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CHOICEs: Patients as Participants in Shared Care Planning at the Point of Care

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Recent years have seen a proliferation of health information and self-help communication on the Internet, together with a growing trend toward empowering patients to take a more active role in their own health care [1,2]. There is evidence that patients want to be informed about their medical conditions and to participate actively in their own care [3]. Access to health information can enable patients to be more active participants in treatment processes [1,4]. Customized computer-based support systems provided to patient over the Internet such as "CHESS" [5,6] and "HeartCare" [7,8] have been shown to increase confidence in patients' decision making, improve health status, reduce social isolation [7–9], and significant effects on self-reported quality of life, social support, participation in health care, negative emotions [6,10,11], and reduction in symptoms and depression [12].

Although Internet-based support can provide important assistance for consumers and patients who seek health information from home, this does not automatically change patient care for patients who enter the healthcare system. Patients may be well informed about their conditions and treatment options and explicit about their preferences; however, unless they are treated as partners and patient preferences are acknowledged as important by their clinicians and integrated into actual patient care, it may have little impact on the actual care patients receive. In reality, patient problems are often still identified from the perspective of healthcare providers and their assumptions about what care is in the patient's best interest, without verifying these assumptions with the recipient of care, the patient. Therefore, systems are needed at the point of care that facilitate shared decision making (SDM) between patients and their healthcare providers. Such systems can assist in systematically eliciting patients' perceived health problems and preferences and in selecting treatment and care consistent with patient preferences.

This chapter discusses shared decision making tools at the point of care in the context of consumer health informatics and their state of the art. To illustrate such a tool, CHOICEs (**C**reating better **H**ealth **O**utcomes by **I**mproving **C**ommunication about Patients' **E**xpectations) is used as an example of a computerized support system that assists clinicians at the point of care in shared decision making and patient preference-adjusted illness management of cancer patients.

The Need for Shared Decision Making Systems at the Point of Care

A rapidly growing amount of literature has addressed the importance of shared decision making between health providers and patients, working collaboratively to select treatment and care that includes patient preferences [13–16]. Along with a strong focus on evidence-based patient care, there is an increasing awareness that an important piece of evidence to support clinical decision making is missing in the absence of patients' perspectives of their health problems and preferences for treatment and care. Evidence-based patient care and SDM are, at least in theory, viewed as models for good clinical practice [17,18].

The underlying assumptions for these efforts are that illness, treatments, and outcomes have value dimensions to patients that are highly personal. The vast differences in values patients place on clinical outcomes make an individual approach to patient care particularly important. To make the best care decisions from the perspective of the individual, patients must be asked in the clinical encounter to participate in the decision process about their care [17,19,20].

A number of studies have demonstrated that healthcare providers often do not know how patients experience their health problems and symptoms, nor can they infer what patients value, or assume what care decisions are in the patients' best interest [21–25]. Patients may have their own ideas about the nature, causes, severity, and consequences of their problems. In addition, cultural beliefs, values, and practices affect patients' perceptions of illness and preferences for treatment. Even people with similar disease and functional limitations vary considerably in their tolerance and attitudes toward symptoms [26]. Also, what healthcare professionals perceive as excellent outcomes may not be experienced in the same way by the patient. Wennberg et al. found that nothing in the objective reality of the patient, such as clinical history, physical findings, laboratory scores, urine flow, or symptom level, strongly predicted the degree to which patients were bothered from benign prostatic hyperplasia and had aversions to the risks of surgery [27,28]. In a recent study among cancer patients [29] many of the symptoms that were most frequently reported by patients were usually not included in routine assessments, and there were large variations in patients' reports of the frequency, severity, and degree of bother of these symptoms. Therefore, patients and clinicians can benefit from the assistance that tools to support SDM at the point of care can provide.

It is the experience of illness that brings people to the healthcare system. People do not come primarily for diagnosis and treatment; they come to be made well, made whole, and to recover a sense of health and well-being [13]. Lack of shared understanding about the patient's subjective concerns and the more objective approach to diagnosis and treatment by healthcare providers can lead to poor clinical management, poor care, and poor compliance. Professional care providers need, therefore, to understand, acknowledge, and integrate patients' perspectives of their needs into clinical decision making. This has become even more imperative in the Internet age, when more and more patients come well prepared and articulate about their needs to the healthcare system and are expecting that their preferences and health perspectives will be acknowledged. If the healthcare system does not adjust to these changing patient roles and expectations, for example, by introducing ways to increase patient–provider communication and SDM, discrepancies between patients' expectations and health care, poorer patient outcomes, and patient dissatisfaction may result.

