control over accepting advertising content, and disclosure of all sponsorships or financial incentives (http://www.ihealthcoalition. org/community/draft.html). Another ethics code push comes from an organization called the Internet Healthcare Coalition (IHC). In addition to involvement from the American Medical Association, the IHC also represents the views of profit-making companies such as those affiliated with the HI-Ethics committee, as well as nonprofits, academic journals, advocacy groups, and other Web-based medical information services.

Privacy and Liability

Issues of privacy, confidentiality, and security in both well-recognized and enterprise-specific medical information systems (Lindberg & Humphreys, 1998) are compounded by the interorganizational linkages characteristic of CHINs and networked health systems (Barrows & Clayton, 1997; Donaldson & Lohr, 1994). The three primary information security goals in health care include "prevention of unauthorized disclosure of information . . . prevention of unauthorized modification of information . . . and prevention of unauthorized or unintended withholding of information or resources" (Barrows & Clayton, 1997, p. 300), leading to 14 areas needing security policy development for computer health networks, ranging from user authentication, data protection, hard copy materials security, legal and liability issues, and system reliability and backups, to audit trails and informed consent. Pemble (1997) also emphasizes the crucial areas of security and authorization for data access.

Other aspects of privacy and confidentiality noted in other sources include: authentication of and security profiles for individuals; validating individuals' access to systems and databases; levels of priority and associated access means; levels of security associated with different information, policies, and procedures for those who have the responsibility of protecting and maintaining the confidentiality of information they can access; ensuring integrity and protection of transferred patient-client information; applying privacy policies and measures to interdependencies among various databases; ensuring protection during transmission and conversion from manual to computer systems; access and integrity audits; validating and maintaining passwords; firewalls; access to patient information by third parties; disaster recovery; protection of remote access interfaces; encryption; electronic authentication; and so on. The U.S. Institute of Medicine and the National Academy Press published a comprehensive book on this issue (Committee, 1997). The Office of Technology Assessment, before it was dissolved, also released at least three related reports on this topic (http://www.princeton.edu/~ota; U.S. Congress, 1993). Another set of issues that overlaps with privacy and confidentiality is "standards," such as unique and uniform client and service provider identifiers; data definitions of encounters, diagnoses, and treatments; and data and system security.

The National Library of Medicine has two large funding programs in these areas, both emphasizing health data confidentiality and standards. One supports increased Internet access for education, research, clinical care, and administration by health professionals, while the other fosters the development and use of the National Information Infrastructure (NII) for public health and health care research (*Federal Telemedicine Directory,* 1998).

Schneider (1997) acknowledges that there are fears that partner notification programs, such as those used to fight AIDS and sexually transmitted diseases, could suppress participation in programs. However, he argues that a computer-mediated partner notification program that will respect confidentiality of patients and partners will actually increase participation. Slack (1997) also believes using computers properly can empower patients and give them greater control over their own destiny, enhancing their health. Unfortunately, although the author makes powerful assertions about the value of this approach, little supporting evidence is provided. Regardless of the likely value and security, most respondents have major concerns about the privacy and confidentiality of medical information, and about making their medical records available via the Internet (Pennbridge et al., 1999).

Credibility and privacy of health information are directly related to legal issues (Hodge et al., 1999). Personally identifiable health information is now more available through intra- and interorganizational networks, providing benefits such as greater patient autonomy, improved treatment, faster diagnoses, reduction of adverse drug interactions and reactions, broader dissemination of medical research and practice, improvements in research, better monitoring of morbidity and mortality, and increased security and audit trails. However, such systems also generate legal challenges associated with privacy of identifiable health information, data reliability and quality, and tort-based liability (p. 1466). There is no comprehensive legal protection of personally identifiable health information; instead, there is a wide variety of existing federal and state privacy laws and several proposed federal privacy laws, such as Health Insurance Portability and Accountability Act and regulations by the Department of Health and Human Services. The DHHS has provided Congress a set of recommendations covering limitations on disclosure of health care information, required patient authorization for health information distribution, access to and correction of health information by patients, accountability for use and distribution of health information, and the priority of national and public interests over individual privacy interests (Hodge et al., 1999). The authors argue that these areas are interdependent, such that increased privacy improves reliability and quality of information, which in turn reduces the likelihood and need for tort-based liabilities. They provide seven recommendations for health information privacy legal reform.

