DECISION AIDS FOR SHARED DECISION MAKING

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WHAT IS THIS LECTURE ABOUT?

I. DECISION AIDS IN SHARED DECISION MAKING

- Rationale & purposes
- Design elements

In a previous lecture, I talked about decisional conflict and the concept of decision support as a clinical skill.

In this lecture, I'll talk about a particular approach to decision support.

There are 3 main sections to this lecture.

First, I'll outline …

a definition of Shared Decision Making (SDM),

the Rationale & Purposes of Decision Aids (DAs), as they are used in SDM

&

the basic elements of DA design.

NEXT

II. RESEARCH CHALLENGES

- **Fundamental Research**

Woven throughout, I'll also highlight some current fundamental research challenges involved in using DAs in SDM.

FINALLY

III. OUR CURRENT KNOWLEDGE ABOUT DAs in SDM

- Evidence of effectiveness
  - Current media

And finally, I'll also briefly outline our current knowledge about the effectiveness of DAs, given the kinds of media we've worked with so far.

SHARED DECISION MAKING & DECISION AIDS

WHEN THERE IS NO CLEARLY INDICATED "BEST" TREATMENT OPTION

Shared Decision Making

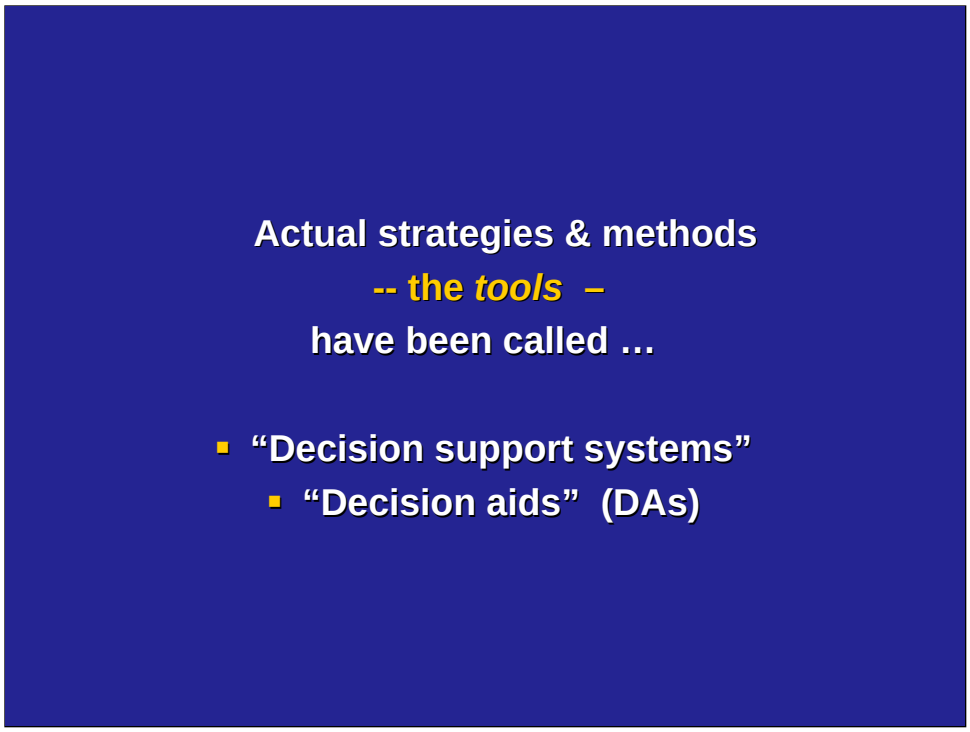
(SDM)

= the *process* of interaction with patients who wish to be involved with their health care providers in making decisions