What Is Shared Decision Making?

In the clinical, health services, and methodological literature, terms such as evidence-informed patient choice [17] and shared decision making are used to describe the process of involving patients, in appropriate ways, in treatment/screening decisions and care planning. The goal is to inform patients by the best available evidence about options and potential benefits and harms, and help them consider their preferences [16,30–32]. The concept of patient preferences capitalizes on the need to modify treatment and care to the particular values and experiences of the individual. Patient preferences can be defined as the appraisal by an individual regarding the relative desirability of entities, such as health states, treatment, outcomes of treatment/care such as symptom relief, or other aspects of health or health care [16].

The model in Fig. 17.1 displays key elements of SDM. SDM requires at least two core players: the patient and the healthcare provider. However, other factors may also influence healthcare decisions such as the patients' families, the cultural context, or societal priorities. The model recognizes the importance of patients as sources of information about their own values and preferences for patient care as well as research evidence to inform clinical decision making.

Communication and information exchange between patient and healthcare provider are crucial elements of SDM. Appropriate clinical decision making requires the consideration and sharing of two important knowledge aspects: (1) knowledge about facts, such as the patient's diagnosis, symptoms, and problems; available treatment options; and associated risks and likelihood of outcomes and (2) information about values, such as the desirability of these outcomes and how one values various aspects of health. Many patients have personal knowledge and experience about living with an illness, about how it affects their personal life and well being, and about their values and preferences. For a clinician to be able to plan individualized, evidence-based patient care consistent with patients' values and preferences this information needs to be communicated by the patient.

For patients to participate in SDM, they need to understand their illness condition, what the available treatment/management options are, as well as the likelihood of various outcomes of treatment according to research evidence. The patients need this information to be able to consider options and outcomes in light of their own values and preferences. Therefore, research evidence and clinical expertise needs to be com-

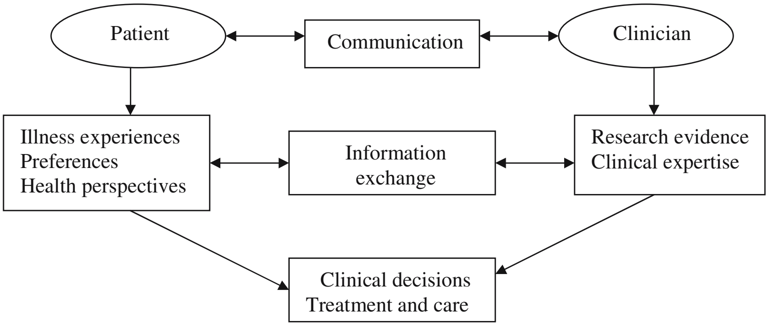

FIGURE 17.1. Participants in and elements of shared decision making.

municated between clinicians and patients. SDM tools can support such patient–provider communication and information exchange.

Support Systems for Shared Decision Making

There are two major types of systems to support SDM that include the elicitation of patient preferences: (1) systems that are primarily designed to assist patients in difficult decisions and that are usually referred to as Decision Aids (DAs) and (2) support systems for preference-adjusted illness management that are designed to assist clinicians in including patients' illness experiences and preferences into patient care of chronic or serious, long-term illness over time.

Decision Aids

The primary purpose of DAs is to help people make specific and deliberate choices among options by providing (at a minimum) information on the options and outcomes relevant to the person's health status [31]. Factors that should be considered in a treatment/screening decision are outlined, often in the context of the individual patient's characteristics. DAs are meant to be adjuncts to clinicians' counseling, so that patients can understand the probable benefits and risk of treatment options, consider the values they place on benefits versus risks of health outcomes, and participate actively with their clinician in selecting treatments that best address the patients' individual values and needs [30,32]. Studies evaluating DAs have reported higher scores on cognitive functioning and social support [11], more active and satisfying participation in decision making [30], better scores on general health perceptions and physical functioning [34], improved knowledge, and reduced decisional conflict [31,35].

