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Consumer Health Informatics

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Over the last few decades, consumer involvement in health care has been dramatically transformed. Not the least of these transformations has been consumers' active participation in decision making about their own health and the health of their family members. The advent and growing popularity of the Internet and its searchable World Wide Web have revolutionized consumers' access to information. The sheer volume of Internet-based information on virtually any subject has been a source of both satisfaction and frustration for healthcare consumers.

In the not-so-distant past, health information for patients was delivered from the perspective of the medical world. This model was understandable, as patients traditionally looked to their healthcare providers as the primary, and possibly only, source of information on health and disease. Although this approach may have been valuable in reducing access to misinformation, it also limited the range of information available to patients or consumers and placed the patient in a less engaged role. During the past decade, involving consumers in the process of health care has been increasingly emphasized, with an appreciation for the positive impact on outcomes that follows. This paradigm shift from physician-centered to patient-centric care and the impact of Internet access to health information has formed the basis for the development of consumer health informatics. This chapter presents several definitions that have been advanced for consumer health informatics and provides an overview of the process of consumer health information delivery.

Toward a Definition of Consumer Health Informatics

To begin, it is helpful to define what is meant by "health consumers." The American Medical Informatics Association, Consumer Health Informatics Working Group, and the International Medical Informatics Association, Nursing Informatics Interest Group [1,2] have defined a health information consumer as a person who seeks information about health promotion, disease prevention, treatment of specific conditions, and management of various health conditions and chronic illnesses. Consumers of health information have consisted not only of persons with specific health conditions and their friends and family, but also of the public concerned about promoting optimal health.

As noted earlier, several definitions exist for consumer health informatics. According to the U.S. General Accounting Office, consumer health informatics is "the use of modern computers and telecommunications to support consumers in obtaining

information, analyzing their unique health care needs and helping them make decisions about their own health" [2].

Consumer health informatics has been defined by Gunther Eysenbach as "the branch of medical informatics that analyses consumers' needs for information; studies and implements methods of making information accessible to consumers; and models and integrates consumers' preferences into medical information systems" [3, p. 3].

Tom Ferguson defines consumer health informatics as "the study, development, and implementation of computer and telecommunications applications and interfaces designed to be used by health consumers" [4, p. 2].

Although this is likely not a complete collection of all definitions of consumer health informatics, these key definitions acknowledge the importance of the use of computer and information technology to support the process of health information delivery in an integrated manner to healthcare consumers. They also consistently focus on the importance of meeting the consumer's personal information needs.

Consumer health informatics is differentiated from the existing field of medical informatics by Houston et al. "First, because of its frequent patient-centered approach, consumer health informatics may have an even stronger overlap with public health. In addition, the design of consumer health informatics applications require more frequent input from patients and consumers" [5, p. 1, sub 4,6].

Tom Ferguson describes the importance of addressing the personal information needs of modern healthcare consumers: "When they have a serious medical concern, they (healthcare consumers) don't just accept whatever treatment their local doctor offers. They'll spend hours and hours on the Internet learning about their condition, communicating with other patients and clinicians who share their interests, and tracking down every lead they can find on the best new treatments" [6]. Dr. Ferguson has delineated 10 levels in which consumers participate in the access and use of health care information [7, pp. 1–2], as follows:

Level 1.   e-Patients search for health information.
Seventy-three million American adults currently use the Internet to look for information regarding their health concerns. Four out of five of their online sessions begin with a search engine. Patients give themselves online crash courses on their newly diagnosed diseases and disorders. They prepare for doctors' appointments and look up information on the drugs and other treatments that their doctors recommend. They look for new ways to control their weight. But above all, they search for information that might help others. According to a recent Pew Internet & American Life survey, more e-patients search for medical information for friends and family members (81%) than for themselves (58%) [7, pp. 1–2].

Level 2.   e-Patients exchange e-mail with family members and friends.
Online patients reach out via e-mail to those they know and love, reporting on their health problems and concerns, and seeking information, advice, and support from their personal network of friends and family members. Their loved ones typically respond with sympathy, understanding, and support. They recommend specific resources: doctors, treatment centers, Web sites, books, and support groups. They refer e-patients to "second-level" contacts, for example, another friend who knows about the topics of concern to them. They also use e-mail to coordinate face-to-face visits and assistance [7, pp. 1–2].