RATIONALE

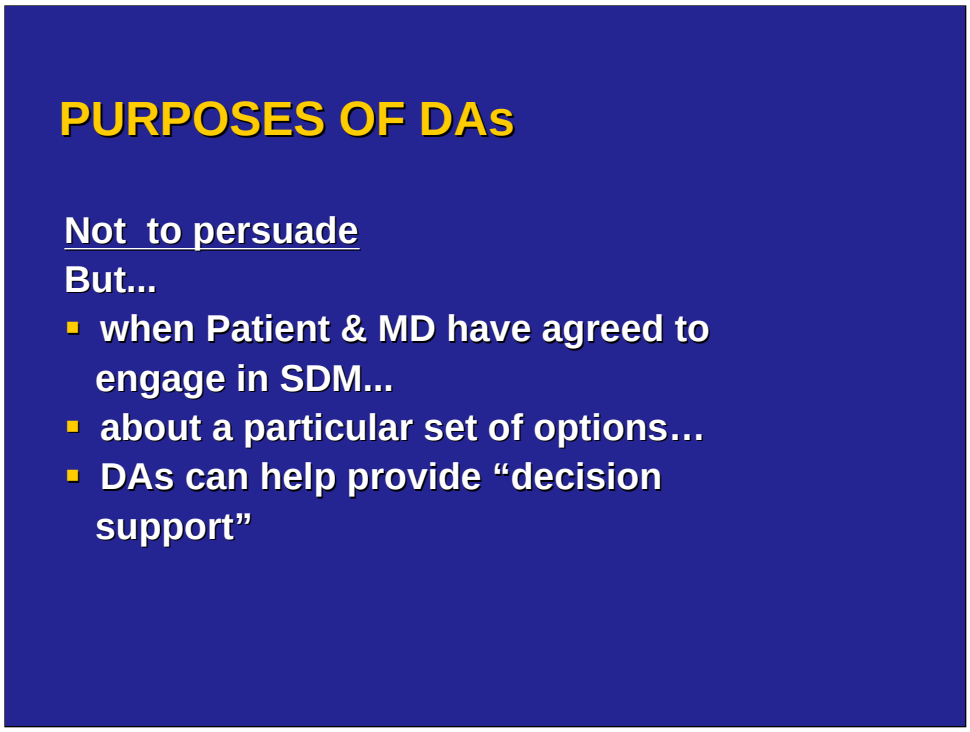
WHEN THERE IS NO CLEARLY INDICATED SINGLE "BEST" TREATMENT OPTION,

the term "Shared Decision Making" (SDM) refers to the process of interaction with patients who wish to be involved with their health care providers in making screening / testing / treatment decisions.



