



Impact of Cancer-Related Decision Aids

Summary

Overview

Decision aids are mechanisms or interventions that have been developed to improve communication between health professionals and patients, and to help involve patients in making decisions regarding their health care. Decision aids can include brochures, videotapes or interactive computer programs. Recent reviews have suggested that decision aids may be effective in supporting general health care decisions.

Cancer screening or treatment have been found to be particularly prone to difficulties in communication and decisionmaking between health professionals and their patients. There are a number of reasons for these problems, including difficulties in communicating information about poor prognoses and the modest benefits of the treatments used. The objective of this study was to conduct a comprehensive, systematic review of the literature to determine the impact of decision aids on cancer prevention, screening, and treatment decisions.

Reporting the Evidence

A set of questions was initially proposed by the National Cancer Institute's Division of Cancer Control and Population Sciences, and was further refined with input from members of the McMaster University Evidence-based Practice Center (MU-EPC) and the project officer at the Agency for Healthcare Research and Quality (AHRQ), which funds the EPC program.

The Technical Expert Panel (TEP) for this project included individuals who represented providers of health care, experts in study methodology, and researchers. After

consultation with the TEP, the following key questions were selected as the focus of the Evidence Report.

Types of Decision Aids

- What models of decision-making (e.g., informed, shared) underpin decision aids that have been used?
- What clinical contexts (e.g., prevention, screening, and treatment) have been investigated?
- What has been the clinical focus of the decision aids (e.g., type of cancer and extent of disease)?
- What has been the mode of delivery (e.g., print, interactive video)?

Populations Using Decision Aids

- On what populations has the research been conducted?
- Have decision aids been developed for or used by members of special populations (e.g., elderly, ethnic groups, and low level of education)?

Decision Aids and Outcomes

- What outcomes have been evaluated (e.g., increase in knowledge, satisfaction, and behaviors)?
- Are there any key outcomes that are associated with specific characteristics of decision aids?

Effectiveness of Decision Aids

- What is the effectiveness of decision aids?
- What is the effectiveness of decision aids in different clinical contexts?

- What is the effectiveness of different modes of delivery?
- What is the effectiveness of decision aids on special populations?

Future Directions

- What specific direction is needed in future research on cancer-related decision aids?

Methodology

Selection Criteria and Screening Process

The authors regarded as potentially eligible any article 1) that described a study in humans; and 2) that was about the development or evaluation of a cancer-related decision aid. There was no exclusion based on study design or language of publication. Primary studies about prevention, screening, and treatment decisionmaking; that focused on cancer; and that met the definition of a decision aid were included. A decision aid was defined as “*an intervention designed primarily to help patients (or patients and clinicians together) with making cancer-related health care decisions, when options are available for prevention, screening, and treatment. At a minimum, it should target some component of decisionmaking (e.g., information exchange or involvement in the decision process).*”

Studies of benign prostatic hyperplasia, hormone replacement therapy, and smoking cessation were excluded as were studies published in abstract form only.

The research team used a two-stage screening process. In the first step, six raters worked in pairs to screen the titles and abstracts identified by the searches. In the second step, randomly assigned pairs of raters screened full text articles, then three reviewers checked all included studies and categorized them according to the context of the decision and type of study. Discrepancies were resolved by discussion.

Literature Search

Citations of potentially relevant studies were identified through a systematic research of: MEDLINE from 1977 to the end of April 2001; HealthSTAR, CANCELIT, CINAHL, Sociological Abstracts, PsycINFO, from 1977 to August 2000; EMBASE (from 1995 to August 2000); The Cochrane Library (issue 3, 2000); reference lists of included studies; and, the personal files of research team members. The development and refinement of the search strategy followed an iterative process using the MEDLINE database. The refined MEDLINE strategy was modified to meet the specific features of the other electronic databases.

