Chapter 10
Decision Support for Patients

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Abstract Research studies have shown that access to health information and decision support can enable patients to be more active participants in the treatment process, leading to better medical outcomes. Decision support may take the form of health risk appraisals, understanding symptoms and when to see a doctor, as well as support for treatment choices and health management in the home. Many systems are designed to improve shared decision making, blending the expertise of clinicians in areas of diagnosis and prognosis with patients' knowledge of their preferences and values on potential health outcomes. Technologies designed to provide clarity and improved access to decision support tools for patients have the potential to improve the quality of health care decisions and health outcomes more generally.

Keywords Decision aid • Empowerment • Shared decision making • Patient preferences • Usability

10.1   Introduction

This chapter introduces the concept of technology-based decision support systems for patients. With the rapid growth in smart phones, sensor technologies, and more ubiquitous Web access for patients of all demographics, we have an opportunity to empower patients to be active participants in their health management and decision making. The field of consumer health informatics deals with "developing and evaluating methods and applications to integrate consumer needs and preferences into information management systems in clinical practice, education, and research" [1]. This technology ranges from systems providing background information on wellness, symptoms, diseases, and possible treatments to more comprehensive and interactive systems that support the management of chronic diseases. There are also

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systems that support a patient's shared decision making with a clinician for important medical issues. Today more than ever, consumers and patients are using information technology as an important component of their medical care.

10.2   Role of Consumer Health Informatics in Patient Care

Research studies have shown that access to health information can enable patients to be more active participants in the treatment process, leading to better medical outcomes [2–5]. Health education is an important aspect of doctor-patient communication. Patients report that they want to be informed about their medical condition [6, 7], and the process of sharing information enhances the doctor-patient relationship. In Pew Internet's Health Online 2013 Survey, they found that 72 % of U.S. adults reported having looked online for health information in the past year, and that 35 % reported having looked online to determine what medical condition they or someone else might have [8]. Of those seeking health information online, 46 % said that it led them to think they needed to seek medical care, while 38 % found it was something they could take care of at home, and 11 % reported that it was both or in-between. Clearly, the Web is a common source of health information. However, many people still consult with family and friends in addition to seeing a clinician. In fact, the Pew Health Online Survey found that, for serious conditions, 70 % sought information, care, or support from) a health care professional, 60 % consulted with family and friends, and 24 % discussed it with patients with a similar diagnosis [8].

Materials for patients and consumers on the Web run the gamut from generic patient education materials and background information presented in an electronic format to interactive decision aids. Most consumers (77 %) begin looking online for health information using a search engine (e.g., Google, Bing, Yahoo). Others (13 %) limit their search to known specialty sites, such as WebMD.com or MayoClinic.org. Often, search engines will return links to these specialty sites or to a general reference site like Wikipedia. The vast majority of people looking online for health information end up on these specialty sites [8].

Websites that specialize in health information usually organize the material so that it is accessible by both symptoms and condition/diagnosis. Each condition or diagnosis will contain background information on causes and symptoms, information on how the disease or condition is diagnosed, and possible treatment options. A key feature of these sites is letting the user know when and how soon to see a clinician or if the condition can be managed at home. Many health websites offer wellness information and information on other health topics, such as aging. One of the clear advantages of being able to search for information on these sites is that photographs (especially useful for skin conditions), diagrams, and videos can be readily accessed and used both educationally and to help clarify symptoms.

Additionally, many health websites offer interactive tools for patients. These range from simple calculators of BMI (body mass index) to health risk appraisals

and checks for drug-drug interactions. The rapid growth of consumer health software and materials on the Web, as well as new sensor developments and the rapid uptake of mobile communication devices have facilitated patient participation in their health care and decision making. These interactive systems have been developed to assist patients with informed consent [9, 10], health management [11], as well as coping and decision-making skills [9–11].