Level 3.   e-Patients seek guidance from online patient-helpers.
When faced with a new diagnosis of a serious medical problem, e-patients may seek out and communicate with an experienced online self-helper with the same condition,

for example, the Webmaster of a site devoted to their concern. There are thousands of these condition-specific online patient helpers on the Internet, and they are not difficult to find. Patient-helpers can usually recommend the best online resources for a particular condition. In addition, they typically provide a type of uniquely practical and reassuring "been-there-done-that" advice that may be difficult or impossible to obtain elsewhere [7, pp. 1–2].

Level 4.   e-Patients participate in online support groups.

Many e-patients facing serious medical challenges participate in Internet support communities devoted to a single medical condition (e.g., breast cancer or depression). These groups usually communicate via postings on Web-based forums or electronic mailing lists. Participants share their thoughts, feelings, personal stories, and experiences and ask and reply to questions. They also exchange information on medical studies and clinical trials, discuss current treatment options, and recommend treatment centers and professionals with special expertise in the shared condition [7, pp. 1–2].

Level 5.   e-Patients join with other online self-helpers to research their shared concerns.

The members of some Internet support communities organize themselves into online work groups, reviewing the medical literature on their disorder and providing lists of frequently asked questions (FAQs) for the newly diagnosed. Some online support groups conduct informal research on their shared concerns. A few have even developed and carried out their own formal research studies or have partnered with professional researchers to conduct medical research, with group members serving as research subjects [7, pp. 1–2].

Level 6.   e-Patients use online medical guidance systems.

At some sites, e-patients can type in the names of all the drugs they are currently taking and receive a report of all possible drug interactions. At others, they can read reviews of a drug their doctor has proposed, written by dozens of patients who have actually used it. There are sites where patients can answer a series of questions about their symptoms and receive a listing of possible diagnoses, along with a list of the medical tests and observations that could help them decide which might be most likely. Further, a number of online physician directories are available where e-patients can find detailed information about individual doctors and hospitals, for example, patient evaluations, surgical success rates, and reports of malpractice settlements. I have come to think of such sites as early prototypes of what my colleague Richard Rockefeller has called medical guidance systems—information technology (IT) systems that use computing power to help e-patients make good medical decisions. In the future, such systems could make it possible for e-patients to play an even more knowledgeable and responsible role in contributing to their own medical care.

Within these first six levels, e-patients operate primarily in the world of lay medicine and self-managed care, with little or no involvement with health professionals. The four levels that follow involve interactions between e-patients and health professionals [7, pp. 1–2].

Level 7.   e-Patients interact with volunteer online health professionals.

Online patients sometimes send their e-mailed questions to health professionals they have found on the Internet. Or they may visit Web sites (e.g., *drgreene.com* or *drweil.com*) at which physicians or other health professionals offer to answer visitors' medical questions. Hundreds of health professionals currently provide such services. Many sites (e.g., *http://www.goaskalice.columbia.edu*) list hundreds of previously asked questions and answers in a searchable or browsable format [7, pp. 1–2].

Level 8.   e-Patients use the paid services of online medical advisors and consultants.

Some e-patients take advantage of the online-only services now offered by a growing number of professionals: They may pay a physician or a nurse to answer their e-mailed questions. They may seek an online second opinion from a physician specializing in their condition. They may sign up for a series of e-mailed counseling sessions with an e-therapist. They may employ the services of an online medical researcher. Or they seek the advice of an online personal trainer, nutritionist, or weight loss coach. Because level 8 medical professionals do not require face-to-face contact, they can offer their services to anyone with an Internet connection [7, pp. 1–2].

Level 9.   e-Patients engage in electronic conversations with their local clinicians.

Growing numbers of e-patients exchange e-mail with their local brick-and-mortar physicians. The content of these communications frequently resembles that of a provider–patient phone call. Patients ask questions to help them prepare for, or follow up on, a clinical visit. But because e-mail is more convenient and less time pressured, e-patients need not worry about interrupting their busy doctors. Patients who communicate with their doctors via e-mail may find it easier to pose thoughtful questions, introduce new topics, and report on the results of their online searches. Some providers now offer more sophisticated online patient services, for example, threaded patient–physician messaging, online advice nurses, online support communities, shared access to the patient's electronic medical records, online appointment scheduling, and online prescription refills [7, pp. 1–2].