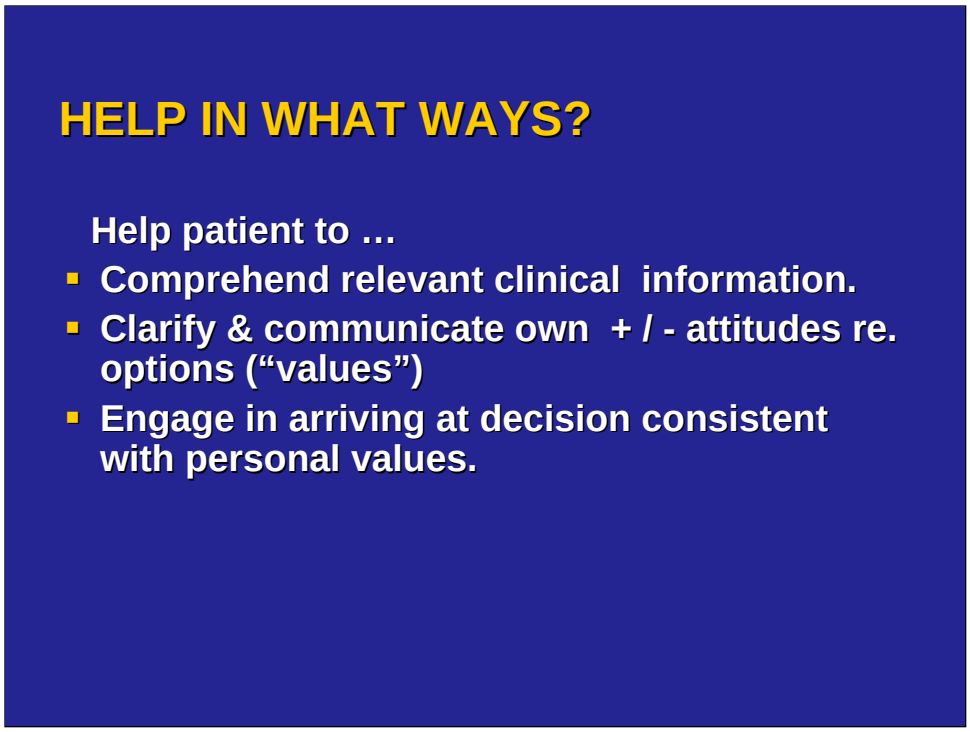
RATIONALE

The actual strategies & methods -- i.e., the tools to help with this -- have been called "Decision Support Systems" or "Decision Aids" (DAs)



It’s important to note that decision aids are not designed to persuade individuals to accept or reject particular screening / testing / treatment option.

Instead, when clinician & patient have agreed to engage in the deliberate process of SDM about a particular set of screening / testing / treatment options, the purpose of DAs is to help with this clinical counselling, or “decision support”, as outlined in the first lecture.



“HELP” IN WHAT WAYS?

Decision aids are designed to…

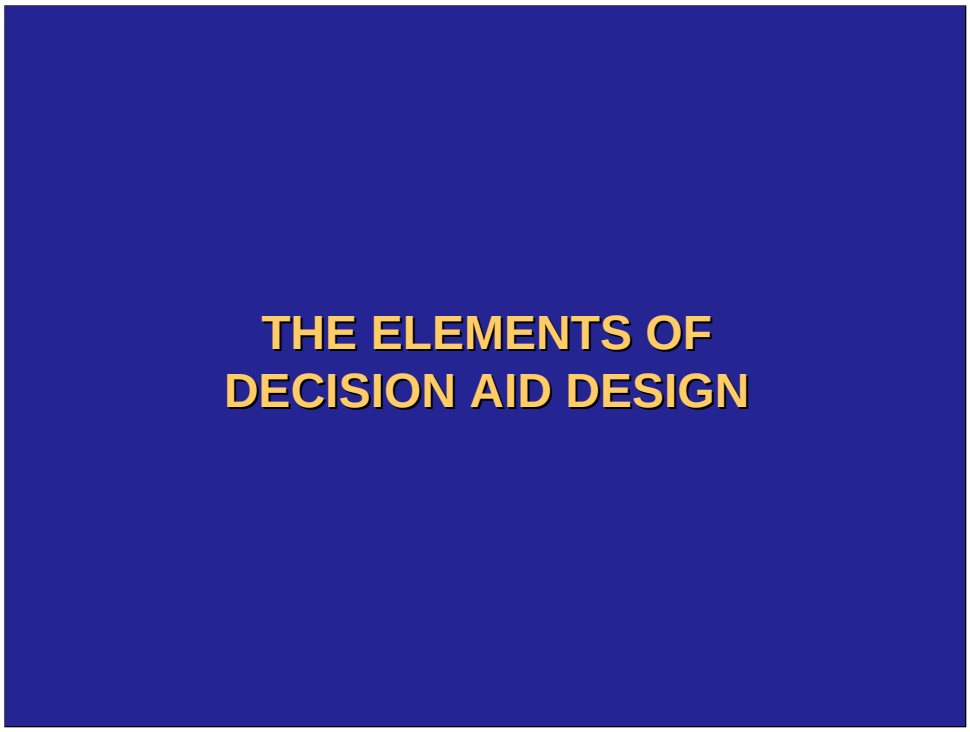
Help the patient to comprehend relevant clinical information.