Policy and Access

In spite of the promise of computer-based and computer-mediated medical information and communication, it is still true that people with preventable health problems and those who have little or no health insurance are also those least likely to have access to the necessary technologies (Eng et al., 1998). A wide variety of barriers exist, such as cost, location, illiteracy, physical ability, and capacity. Public and governmental efforts are needed to reduce the gap between health information "haves" and "have nots." Eng et al. discuss a number of these, from providing public and residential access, to diverse applications, improving access through research, increasing health and technology literacy, and integrating universal access into health planning, at the levels of private-sector health services, federal and state funded health programs, federal grants, charitable organizations, corporate marketing, and private and public long-term community investment. They argue that such activities have both moral and pragmatic motivations: Most health information is produced by public funding, so should be made public; improved public health benefits society at large; and improved access reduces health costs.

Harris (1995) proposed "three clear indicators of progress toward our goals of improved health for all at affordable costs": increased access, improved quality, managed costs. She also described three primary characteristics of new media: interactivity, interconnectedness (due to digitization and infrastructure), and user-driven (both producers and consumers can customize information and systems). This leads to a 3 × 3 matrix of improved health care goals by new media characteristics: "customized information breaks down educational barriers, universal access reduces financial barriers, participatory learning challenges motivations barriers;

simulation enhances education, distributed collaboration coordinates services, all decision makers are participants; and service options are linked to individual health status, multiple service providers share network costs, all participants are accountable" (p. 14).

McGinnis, Deering, and Patrick (1995) argue that new media provide the potential for improving disease prevention and health promotion, including "online information resources, interactive multimedia educational materials and computer-assisted decision-support programs" (p. 127). However, they note two major challenges for health in America: health inequality, and prevention. There are vast disparities in health in the United States: Even though we spend more than other nations, costs are rising faster than inflation, and health levels are lower than in some other nations. Information-based activities can foster prevention activities, which influence nearly half of all deaths in the United States. However, most health costs are currently allocated to the treatment of "leading causes of death" instead of to the (preventable) "real causes" such as tobacco, diet, alcohol, firearms, sexual behavior, motor vehicles, and drug use.

Healthy People 2000 (*National Disease Prevention and Health Promotion Objectives*, 1990) identifies and explains those activities that should have the greatest influence on improving health status, with 300 objectives in 21 priority areas. Central to such efforts is patient education and counseling, both information-based efforts. The U.S. Public Health Service intends to take advantage of the recent national initiative to wire schools, libraries, clinics, and hospitals to create a "seamless, interactive, information-based health support system" (p. 136). Perhaps the most accessible of these public health information services is Internet Grateful Med, noted above.

Fisher (1995) argues that free market forces may not be enough to produce either the national information infrastructure or the health information products necessary to provide sufficient health prevention and treatment. The necessary components of the NII should be provided for every home as well as the current goal of classrooms, libraries, clinics, and hospitals. These include broadband capacity (e.g., for X rays), open/switched/interactive networks (allowing content choice and individual production as well as consumption), upstream video (for distant diagnosis, video publishing), upstream interaction (for peer support via discussion groups), search tools (directories), geographic and economic universal access (from central business districts to rural communities), and content (medical records, knowledge, and health information). The National Library of Medicine is a good initial model for such a service, as it not only provides health information and online analysis but also helps ensure the credibility of that information. Similarly, the New York Online Access to Health site, http://www.noah.cuny.edu, aims to provide "quality health information . . . that is accurate, timely, relevant, and unbiased" (Voge, 1998, p. 326) by means of many links to and from a wide variety of partners, as well as full-text articles, in both English and Spanish. This site, designed by library professionals, has extensive and well-researched search mechanisms and approaches, including using a controlled list of subject terms.

Further, differences in intellectual property issues between traditional print and new online sources could reduce access and fair use of electronic publications, data, or facts (Lindberg & Humphreys, 1998).

Gorry, Harris, Silva, and Eaglin (1995) analyze the problem of boundaries and separations between providers and patients due to specialization, access, and institutions. Solutions involve interactions among strategies, people, structures, and technologies, across organizations. They discuss a case of providing multimedia, networked health services involving technology companies, a social services consulting firm, universities, social services agencies, and governmental agencies.