Interactive tools for patient decision support or health management include the following:

- Support algorithms for when to see a clinician or when to manage at home
- Health risk assessments, health metric calculators
- Interactive systems for health management (e.g., fitness, weight loss, smoking cessation)
- Interactive systems for disease management (e.g., heart failure, diabetes, asthma)
- Online forums on health topics for social support and condition management advice
- Patients' access to their electronic health record, patient/physician email, tailored discharge summaries
- Decision support tools for patients to make treatment or care choices
- Decision support tools to prepare patients for shared decision making in a clinical visit

Interactivity and tailoring of health materials has been shown to improve health outcomes [12–15] and is an important aspect of the more intensive tools for patients. The remaining topics in this chapter will relate to computer tools, sensors and communication devices that interface with the patient directly with interactivity and tailoring to facilitate their decisions and management of their health.

10.2.1 Empowerment and Self-efficacy

Involvement in one's medical care also involves the concepts of patient empowerment and self-efficacy. Empowerment and self-efficacy are closely linked concepts. In general, empowerment can be thought of as the process that enables people to "own" their lives and have control over their destiny. It is closely related to health outcomes in that powerlessness has been shown to be a broad-based risk factor for disease. Studies demonstrate that patients who feel "in control" in a medical situation have better outcomes than those who feel "powerless" [16–18].

Similarly, self-efficacy is a patient's level of confidence that he or she can perform a specific task or health behavior in the future. Several clinical studies have shown self-efficacy to be the variable most predictive of improvements in patients' functional status [19–26]. For example, in a study of functional status after bypass surgery, self-efficacy explained more variability in functional status outcomes than did measures of disease severity, functional capacity, comorbidity, or preoperative functioning [27]. Additionally, in a study on patients with rheumatoid arthritis, the

degree of perceived self-efficacy was correlated with reduced pain and joint inflammation and improved psychosocial functioning [21]. In cancer patients, a strong positive correlation was found between self-efficacy and quality of life and mood [28]. In the prevention area, perceived self-efficacy was shown to play a significant role in smoking cessation relapse rate, control of eating and weight, and adherence to general preventive health programs [29].

Given the strong influence of empowerment and self-efficacy on health outcomes, it is important to incorporate a focus on these concepts when designing systems for patient use. The feeling of empowerment and self-efficacy can be enhanced, for instance, by online support groups where patients are able to connect, communicate, and engage in problem solving with others who have similar medical problems. This has been investigated and demonstrated with several life-changing health conditions, such as breast cancer and HIV/AIDS [12, 30–34]. An important measure of the success of health information systems is how well they promote empowerment and self-efficacy for patients.

10.2.2 Incorporating Patient Preferences

As medical care increasingly focuses on chronic disease, it is especially important that patient preferences regarding the long-term effects of their medical care be taken into account. For patients to be adequately informed to make decisions regarding their medical care, it is important that they obtain information about the quality of life associated with the possible medical outcomes of these decisions. Yet the reliable assessment of a patient's preferences and risk attitudes for clinical outcomes is probably the weakest link in most clinical decision making. Efforts to explore the use of computers in communication about health outcomes, and in assessing patients' preferences for various health outcomes, have addressed these issues [13, 14, 35]. Information on patient preferences is important for tailoring information to patients and for providing decision support [13]. Tailored information has been found to be more effective in providing consumer information [36] and is preferred by patients [37]. In addition to differences in preferences for health outcomes, patients differ in the degree to which they choose to be involved in decision making. Research confirms that age (younger), gender (females), and education level (higher) are strong predictors of the desire to be involved in medical decisions. There is also a higher desire to be involved in medical decisions that appear to require less medical expertise, such as a knee injury, as opposed to a cancerous growth [37].

10.3   Interactive Tools for Patient Decision Support

The number of commercial computer and Web-based products to support patients' health information needs is growing rapidly. The information and decision aids range from general home healthcare reference information to symptom management and diagnostic decision support. There has been a dramatic surge in consumers' use of the Web to acquire health information [8]. Physicians, clinics, hospitals, and insurers are all redefining their business practices to incorporate the Internet and Web delivery systems. The following sections describe the various types of health information and decision support applications available for patients and their families.