Help the patient to clarify and communicate his or her own personal values to their clinician.

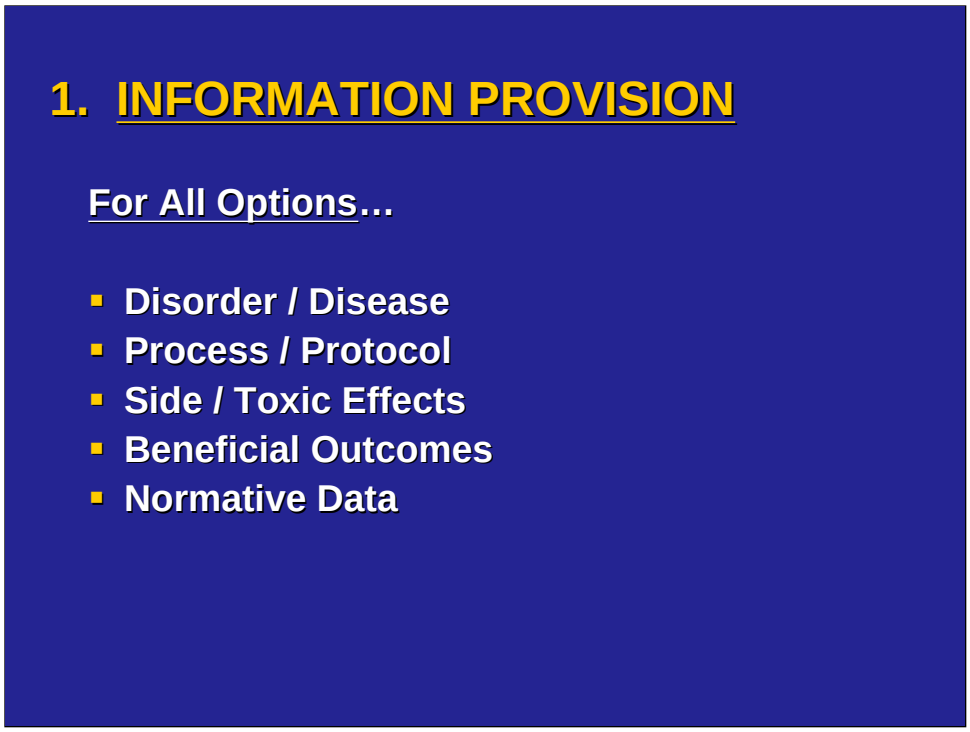
&

Help the patient to engage with clinician in arriving at screening / testing / treatment decision that is consistent with the patient’s personal values.

That is, to help with shared discourse & deliberation about the decision at hand.



So let’s talk about the elements of decision aid design.



ELEMENTS OF A DECISION AID

One element is a synopsis of the EVIDENCE that clinicians have at hand re. each of the options.

This evidence is usually derived from recent, high-quality clinical empirical literature, systematic reviews, and meta-analyses.

It involves describing …

a) The disorder / disease itself and the indications for screening / testing / treatment.

b) The process or protocol for each option – that is, what each option involves (eg. pill-taking; surgery). Doing nothing is also included as an option.

c) Then, for each of these options, the likelihood of the potential side / toxic effects (often referred to as “harms”) that are associated with each option, in both the short- and the long-term AND the likelihood of the benefit to be gained from each of the options.

d) Sometimes, this information will also refer to “normative” data – that is, to variations in choices across patients & MDs, to recommendations in published guidelines, or to the published results of RCTS or decision analyses involving the choice situation.

INFORMATION RESEARCH

- **Teaching about probabilities ?**
- **Interactive components re. changes in risk / benefit ?**
- **Icons, graphs to portray probabilities ?**
- **Absolute, relative risk, NNT probability formats ?**

We need to know much more about how best to organize and present the information provided by these aids.