Of course, major health agencies are moving toward providing many services through Web-based forms. Neu, Anderson, and Bikson (1999), for example, provide a case study of current and potential uses of the Internet to provide Medicare services. Vickery (1995) discusses how new media might improve the management of health services demand through self-care, as the management of supply is insufficient. Four components of demand are considered: morbidity (illness, prevention, health habits, accidents, secondary prevention through screening), perceived need (knowledge of risks and benefits, assessing medical problem, severity of problem, ability to self-treat, self-efficacy—all influenced by knowledge, education, culture, social support, attitudes of health providers—these explain more than 40% of variance in decisions to seek care), patient preference (economic appropriateness, informed choice, risk aversion, care for terminal illnesses), and nonhealth motives (sick leave, disability, compensation benefits). Self-care interventions involving lifestyle, immunization, safety, self-management, informed choice self-help, life management, screening, and provider information are associated with a variety of medical benefits and cost savings. While mediated self-care would provide immediately available, personalized, and multimedia information, it would be less successful at providing emotional and social support. Thus a fully integrated infrastructure would "support interactions among individuals, the demand management system, and the medical care system" (Vickery, 1995, p. 58).

As another example, Zallen (1995) described the Harvard Community Health Plan's increasing emphasis on providing services that allow members to become more involved in their own health care, as part of the managed health care movement. Services include online initial diagnosis, health assessment and health risk appraisals, and online health support groups. Zallen emphasizes the shift from information being provided by the clinician to the patient, to the patient seeking information from comprehensive systems, including public "health booths" providing interactive video and online information.

SUMMARY

Some of the relationships among some of the major issues discussed so far can be summarized by the overall model shown in Figure 1.1. Current practices and uses of the Internet for health communication and information, and the outcomes associated with them, are highly socially situated and not just outcomes of specific technology implementations. They are influenced by (or are interdependent with) Stakeholders, Systems and Infrastructure, available Applications, and Policy, Legislation, Regulation, and Economic forces.

Applications include education, continuing medical education, testing, consultation, support, clinical trials, diagnoses, analyses, interaction, collaboration, information flows, online support, online communication campaigns, e-commerce, search and retrieval, records, and images. Stakeholders include patients, physicians, health care professionals, insurance companies, resources, social networks, administrative and technical support, customers, referrals, supplier and purchaser commercial organizations, and so on. Relevant aspects of Stakeholders include their characteristics, information-seeking behaviors and needs, social agenda, and personal needs. For example, recently Hoffman and Novak (1998) have argued that there is a digital divide among U.S. Internet users, with African Americans being dramatically less likely to use the Internet than other ethnic/racial groups. If this assertion is correct, it has dramatic implications for the quality of health care that this portion of the citizenry receives.

Systems and Infrastructure includes the Web, National Information Initiative, Internet II, telemedicine, Community Health Information Networks, and characteristics of media sources and channels. Relevant Policy, Regulations, and Issues include privacy, authentication, intellectual property, access, quality, equity, efficacy, educational practices, personalization, barriers, and trust.

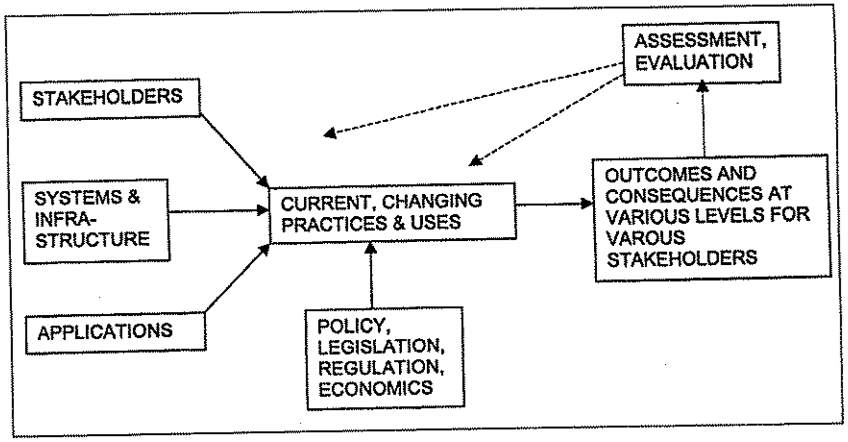

Figure 1.1. General Model of Components of Internet and Health Communication System

General categories of Outcomes and Consequences include rewards and peer evaluation, health outcomes, institutions, knowledge communication, and economic structures and markets. These may vary highly across stakeholders and levels of analysis, such as the individual, family, community, organization, and industry.

The outcomes, as well as the various applications, practices, and uses, may be more or less extensively Assessed or Evaluated. Examples include health care and access models, information, doctors, institutions, quality, efficacy, and credibility/seal of approval. Such assessments and evaluations may (should) influence redesign and change in the prior factors.

Clearly, the intersection of the Internet and health communication is a socially significant, ethically and politically consequential, dynamic and innovative, intriguing and interesting, and methodologically challenging arena.

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