10.3.1   Patient Decision Support for Diagnosis

Some of the health portals that offer general reference and drug information also offer interactive tools to assist patients in health assessment, symptom management, and limited diagnostic information (usually in preparation for shared decision making in an office visit). Health risk assessments usually take the form of a questionnaire with questions on family history and health behaviors. After completion, patients receive a tailored report with a summary of results that may help them prioritize their health goals. There are many vendors providing health risk appraisal instruments [38] with most having certification from the National Committee for Quality Assurance [39]. The tailored information identifies an individual's health risk factors and researchers have shown that this information alone may improve health behaviors and outcomes [40]. In some cases, the health risk assessment information may then be linked to a personal health record and shared with one's clinician.

Many health portals on the Web also offer various health screening tools. For example, several sites have depression screening self-assessments using a questionnaire style format (e.g., Web MD's depression test embedded in a page with links to further information on depression) [41]. These types of assessments allow the patient to know when to pursue diagnostic advice from a health care professional and when to seek treatment. Other types of self-assessments include screening for childhood and adult attention disorder [42, 43], Alzheimer's disease [44], eating disorders [45], etc.

Several health portals also offer calculator style tools to help patients manage their health. For example, after entering height and weight, patients can obtain their body mass index. Pregnancy calculations and target heart rate calculations are also amenable to this approach. Websites such as HealthStatus.com{healthstatus.com} additionally offer "calculators" to estimate blood alcohol level, basal metabolic rate, body fat, ideal weight, and recommended calories per day to achieve goal weight.

Occasionally, the health websites will offer diagnostic aids for patients. However, there has been some reluctance to offer advice that is overly specific. The usual approach on the health sites that offer symptom-based diagnosis is to assess a symptom or two and then present a list of possible causes, with links to further reading. As an example, WebMD [46] has an integrated Symptom Checker. The patient first enters a symptom and then selects related factors, such as frequency or "triggered by." Possible causes/diagnoses are then presented to the user with links to associated reading material. The next step for many individuals is to decide when to see a clinician. For symptoms like shortness-of-breath, rectal bleeding, or even cough, the sites will generally offer guidelines on "when to see a doctor," distinguishing between emergency care, making an appointment, or self-care.

10.3.2 Support for Patients' Treatment Decisions

Most of the interactive decision aids that have been developed recently have focused on the patient's role in participating in treatment decisions. As noted above, optimal decisions incorporate not only quality information about the diagnosis and prognosis (areas of a clinician's expertise) but also information on a patient's preferences with regard to the potential health and treatment outcomes. To varying degrees and depending on the condition, the process of shared decision making, whereby the patient and physician jointly contribute background information to generate a treatment decision, becomes an important element of health care management. The Robert Wood Johnson Foundation report on Shared Decision-Making and Benefit Design [47] points out that eight out of ten adults over the age of 40 make health decisions on a regular basis. This includes surgical decisions, whether to have screening tests, or what medication to take. Yet many patients report a lack of involvement in these decisions. Conditions such as breast cancer, early stage prostate cancer, and chronic stable angina are examples of situations where various treatment options are available, including "watchful waiting", but also where the decision on treatment choice is sensitive to patient values and preferences. Researchers have found that when patients discuss preferences with their physicians, they are more likely to get the care they want [48], and that patients who are more engaged in their health and health care have better outcomes [49]. The Cochrane Review led by Stacey et al. looked at the effectiveness of decision aids for patients' treatment decisions [49]. They found that these tools improved patients' knowledge about their treatment options and reduced decisional conflict related to feeling uninformed or unclear about their preferences and values. They also found moderate quality evidence that the decision aids promoted patients to take a more active role in decision making and have a better understanding of risk.

Many of these treatment decision aids can be found on health portals, such as WebMD.com or MayoClinic.org. The Agency for Health Care Research and Quality offers shareable decision aids [50] for a limited number of diseases and conditions.

The guides consist of background material on the condition, how the condition is diagnosed, treatment options with thorough descriptions, and the pros and cons of each option. The background material is supplemented with video clips on the Web. The goal of this approach is not to provide the patient with a diagnosis or specific recommendation, but to prepare the patient to be an informed participant in making treatment decisions during the next visit to the clinician. Their tools often offer supplementary video education and patient testimonials, as well as questionnaires with printable results that reflect the patient's submitted values, questions and concerns. These can then be taken to an office visit with a clinician in preparation for shared decision making regarding a test or treatment.