Data Extraction

In consultation with the TEP and project officer, all data extraction forms were developed, pilot-tested, and revised by members of the local research team. Two reviewers completed data extraction independently for all studies. Any disagreements were resolved by consensus. Following consensus on each item, the data forms were scanned into a Microsoft Access database using Teleform software.

Data Synthesis

Descriptive statistics were calculated for all fields of the database. Evidence tables were constructed to describe the most salient features of the included studies according to the review questions. The local research team at the MU-EPC, in consultation with members of the partner organizations and the project officer, evaluated the overall quantity and quality of the data available. A draft of the report was sent to an international Peer Review panel, comprised of researchers in the field of decisionmaking, experts in study methodology, and consumers. This report incorporates many of the suggestions of the Peer Review panel and represents a detailed qualitative synthesis of the existing evidence, emphasizing the directions that future researchers could take to fill knowledge gaps.

Findings

The analysis of the yield of the literature and the general characteristics of the studies showed that:

- A total of 1,056 full text articles were retrieved and screened. After a preliminary screening process, 207 articles met the inclusion criteria. Of the 207 articles, there were 168 unique studies with 39 reported in more than one publication. After the final screening process, 61 studies that focused on either the development or effectiveness of a cancer-related decision aid were included and form the basis of the Evidence Report.
- Sixty-seven percent of studies were published between 1996 and 2001.
- Ninety-seven percent of studies were published in English.
- The setting for 74 percent of studies was North America.
- Overall, 18 studies were randomized controlled trials (RCTs), five were non-randomized controlled trials, and the remaining studies had a mix of designs.
- Overall, the studies had low methodological quality scores.
- Twenty-two studies examined the development process of decision aids. In general, all studies had the same phases: testing of content and construct validity followed

by the assessment of reliability in non-cancer participants. There were three studies of prevention or screening decisions and 19 of treatment decisions. There were 14 studies involving breast cancer patients; two each of prostate, ovarian, and lung cancer patients; and one study each of colon cancer and leukemia patients. Only two developmental studies focussed on special populations (Mexican-American women, and impoverished African-American women).

- The effectiveness of a decision aid was assessed in 39 studies: 16 RCTs, four non-randomized studies, two non-concurrent controlled studies, six pre–post designs, and 11 case series. Various decision aids or a combination of strategies were used: brochures, audiotapes, videotapes, interactive computer programs, educational scripts, decision boards, counseling, and informal decision analysis. Breast (23) and prostate cancer (11) were the most frequent type of cancer included.
- Of the 39 studies that evaluated a decision aid in a clinical context, the ethnicity of participants was reported in 11 studies. In 10 studies, the majority of participants were Caucasian. Only one study evaluated the effect of a decision aid in a special population.
- Across the studies, patients' decisions, knowledge, anxiety, depression, satisfaction, and acceptability of the decision aids were the most frequent outcome measures evaluated.
- Overall, among RCTs, the decision aids appeared to increase knowledge, and patient involvement in decisionmaking. Anxiety and depression scores did not appear to be increased. In patients making prostate cancer screening decisions, significantly fewer men decided to proceed with screening after receiving a decision aid.

Future Research

Our results support the proposal that decision aids are helpful for a number of cancer screening decisions. In these situations, such instruments can increase knowledge, do not increase anxiety, and can influence the decision made. In contrast, there is little data available evaluating aids for decisions related to cancer treatment. Unfortunately, further evidence is still needed before making specific conclusions regarding decision aids in this situation.