DAs differ from the traditional patient education programs that primarily provide information, advice, and support with regard to already prescribed treatment [30]. DAs are appropriate when decisions are difficult, for example, under conditions in which more than one treatment alternative is available, or when outcomes are uncertain or there are major differences in outcomes or complications. Furthermore, they are beneficial when decisions require making tradeoffs between near- and long-term outcomes, when a choice can result in a small chance of a grave outcome [15] or the values for the benefits relative to the risks are more variable or unknown [32,36]. Also, DAs are useful in situations where patients may be very risk aversive or attach unusual importance to certain possible outcomes. In contrast, treating a patient with urinary tract infection with antibiotics is the recommended treatment where no other equally effective alternative exists [37]. For these kinds of more straightforward, less problematic decisions there is no need to employ a DA.

However, DAs have been confined primarily to the relatively narrow segment of decisions about single episodes of screening/treatment choices. Also, similar to Internet support for patients, DAs are designed mostly for use from home and less at the point of care, and there is evidence that DAs have been difficult to integrate into busy clinical practices [18]. Yet clinicians often encounter situations in which a major task is not how to select one treatment versus another, but how to attend simultaneously to multiple problems in a manner that gives priority to those that matter most to the patient, which may change over time along with changes in patients' symptom and health status. This is often the case in management of a chronic illness associated with multiple, complex symptoms and functional problems for patients and that clinicians need to attend to simultaneously. For example, a patient may suffer from acute stroke that causes impaired functioning, involving loss of coordination skills and problems eating; he or she may be at risk for falling, may have problems dressing, may be worried how he or she will be able to manage at home with three flights of stairs, or whether he or she will be able to return home at all. It is these types of problems that are experienced and valued differently by individual patients.

Support Systems for Preference-Adjusted Illness Management

While a recent Cochrane review identified 87 DAs to support patients in treatment or screening choices, where 24 DAs were tested in randomized clinical trials [35], much less work has been devoted to the development of computer-supported systems to assist clinicians in eliciting and integrating patients' illness experiences and preferences into symptom/illness management of seriously or chronically ill patients. It is only recently that systems have been developed that assist clinicians in eliciting and integrating patient preferences into the processes of illness management over time [29,33,38]. These types of systems are particularly relevant because a large part of health care is directed toward management of chronic illness that often affects multiple, value-laden dimensions of patients' personal lives. Support systems for patient preference-adjusted illness management are, therefore, somewhat different from those designed to assist in making treatment choices. They provide patients and clinicians with the salient symptoms and problems associated with a specific health condition based on research and clinical evidence, and a method for helping patients to establish the importance they place on their problems and outcomes to denote their preferences for treatment and care. CHOICE is such a support system to assist clinicians in preference-adjusted illness management of cancer patients and is described in the following section.

CHOICEs

CHOICEs includes (1) a comprehensive patient assessment tool for cancer-specific symptoms, functional problems, and preferences along physical, psychosocial, emotional, and spiritual dimensions and (2) a SDM/Care Planning component that highlights in an easy-to-use format for clinicians which symptoms patients are experiencing, including their severity, degree of bother, and importance to patients. This information can be used to discuss with the patient an appropriate plan of treatment and care in hospital as well as in ambulatory settings.

The CHOICEs application builds on experiences from previous studies and beginning cumulative evidence of the effectiveness and feasibility of such systems to improve patient-centered care. Two previous studies on a palm-top–based support system for preference-adjusted care of rehabilitation patients have shown significant effects on congruence between patients' problems and patient care and on patient outcomes of functional status and preference achievement [33,38]. Similar to this earlier system, CHOICEs for preference-adjusted symptom management of cancer patients was developed based on a thorough and critical review of the evidence-based literature to identify problems, specific symptoms, and functional limitations commonly encountered by cancer patients. This search and literature review included the healthcare bibliographic databases as well as the World Wide Web (WWW) for clinical guidelines, educational material, workbooks, measurement tools, and other relevant material. It resulted in a preliminary list of symptoms and functional problems for potential inclusion in the CHOICEs assessment. An expert focus group with specialists in cancer care (physicians, nurses, social workers) met in parallel. They critically reviewed the clinical evidence abstracted from the literature and the WWW for relevance, comprehensibility, completeness/level of detail, and supplemented with expert opinion. Particular attention was paid to describe symptoms and problems in simple, understandable, nonmedical lay language. The focus group also critically reviewed the design and interface during the development of the CHOICEs application. A preliminary version was pilot tested among 15 cancer patients who were asked to complete and evaluate the assessment for clarity of meaning, appropriateness, wording, completeness, redundancy, and format, and add comments [29]. These evaluations provided suggestions for revisions that were then discussed in the expert focus group before final revisions were made.