The research questions about information include the following:

1. Can we foster greater comprehension of the risk/benefit information presented in SDM tools by …

a) Providing learning templates about probabilities (for example, illustrations and application exercises) before the patient actually begins to work with the decision aid ? and

b) Providing tailored interactive components (for example, probability sliding scales, probability tradeoff techniques) that allow the patient to visualize the meaning of changes in probabilities?

2. How can we best help patients to moderate their exaggerated perceptions of risks and benefits? By …

a) Using different ways of portraying probabilities (for example, icons, graphic displays, numeric displays, nested scales) ? and

b) Using different probability formats (for example, absolute risk, relative risk, numbers needed to treat) ?

INFORMATION RESEARCH

- **Characteristic processing pathways ?**
- **Affected by media, sequences, detail, frames , portrayals of probabilities ?**
- **Associated with decisional conflict, comprehension, actual Rx choice, adherence ?**

As patients work through the INFORMATION provided in interactive SDM tools, can their deliberation pathways be tracked?

If so, can sub-groups of patients who use characteristic information processing pathways be identified?

How are these information processing patterns differentially affected by

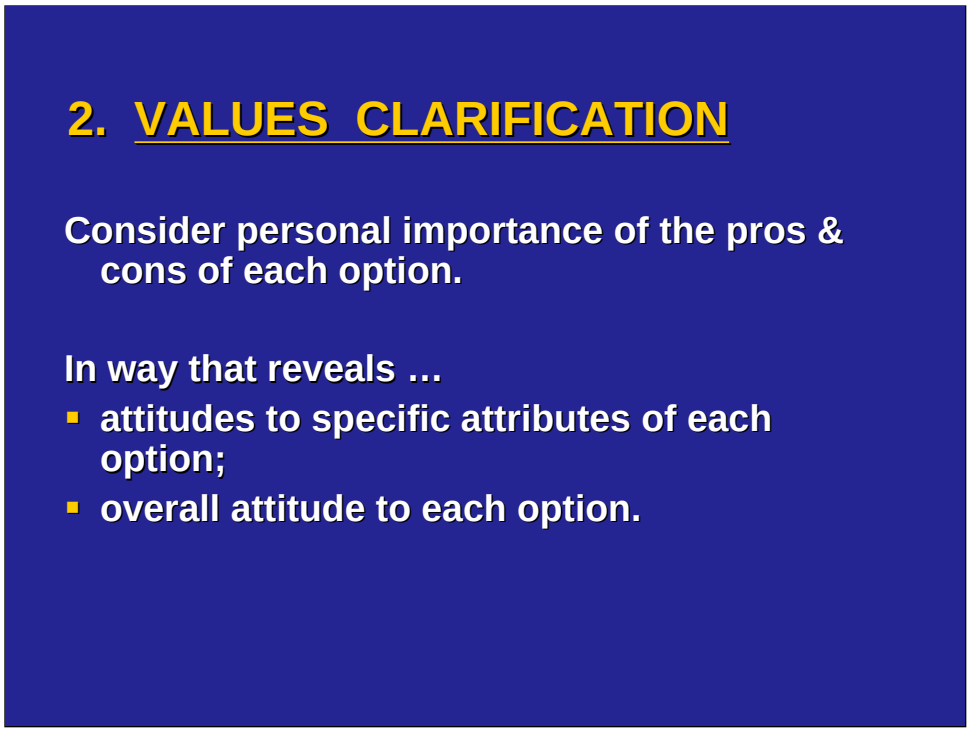
a) using different presentation media like videodisks, decision boards, and audiotape booklets?

Or

b) using different presentation sequences (like risks before benefits, or vice versa),level of detail, and “frames” (for example, 90% chance of surviving for next 5 years = positive frame; 10% chance of death in next 5 years = negative frame”) ?