Level 10.   e-Patients receive one-way electronic messages from their clinicians.

Some health professionals use the Net to send their patients unrequested messages that are not interactive, for example, targeted suggestions for behavioral change or patient education materials of the doctor's choosing. In most cases, the effectiveness of these offerings can be increased by presenting them in an "opt-in" manner, by adding a "talk back" option, or both, moving the interaction to level 9. Although such one-way communications may be acceptable to older or less sophisticated patients, some experienced e-patients think of unsolicited one-way messages as spam and may find them offensive [7, pp. 1–2].

Toward a Model for Consumer Health Informatics

Drs. Lewis and Friedman [8] have proposed a model for consumer health informatics (Fig. 1.1) that places the consumer at the center of the process of information transformation. This model illustrates how relevant and valid information—integrated appropriately into an environment of shared decision making—can improve both the satisfaction with the process of care delivery and measurable outcomes reflected in consumers' health status. Information technology, as a mode of message/information transfer, serves to assemble and process the information and act as a catalyst for feedback. Healthcare consumers work with their healthcare providers to assemble and understand the retrieved information in the context of their personal health concerns. The ideal system output is an informed healthcare consumer who is making health choices based on personal health goals that lead to improved health outcomes. The model is graphically represented in Fig. 1.1.
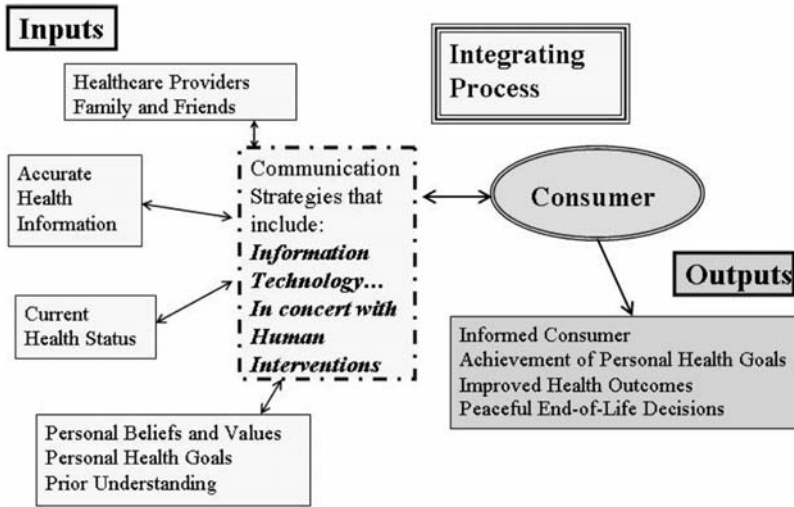
FIGURE 1.1. A model for consumer health informatics. (The consumer in this figure is meant to represent persons of all genders, races, and ethnicities.)

One Consumer's Experiences and Perceptions: Jason G. Cooper, MS

Consumer health informatics is best illustrated through the actual experiences of a healthcare consumer. We recognize Jason Cooper for his willingness to share his story and for the understanding that it brings to our study of consumer health informatics.

Case Study

I was diagnosed with Crohn's in 1993—a life-altering event for anyone with this chronic disorder. Instead of entering the military as an officer, I was medically discharged and decided to attend graduate school. Although I didn't know it then, this is where my education with community health informatics would begin.

   Wanting to learn more about this disease, I searched for health resources. Beginning with my mother's books (she's a nurse), I read for hours on end. Most of these books dealt with people who were extremely sick from inflammatory bowel disease (IBD), which served to do nothing more than frighten me. Sadly, nothing informatively satisfying was given to me when diagnosed. I was prescribed Azulfidine, given a one-page brochure, and sent on my way.