The largest selection of links to patient treatment decision aids (at least 300) can be found at the Ottawa Hospital Research Institute (OHRI) Web page on decision aids for patients [51]. Most of the decision tools are produced and maintained by Healthwise, Inc. [52], which then serves as a provider of content for Web-based health portals, such as WebMD.com [53]. These decision aids typically list the relevant treatment options, provide background information, and describe the various risks, benefits, and why a doctor might recommend a particular treatment or procedure versus "watchful waiting". Although available online, they are typically paper based and printable for the patient to take to a clinic visit. A key contribution with these is that the probability of success or risk associated with treatment is displayed in a graphical format for the patient. Assistance with understanding side effects and a method for describing patient values (using a scale from Not Important to Very Important) is provided.

Researchers associated with the International Patient Decision Aids Standards (IPDAS) Collaboration have created a framework [52, 53] for evaluating each of the identified patient decision aids on the OHRI website [51]. They classify the decision aids according to health condition, options available, appropriate audience, developer, year of last update/review, format, language, and provide a link to the source. They then evaluate each decision aid on 11 content criteria, 9 development process criteria and 2 effectiveness criteria. Table 10.1 summarizes the guidelines and evaluation criteria they developed using a two-stage Web-based Delphi process.

The goal of having a process to define the quality of decision aids for patients is to influence developers in creating more usable and effective tools for patients and to help providers and patients in finding, selecting, and using the best tools available to support shared decision making.

10.3.3   Other Areas of Decision Support for Patients

In addition to decision support tools for health risk appraisal, diagnosis, screening tests and treatment decisions, support is required for many areas of patient self-management and decision support in the home environment. Self-management is important for a number of chronic conditions, including diabetes, heart failure, and

Table 10.1 Criteria developed by the International Patient Decision Aids Standards Collaboration to judge the quality of patient decision aids [54, 55]

Information	Health condition
	Decision
	Options
	Potential benefits
	Potential harms
Probabilities	Potential outcomes – general
	Potential outcomes – subpopulation
	Ability to compare (e.g., same denominator)
	Multiple ways to view probabilities (e.g., words and diagram)
Test interpretation	If test, description of false positive and false negative
	Estimated chances of false positive and false negative
Values	Description of potential outcomes (positive and negative)
	Method to clarify and state personal values for outcomes
Guidance	How to make the decision
	Topics to discuss with a clinician
Development	Needs assessment with patients and professionals
	Reviewed by patients and professionals
	Field tested with patients and professionals
Evidence	Description of evidence from previous research
	Description of quality of evidence
Disclosure	Author/developers' credentials and affiliation
Plain language	Report of readability level from standard scale
Evaluation	Demonstrate improvement in patient's knowledge
	Correspondence between patient values and treatment choice

asthma. These conditions require vigilant monitoring and self-care on the part of patients and/or family members. For example, patients with diabetes must monitor blood glucose levels on a regular basis, as well as manage diet and exercise. For patients with heart failure, it is important to monitor weight and symptoms of shortness of breath or fatigue, along with careful medication management. Patients with asthma must also regulate medications with symptoms and environmental triggers. Especially for newly diagnosed patients, these care regimens can be quite daunting. There are many forms of technology support for patients with chronic conditions, ranging from mobile phone applications directly available to a patient to sophisticated disease management interventions delivered by a clinic or health insurer.

Monitoring technologies include a variety of blood glucose meters, wireless weight scales, peak flow meters for asthma, wireless blood pressure cuffs, bed sensors to measure sleep quality, wireless ECG leads for heart rate, heart rate variability, and arrhythmia monitoring, as well as the new wrist-worn devices with accelerometers (activity), and measures of electrodermal activity (stress), and heart rate. Disease management systems typically share the data both with the patient and

with a nurse care manager at a remote facility who can then respond to system generated alerts (e.g., to change the diuretic medication dose for a patient who retained too much water weight in the past 3 days).

With the recent increase in popularity of wearable sensors and coaching technologies, many patients and consumers interested in wellness interventions are directly purchasing sensors and services to promote health behavior change. Many of the devices with accelerometers and heart rate detectors offer real time and summary feedback on activity levels and sleep. Many have accompanying goal setting modules and feedback to encourage users to achieve their health behavior change goals.