The current CHOICEs application is contained and administered on a touch-pad, tablet computer. It supports complex branching, so that only relevant questions are asked, and conditional tailoring, so that questions and summary reports are tailored to a subject's previous responses [29].

When using CHOICEs on the tablet computer, patients are presented with a series of questions and select their answers with a pen on the touch screen. After an introduction screen that introduces patients to CHOICEs and explains its purpose, patients are first asked two questions about their perceived overall health and Health-Related Quality of Life (HRQoL) on analog scales (range 0 to 100).

Thereafter, patients are asked to identify among 19 problem categories those that apply. If a patient is not sure whether a problem area applies to him or her, he or she can look up the specific associated symptoms/problems associated with that category by touching the info-button next to it. For example, given that a patient had selected problems with "eating and drinking," "bowel and bladder," and "mood and feelings" on the previous screen as applying to him or her, the more detailed list of symptoms is triggered from which the patient again selects those that apply, for example, taste changes, nausea, lack of appetite, and so forth under "eating and drinking." Then patients are asked about the degree of bother from their selected symptoms. In this manner patients are not troubled with many detailed questions that are not relevant to them, while focusing particularly on those symptoms and problems that are difficult.

Finally, patients are asked to rate the importance of their problems as priorities for treatment/care on analog scales from 0 to 100 (patient preferences). This allows clinicians to pay particular attention to those problems that are most important to patients to be addressed by their provider. After the patient is finished, an assessment summary is displayed in which patient problems are rank ordered by importance to patients, and that can be printed and used by the clinician and patient to jointly plan appropriate care.

Effects of CHOICEs and Similar Systems on Patient Care

There is beginning evidence about the usefulness and feasibility of use of support systems in clinical settings such as CHOICEs [29,33,38]. In a recent study 52 outpatients undergoing cancer treatment (mean age: 56.6 years; 59% women) used CHOICEs for assessment of their perceived HRQoL, symptoms, and functional problems, including severity, bothersomeness, and preferences for treatment/care, on a touch-pad computer in the outpatient waiting room prior to being seen by their physician or nurse [29]. This information was processed, printed, and given to the clinician in the subsequent consultation in the experimental group, but not in the control group. While equivalent at baseline, there was significantly greater congruence between patients' problems and symptoms and those addressed by their clinicians in the experimental group. Patients had few problems with the touch-pad computer, and CHOICEs received high scores on ease of use and usefulness by patients [29]. Comparable effects were found for a similar system for preference-adjusted symptom management in rehabilitation patients [33,38]. Two clinical trials with patients from acute care for the elderly and rehabilitation units demonstrated significantly higher congruence between nursing care and patient preferences and better outcomes of preference achievement and functional status when the system was used [33,38]. A multisite RCT that follows 220 hematological cancer patients for one year is currently underway to test the effects of CHOICEs for cancer patients on patient care as well as on patient outcomes in a larger study. The aforementioned studies demonstrate that a system such as CHOICEs can effectively help clinicians eliciting patients' symptoms and are a useful and feasible strategy to improve patient-tailored illness management for cancer patients.

Furthermore, CHOICEs extends previous SDM tools in two significant ways: (1) it is designed to support clinicians in eliciting and including patients' reported symptoms and preferences at the point of care; and (2) it extends SDM tools from supporting patients in single episodes of treatment/screening choices into the realm of symptom management for cancer patients over time. Extending SDM tools into symptom management of serious/chronic illness is important and was supported in the aforementioned study by the fact that almost all symptoms available in CHOICEs were selected by at least one patient. Large variations in patients' reports of frequency, severity, and degree of bother of these symptoms indicated that clinicians cannot automatically anticipate what symptoms and problems patients are experiencing or what patient care is in their best interest. Therefore, clinicians can benefit from the assistance that support systems such as CHOICEs can provide.