Are particular information processing patterns associated with different outcomes like…

Differences in level of decisional conflict (a term referring not to negative transactions between the Pt. and the MD, but to an inner state of psychological tension in the patient), differences in level of comprehension, differences in actual treatment choice, and with differences in adherence with therapy?



ELEMENTS OF A DECISION AID

Another element in a DA is the inclusion of ways to help the patient to think about the personal importance of the pros & cons of each option, and about whether or not they are relevant to other aspects of his/her life.

Some DAs do this implicitly, by using “testimonials” in which other patients talk about the choices they made and the reasons for those choices.

Other DAs use some sort of explicit VALUE CLARIFICATION exercise.

An explicit values clarification exercise tries to do this in a salient way that reveals to the patient his or her

a) attitudes towards the specific positive & negative attributes of each option and / or

b) overall relative strength of preference for each option.

APPROACHES TO VALUES CLARIFICATION

a. UTILITY-BASED
- Formal dec. analysis

b. NON-UTILITY-BASED
- Analytic hierarchy process
- Balance technique / “leaning scale”
- Probability / Threshold tradeoff tech.

KINDS OF VALUES CLARIFICATION TASKS

There are a number of ways to carry out explicit value clarification.

Some are UTILITY-BASED, derived from formal decision analysis (S. Pauker, M. Holmes-Rovner, R. Nease, J. Dowie, R. Thomson.)

Others are NON-UTILITY-BASED, using comparative kinds of strategies like the Analytic Hierachy Process (J. Dolan), the Balance Technique & Leaning Scale (A. O’Connor), or the Threshold Technique (H. Llewellyn-Thomas).

VALUES CLARIF. RESEARCH

- Different effects on decisional conflict, on comprehension ?
- Results consistent with each other ?
- Which predicts actual Rx choice and adherence ?
- Triage to different approaches ?
- How do different methods work with different kinds of media ?

The research questions about values clarification include the following:

What are the diff. effects of using utility & non-utility-based values clarification exercises on outcomes like …

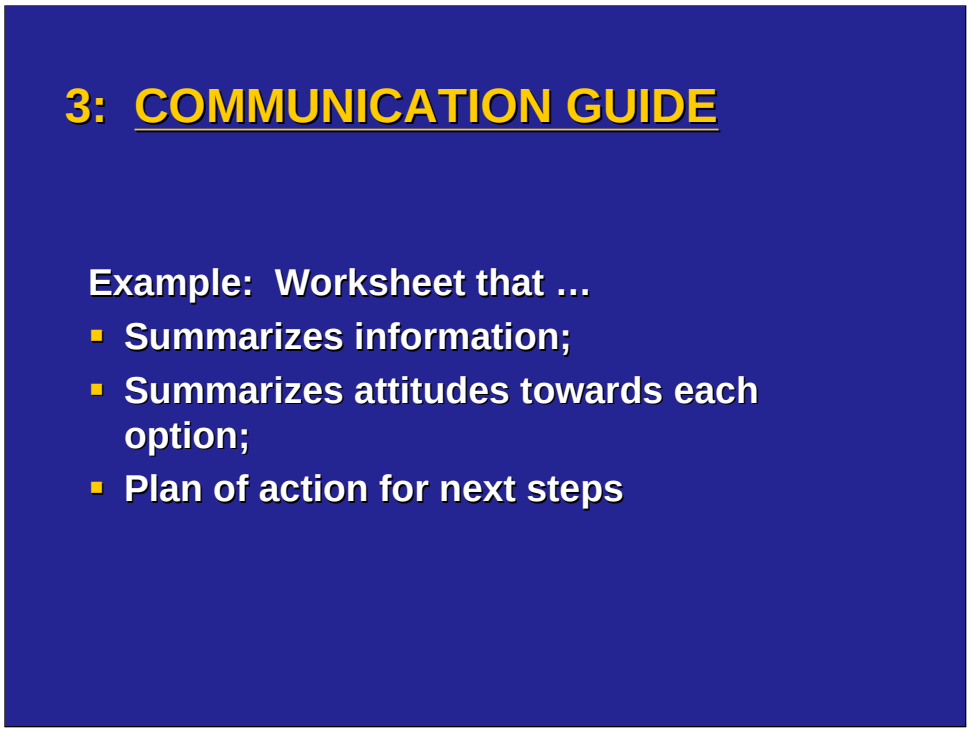
decisional conflict, comprehension, actual treatment choice, and adherence with therapy?