   At the time, the Internet was just beginning to blossom into the public and private sectors. After a couple of years of unsuccessfully "dealing" with my condition alone, I decided to seek help from my peers. Online discussion groups, varying Web sites, and the Crohn's and Colitis Foundation of America's (CCFA's) "Ask the Physician" forum are where I spent many hours. By far, these were the most enlightening experiences— learning that others had similar food interaction problems; learning that I was not

alone; and, asking volunteer gastroenterologists specifics about prescription medications, diet, and a myriad of other questions.

I had found what I truly needed years before when my diagnosis was first made: an information resource, a self-help and support group, and a healthcare professional willing to lend personal advice. For those suffering with many chronic ailments, these are three very important issues: educating oneself, knowing there are peers that are experiencing the same and supporting one another, and professional advice without the need for an office visit.

In retrospect, an information kiosk at the gastrointestinal (GI) doctor's office where I was diagnosed, to address all of these concerns, would have helped considerably. The Internet has come a long way since 1993 and advances in informatics research will open more doors for patients to self-inform. I am currently pursuing a Ph.D. at Duke University and I am focused on IBD diet and wellness research. I believe the future of community health informatics will be to assist individuals in learning, finding applicable resources, and seeking professional advice outside the standard office visit.

As a fellow informatician, I perceive the principal challenges to be:

- Electronic Health Record (EHR) standardization, which without we cannot confidently deliver complete and accurate health information.
- Standardizing the delivery of patient health information outside the current care paradigm (i.e., Web delivery of tests, findings, and billing; Web and e-mail reminders for normal visits, special visits, bills, and insurance; and personalized health-related news and information).
- Enriching patient education and compliance.

I believe that we can address these challenges and change the way information is delivered by:

- Widely standardizing the EHR (IEEE, ISO, other standards organizations, and e-health leaders).
- Implementing e-capable (Internet, mobile devices, etc.) health information distribution.
- Educating patients on diverse levels such as hard-copy brochures (perpetual method), information kiosks in specialty clinics and community/family medicine clinics, e-health delivery, and e-health education (oneself, loved ones, or academia).

On a closing note, my heartfelt understanding is shared with those indomitable sufferers of IBD—Crohn's disease or ulcerative colitis, as well as those with irritable bowel syndrome (IBS). I've been through 11 years, lots of Crohn's medications, countless procedures, and a bowel resection . . . yet I continue to dream of a cure of these troubling disorders. I plan to dedicate time and effort for research toward quality-of-life issues and patient education. I also applaud the tireless work and contributions of researchers, educators, philanthropists, and the innumerable healthcare professionals.

Summary and Issues

Healthcare consumers are actively involved it seeking health information and in using the information they are finding to make decisions about their health. People seek healthcare information from a variety of sources, which include print and electronic resources, healthcare providers, other consumers, and their families and friends. The

information may be delivered in a variety of print and media-based formats, through electronic access, that is, Internet-based delivery, telephone delivery, e-mail and chat, access to electronic databases, and other formats too numerous and constantly evolving to mention. It is important that access to health information is consumer centered and accessible for the person involved and for his or her provider, and that the process of consumer health information delivery focuses on the personal information needs of the healthcare consumer. To meet the unique information needs of healthcare consumers and support the process of optimal health outcomes consumer health informatics applications need to support the synergy between patient and provider.

The example provided by Jason Cooper illustrates the need for integrated systems that support healthcare consumers' access to the information combined with access to healthcare providers working and interested to discuss, validate, and assist consumers in understanding the information in the context of their own health concerns. In the course of creating consumer health informatics tools, consumers, providers, and informaticians must pay attention to ethical and social issues so that together they shape the future as they would like it to be, in terms of both how technology is used and what kinds of regulations are put in place. Certification and self-regulation, instead of only government regulation, are needed to ensure information accuracy and to help users evaluate the credibility of information providers and information sources [9, p. 312].

In this text we are presenting the science of consumer health informatics. Each chapter makes a unique contribution to this effort. We are ever aware that any discussion of consumer health informatics should represent the science of healthcare informatics within the context of the healthcare consumer we seek to serve. The text is organized to move the reader from a discussion of definitions for consumer health and health informatics through theory-based approaches for design to a presentation of "best-practice" strategies for development and evaluation. The text ends with discussion of model initiatives in consumer health informatics. Critical issues are examined that challenge providers, consumers, and informaticians who seek to create and use consumer health informatics applications.

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