An interesting observation that deviates from most findings in the SDM literature was the effects on patient care of the CHOICEs intervention. Studies examining the adoption of SDM tools to support patients in treatment or screening decisions have reported clinicians' reluctance to use such tools, primarily because of their concern that this may add additional tasks for which they do not have time [18]. Attention to the workload, time requirements, feasibility, and acceptability are important factors to consider when introducing new SDM tools in clinical practice. Systems such as CHOICEs may be easier to implement than other types of SDM tools that have been primarily designed to support patients while at home. From the beginning its purpose was to support clinicians, and, therefore, particular attention was paid to streamline the CHOICEs application into the workflow of clinical practice. When patients were seen by clinicians in this study, assessments of their symptoms and problems that usually are part of the consultation were already completed beforehand. Thus, clinicians had this information ready when they saw their patients and could use it actively together with their patients.

In summary, although Internet support can provide patients with health information and self-help tools as important means to empower and prepare them for active participation in decisions regarding their health care, this does not automatically change the health care they receive. Healthcare institutions and clinicians need to adapt to changing patient roles and expectations and treat patients as partners in clinical decision making. Methods and tools are needed that facilitate SDM at the point of care. This chapter discusses SDM tools and methods and how they can be implemented into clinical practice. The example of CHOICEs is used for illustration, a support system that assists clinicians in eliciting cancer patients' illness experiences and preferences at the point of care. With the help of such systems clinicians can easier engage in partnerships with their patients and integrate patients' perspectives and preferences into patient care. The novelty of systems such as CHOICEs, however, requires considerably more work in this field. A particular interesting line of research would be to develop systems for preference-adjusted illness management for a wider range of patient populations other than rehabilitation and cancer patients and test the effects on patient care and outcomes.

References

1. Jimison HB, Sher PP. Advances in presenting health information to patients. In: Chapman GB, Sonnenberg FA, eds. Decision Making in Health Care. Cambridge, UK: Cambridge University Press, 2000.
2. Brennan PF. Health informatics and community health: support for patients as collaborators in care. Methods Inform Med 1999;38:274–8.
3. Degner LF, Sloan JA. Decision making during serious illness: what role do patients really want to play? J Clin Epidemiol 1992;45:941–50.
4. Greenfield S, Kaplan SH, Ware JE, Yano EM, Frank HJ. Patients' participation in medical care: effects on blood sugar control and quality of life in diabetes. J Gen Intern Med 1988;3:448–57.
5. Gustafson DH, Hawkins RP, Boberg EW, et al. CHESS: ten years of research and development in consumer health informatics for broad populations, including the underserved. Medinfo 2001;10:1459–563.
6. Gustafson DH, Hawkins R, Pingree S, et al. Effect of computer support on younger women with breast cancer. J Gen Intern Med 2001;16:435–45.
7. Brennan PF, Moore SM, Calewell B. Using WebTV to deliver health information into the home: experiences, successes, and regrets. Proc AMIA Symp 1999;1203.
8. Brennan PF, Caldwell B, Moore SM, Sreenath N, Jones J. Designing HeartCare: custom computerized home care for patients recovering from CABG surgery. Proc AMIA Symp 1998;381–5.
9. Brennan PF. The ComputerLink projects: a decade of experience. Stud Health Technol Inform 1997;46:521–6.
10. Gustafson DH, Hawkins RP, Boberg EW, Bricker E, Pingree S, Chan CL. The use and impact of a computer-based support system for people living with AIDS and HIV infection. Proc Annu Symp Comput Appl Med Care 1994;604–8.
11. Boberg EW, Gustafson DH, Hawkins RP, et al. CHESS: the comprehensive health enhancement support system. In: Brennan PF, Schneider SJ, Tornquist E, eds. Information Networks for Community Health. New York: Springer-Verlag, 1997;171–88.
12. Moore SM, Brennan PF, O'Brien R, Visovsky C, Bjournsdottir G. Customized computer home support improves recovery of CABG patients. Circulation (Suppl) 2001;104(II):533.
13. Gerteis M, Edgman-Levitan S, Daley J, Delbanco TM. Through the patients' eyes. Understanding and promoting patient-centered care. San Franciso: Jossey-Bass, 1993.
14. Kasper JF, Mulley AG, Wennberg JE. Developing shared decision-making programs to improve the quality of health care. QRB Qual Rev Bull 1992;18:183–90.
15. Kassirer JP. Incorporating patients' preferences into medical decisions. N Engl J Med 1994;330:1895–6.
16. Holmes-Rovner M, Llewellyn-Thomas H, Entwistle V, Coulter A, O'Connor A, Rovner DR. Patient choice modules for summaries of clinical effectiveness: a proposal. Br Med J 2001;322:664–7.
17. Hope T. Evidence-Based Patient Choice. London: Kings Fund, 2000.
18. Holmes-Rovner M, Valade D, Orlowski C, Draus C, Nabozny-Valerio B, Keiser S. Implementing shared decision-making in routine practice: barriers and opportunities. Health Expect 2000;3:182–91.