Are the results of non-utility-based ways of eliciting treatment preferences consistent with the preferences implied by classic utility-based assessment techniques?

Which are most predictive of actual treatment choice when patients are involved with SDM?

Should we “triage” diff. kinds of pts. to diff. kinds of techniques?

Do these diff. techniques interact with the kinds of media in which they are incorporated ?



ELEMENTS OF A DECISION AID

A third element in the design of a DA is the inclusion of an explicit way of fostering Patient – Clinician dialogue.

The objective of this element is to help the patient engage in partnership with the clinician in arriving at a decision – and a decision can involve making a choice, or deciding not to decide.

An example of such an element is a worksheet appearing at the end of the DA that …

Summarizes individualized information & invites the patient to indicate where more information may be required by the patient;

Summarizes individual's revealed attitudes towards each option; and

Helps set up a plan of action for next steps.

COMMUNICATION RESEARCH

- **Preferences for participating / not participating in DM?**
- **Involvement of others in family ?**
- **Effects of decision support / "decision coaching" on future decision effectiveness ?**

Communication research in the field of DSM / DAs could focus on:

The determinants, communication, and consequences of patients' preferences for participating or not participating in DM;

The DM involvement of others in family;

The effects of coaching in SDM on patients' communication skills in future health care decision making.

COMMUNICATION RESEARCH

- **Kinds of practitioner skills ?**
- **Roles of non-MD professionals ?**

This area of research could also focus on:

The kinds of practitioner skills in communication that are most relevant to the principles of SDM;

and

Demonstration projects of the potential roles in SDM that could be filled by non-MD professionals.

DO THEY WORK ?

… when incorporated into the kinds of media that have been used to date …

So – Do these things work?

THE EVIDENCE

2 RECENT SYST. REVIEWS:

Cochrane Collaboration Review

O'Connor et al. *BMJ* No 7212 (18 Sept.) 1999

Interpretive Review

Molenaar et al. *Med. Decis. Making* 20(1) 2000

DO DECISION AIDS WORK?

SEE 2 RECENT SYSTEMATIC REVIEWS:

Cochrane Collaboration Review

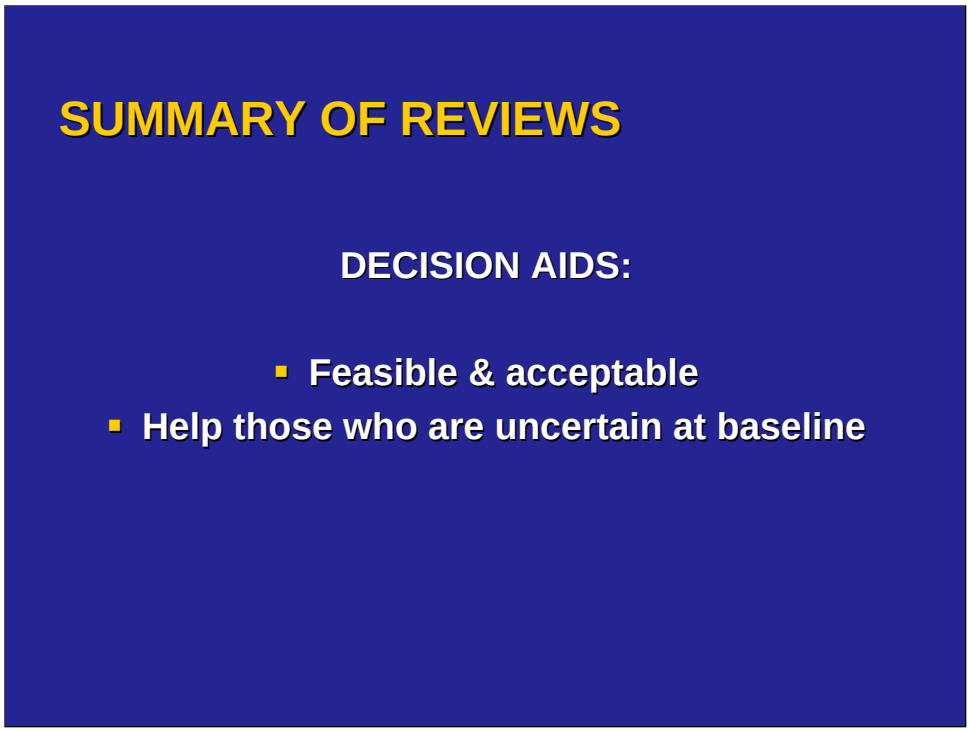
O'Connor et al. BMJ No 7212 (18 Sept.) 1999