In some cases, decision support and advice on care management solutions comes from other patients who have similar conditions. There are a variety of online support groups or discussion boards available for nearly every disease imaginable. Some are formally organized through a health delivery system, such as Kaiser Permanente [56]. Others are accessible through health portals, such as WebMD [53]. Quite often, with chronic conditions where most of the health care actually happens in the home and environment and is related to self-care, patients become the experts in how best to manage and implement care plans. Sites such as WebMD [53] have also found it useful to have a separate section with information for newly diagnosed patients. More detailed information on specific diseases or conditions is often available from societies or groups specializing in a topic. Online medical dictionaries, disease-specific discussion boards, and "ask-an-expert" services are also often found as components of health portal sites. The vast array of health resources available to patients' mobile phone applications and on the Web that provide support in care management also include tools to educate patients about their medications, such as RxList [57], DrugInfoNet [58], and RxMed [59]. Systems available on websites such as Drugs.com [60] can be used to detect drug-drug interactions, similar to systems used in hospitals and clinics, but using pictures and lay language.

10.4   Usability of Patient Decision Support Tools

One of the most important factors in the success of patient decision aids has to do with the usability of the interface and method in which the information is conveyed. General guidelines for developing useable and meaningful decision support for patients are listed below:

10.4.1   Intuitive Interface

- Graphical metaphors easily understood by the general populace
- Designed for use by naïve, untrained users

- Online help available at every stage
- Immediate word definitions available in every application

10.4.2   Complete Coverage/Coordination

- Single location for information on disease and health concerns
- Coordinated with routine medical care

10.4.3   Hierarchical Presentation

- Simple summary information presented first
- More detail and complexity available as desired
- Guided movement through databases
- User requests anticipated, pre-searched to improved speed

10.4.4   Presentation of Materials Tailored to the Individual

- Appropriate for the assessed reading level
- Appropriate for education and medical expertise
- Culturally sensitive
- In the appropriate language
- Tailored to history and assessed patient-specific health risks
- Patient preferences incorporated

10.4.5   Facilitate Quality Decision Making

- Health outcomes information included
- Patient preferences on health outcomes incorporated
- Summary of tailored decision support information

These guidelines are important for the developers of decision aids, as well as for patients and providers as they choose systems to use or recommend to others.

10.5   Helping Patients Judge the Quality of Health Information

Judging the quality of health materials on the Web or as part of decision tools is particularly challenging for patients/consumers. Not all sites are "peer reviewed," published, or created by professionals with expertise in the covered topics. Because the quality of health information is so critical for consumers, several organizations have created guidelines for judging the quality of information on the Web for consumers [61–63]. Some of the criteria included in all of these guidelines are topical relevance, currency of the information, accuracy, and authoritativeness or objectivity.

From the consumer's point of view, topical relevance is certainly important when assessing the usefulness and quality of a website or computer application. The relevance of a site is context-specific and depends on the particular question an individual consumer has in mind. To find appropriate materials, sites must be clearly organized and/or have intelligent search functions. In addition, the relevance of the material depends on the degree to which it is tailored to the individual and is appropriate to their specific needs. Most health material on the Web is generic and not interactively tailored to individuals, basically replicating what could be found in a textbook or brochure. The final aspect of relevance to an individual has to do with whether the material is action-oriented and either helps the consumer make a health-care decision that may lead to an action or promotes health behavior change.

The currency or timeliness of information is an important consideration. It is often difficult to have a generalized policy on how often health materials need to be updated. However, most professional sites ensure at least quarterly review of all materials. Consumers may judge the currency of website information by looking for date stamps or a notice of date of creation and/or update. It is important to note that some websites use algorithms to automatically update their time stamp even if the material has not been changed or even reviewed, giving the impression that the information is current. Responding to the difficulty that consumers are likely to have in judging these aspects of website quality, the Health on the Net (HON) Foundation [63] has promoted an ethical code of conduct and a set of standards for website developers to ensure the reliability of medical and health information available on the Internet. Consumer health sites that display an HON certificate signify that they are in compliance with the HON code of conduct and standards. Providing health information and interventions over the Internet is becoming an increasingly important component of health care. Ensuring that the materials are unbiased, accurate, relevant, and timely is fundamental to providing quality health care.