19. O'Connor AM, Drake ER, Fiset V, Graham ID, Laupacis A, Tugwell P. The Ottawa patient decision aids. Eff Clin Pract 1999;2:163–70.
20. O'Connor AM. Patient education in the year 2000: tailored decision support, empowerment, and mutual aid [editorial; comment]. Qual Health Care 1999;8:5.
21. Wenrich MD, Curtis JR, Ambrozy DA, Carline JD, Shannon SE, Ramsey PG. Dying patients' need for emotional support and personalized care from physicians: perspectives of patients with terminal illness, families, and health care providers. J Pain Symptom Manage 2003;25: 236–46.
22. Shannon SE, Mitchell PH, Cain KC. Patients, nurses, and physicians have differing views of quality of critical care. J Nurs Scholarsh 2002;34:173–9.
23. Higgins PA. Patient perception of fatigue while undergoing long-term mechanical ventilation: incidence and associated factors. Heart Lung J Acute Crit Care 1998;27:177–83.
24. Hiltunen EF, Puopolo AL, Marks GK, et al. The nurse's role in end-of-life treatement discussions: preliminary report from the SUPPORT project. J Cardiovasc Nurs 1995;9:68–77.
25. Reilly CA, Holzemer WL, Henry SB, Slaughter RE, Portillo CJ. A comparison of patient and nurse ratings of human immunodeficiency virus-related signs and symptoms. Nurs Res 1997;46:318–23.
26. Nease RF, Kneeland T, O'Connor GT, et al. Variation in patient utilities for outcomes of the management of chronic stable angina. Implications for clinical practice guidelines. Ischemic Heart Disease Patient Outcomes Research Team. JAMA 1995;273:1185–90.
27. Wennberg JE, Barry MJ, Fowler FJ, Mulley A. Outcomes research, PORTs, and health care reform. [Review]. Ann NY Acad Sci 1993;703:52–62.
28. Fowler FJ, Jr., Barry MJ, Lu-Yao G, Roman A, Wasson J, Wennberg JE. Patient-reported complications and follow-up treatment after radical prostatectomy. The National Medicare Experience: 1988–1990 (updated June 1993). Urology 1993;42:622–9.
29. Ruland CM, White T, Stevens M, Fanciullo G, Khilani SM. Effects of a computerized system to support shared decision making in symptom management of cancer patients: preliminary results. J Am Med Inform Assoc 2003;1–7.
30. Molenaar S, Sprangers MA, Postma-Schuit FC, et al. Feasibility and effects of decision aids. Med Decis Making 2000;20:112–27.
31. O'Connor AM, Rostom A, Fiset V, Tetroe J, et al. Decision aids for patients facing health treatment or screening decisions: systematic review. Br Med J 1999;319:731–4.
32. O'Connor AM, Fiset V, DeGrasse C, et al. Decision aids for patients considering options affecting cancer outcomes: evidence of efficacy and policy implications. J Natl Cancer Inst Monogr 1999;25:67–79.
33. Ruland CM. Decision support for patient preference-based care planning: effects on nursing care and patient outcomes. J Am Med Inform Assoc 1999;6:304–12.
34. Goldstein MK, Clarke AE, Michelson D, Garber AM, Bergen MR, Lenert LA. Developing and testing a multimedia presentation of a health-state description. Med Decis Making 1994;14:336–44.
35. O'Connor AM, Stacey D, Rovner D, et al. Decision aids for people facing health treatment or screening decisions (Cochrane Review). Cochrane Database Syst Rev 2001;3:CD001431.
36. Eddy DM. A manual for assessing health practices and designing practice policies for explicit research. Philadelphia: American College of Pysicians, 1992.
37. Goldstein MK. Applying utitily assessment at the beside. In: Chapman GB, Sonnenberg FA, eds. Decision Making in Health Care, Cambridge, UK: Cambridge University Press, 2000.
38. Ruland CM. Handheld technology to improve patient care: evaluating a support system for preference-based care planning at the bedside. J Am Med Inform Assoc 2002;9:192–201.