The early stage of development of this field and the gaps in our knowledge outlined in this systematic review underline the need for further research. A number of

different areas were identified. Future research efforts should:

- Develop a better understanding of how and when decisionmaking occurs in the real world, who is involved (clinician, patient, or others) and the extent of their involvement. Further work is needed to identify the processes involved and when they occur. Presumably, information transfer is the first step, but what are the stages of deliberation and how do patients and clinicians interact at this stage? How do they ultimately make a decision?
- Determine the key features of quality decisionmaking from patients and clinicians. Such information will have a number of important benefits to help investigators develop instruments to facilitate quality decisionmaking and perhaps, most importantly, to identify, prioritize, and measure outcomes of effectiveness.
- Determine patients' understanding of numerical estimates of risk. Are such numbers meaningful for them? What is the impact of providing risk estimates on real-life decisions?
- Determine whether decision aids are effective for cancer-related treatment decisions. Research in other disease sites besides breast and prostate cancer and for metastatic disease is also necessary. The latter may be particularly challenging in terms of explicit discussion of benefits and risks of proposed treatments.
- Focus on which components of a decision aid are necessary and effective—e.g., besides exchanging information, is counseling helpful? How should it be instituted? Are different types of decision aids more effective than others?
- Investigate whether decisionmaking regarding cancer is really different from decisionmaking in other chronic medical illnesses. In view of the life-threatening nature of this disease, are special approaches necessary here—e.g., psychosocial support techniques, patient support groups, teleconferences, or use of repetition?
- Determine what patient, clinician, or decisionmaking factors influence the effectiveness of decision aids. Are decision aids more or less useful in particular situations, i.e., do decision aids facilitate communication for clinicians who are less likely to spend time talking with their patients? Or, alternatively, do decision aids impede communication in a more interactive clinician-patient relationship? Are there particular groups of patients that benefit from decision aids? Who are they—e.g., patients having difficulty making a decision? Can they be identified a priori?

- Establish whether decision aids are useful for members of special populations, e.g., the elderly, ethnic groups, or people with a low level of education. Should decision aids be modified for these populations and how should this be done?

In addition to focusing on these areas our future efforts should consider:

- Multi-center collaboration to formally set a research agenda. From our review, there appeared to be poor integration of different research efforts in the field. National or international collaboration would permit development of consensus about important basic concepts regarding decisionmaking, what is a decision aid, and important outcomes.
- Development of accepted conceptual framework for decisionmaking, standardized definitions of a decision aid and a core set of outcomes would have important benefits for patients, clinicians, and policy makers. Outcomes should be important to all parties and could include patient and clinician: knowledge, satisfaction, comfort with decisionmaking, involvement in decisionmaking, and resources utilized for decisionmaking, and the treatment chosen.
- With respect to evaluation, larger studies with more rigorous design, more comprehensive reports, and studies with longer-term followup are needed to clearly establish effectiveness and adverse effects (if any) of decision aids, especially for cancer-related treatment decisions. Ideal studies would include evaluation of instruments developed based on sound principles compared to usual practice, with random allocation of intervention. Cluster randomization may be necessary so that the control group does not inadvertently receive the intervention. Appropriate outcomes should be assessed using survey

instruments soon after administration of the intervention and with long followup to determine any latent effects. Studies should have sufficient statistical power to detect important differences and to look at factors predictive of effect. Multi-center collaboration is likely to facilitate this process and may have additional benefits in terms of increasing opportunities for dissemination of research results.

- Other collaborative efforts, such as workshops and the development of practice guidelines by policymakers, clinicians, and patients to improve the dissemination and implementation of decision aids should be instituted.
- More involvement of consumer groups in helping to set the agenda, advocate for funding, facilitate the development of studies, and disseminate results should be considered.

The report concludes that funding should be sought from government and industry sources to support this research.

Availability of Full Report

The full evidence report from which this summary was derived was prepared for the Agency for Healthcare Research and Quality by the McMaster University Evidence-based Practice Center under contract No. 290-97-0017. A limited number of prepublication copies of this report are available free of charge from the AHRQ Publications Clearinghouse by calling 800-358-9295. Requestors should ask for Evidence Report/Technology Assessment No. 46, Impact of Cancer-Related Decision Aids. The final report is expected to be available by Summer 2002 (AHRQ Publication No. 02-E004). At that time, printed copies may be obtained.

Internet users will be able to access the report online through AHRQ's Web site at:

www.ahrq.gov/clinic/epcix.htm



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