10.6   Patient Access, Literacy and Numeracy

As the demand for more health information and decision support grows, the need for wider availability of these systems becomes even more important. Today, these systems can be found in a variety of settings and forms. In addition to consumers searching the Web at home, public access computer systems can be found in public libraries, health resource centers, worksites, schools, and community centers. Different systems may require quite different physical locations. For instance, many patients are uncomfortable exploring sensitive health information in a public space.

There are many factors that influence the health information seeking behavior of patients. As documented by several researchers, these factors include demographic divisions such as age, gender, disability, race and ethnicity, and socioeconomic status [64–68]. Research indicates that these demographic variables can predict differences in the amount and type of health information that patients want. Whereas some patients may not seek much information, for many of those who desire information, serious barriers to the use of these systems still exist.

A lack of reading ability is a functional barrier affecting use of computer systems. According to the U.S. Department of Education's National Institute of Literacy's 2015 survey [69], 32 million adults in the U.S. are unable to read – 14 % of the population. Surprisingly, 21 % of adults in the U.S. read below a fifth grade level and 19 % of high school graduates are unable to read. Most studies on the comprehension of health education handouts typically show that only half of the patients are able to comprehend written health materials [70–72]. Studies confirmed that patients' reading levels were well below what was needed to understand standard health brochures [73]. In developing health information for patients, one cannot assume that a patient who has completed a certain grade level in school can read at the corresponding level. Numerous studies on literacy and readability confirm the widespread problem of low literacy skills [74–76]. Health materials should be written at least three grade levels lower than the average educational level of the target population [77]. Text characteristics also play an important role in comprehension and retention of material. Organization and clarity need to be considered in creating educational materials [78]. Computers with multimedia capabilities can correct some of these problems by conveying information through video, audio and graphics that would normally be presented as written text. These systems can also be adapted for multiple foreign languages.

In addition to language and literacy issues, an area that is often overlooked relates to the cultural issues associated with health information-seeking behavior and the willingness to use computers to access health information. Most developers have not invested the time to develop systems that are culturally and linguistically relevant to diverse populations. Finally, the question of who will pay for the access and use of technologies for consumer health information is still an unresolved issue. Educational and socioeconomic factors still determine access to computers and information technologies. Younger, wealthier, and well-educated patients are more likely to have access to home computers, diagnostic software, and Internet services.

The poor and socioeconomically disadvantaged already have worse health outcomes and worse access to medical care. Special effort is required to ensure ease of access and ease of use of health information systems so as to not further disadvantage the very people who have the greatest need for these resources.

10.7 The Future of Decision Support Systems for Patients

Advances in communications, sensors, data analytics and information processing technology are changing the way in which medicine is practiced, with dramatic impact on how patients are beginning to receive their health information and interact with the medical care system. There has also been a shift toward consumers becoming empowered participants and assuming a more active role in their medical care decisions through increased and more effective access to healthcare information and decision tools. The developers of computer applications for patients have pushed the field of consumer health informatics forward with many innovative systems.

However, to achieve significant improvements in the quality of care and health outcomes, researchers and system developers need to focus on bringing the knowledge gained from previous work in health education and behavior change into the design of new systems. This is a rapidly developing field, with significant innovations in the commercial sector, but research in several areas is still needed to move the field forward in providing real benefits to patients' health outcomes and in showing the effectiveness of the systems to purchasers of health care. The criteria for evaluating computer-based decision support systems for patients are similar to the criteria for physician systems, namely accuracy and effectiveness [79]. However, the rapid deployment of these systems in an ever changing medical care environment makes critical evaluation of consumer health information systems extremely difficult. Websites and smart phone applications change daily, and access to one system usually means increased access to many others. It is important to understand the potential effectiveness of investments in this area. Careful needs assessment before system development, usability testing during development, clinical trials, and studies of use and outcomes in natural settings are all critical to our understanding of how to best provide health information and decision assistance to patients.

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