(Meta-analysis of 17 RCT that met Cochrane Collaboration review criteria)

Interpretive Review

Molenaar et al. Med. Decis. Making 20(1) 2000

(Systematic review of 30 non-controlled & RCT studies)

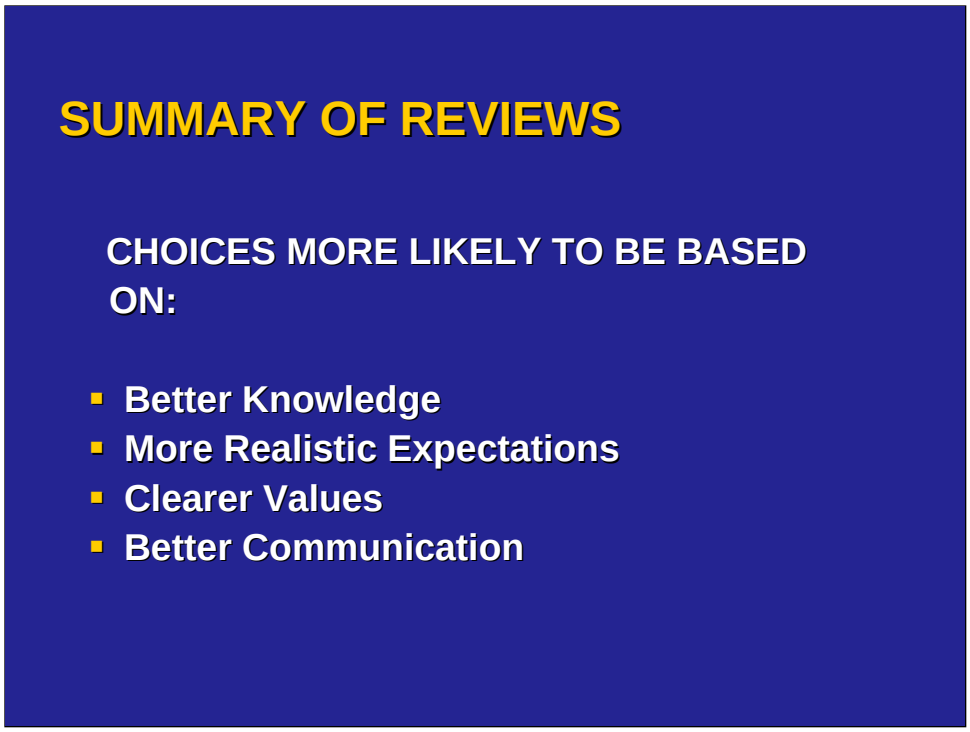


SUMMARY OF REVIEWS

According to the effectiveness evidence, DAs/SDM continue to be a promising field for further development.

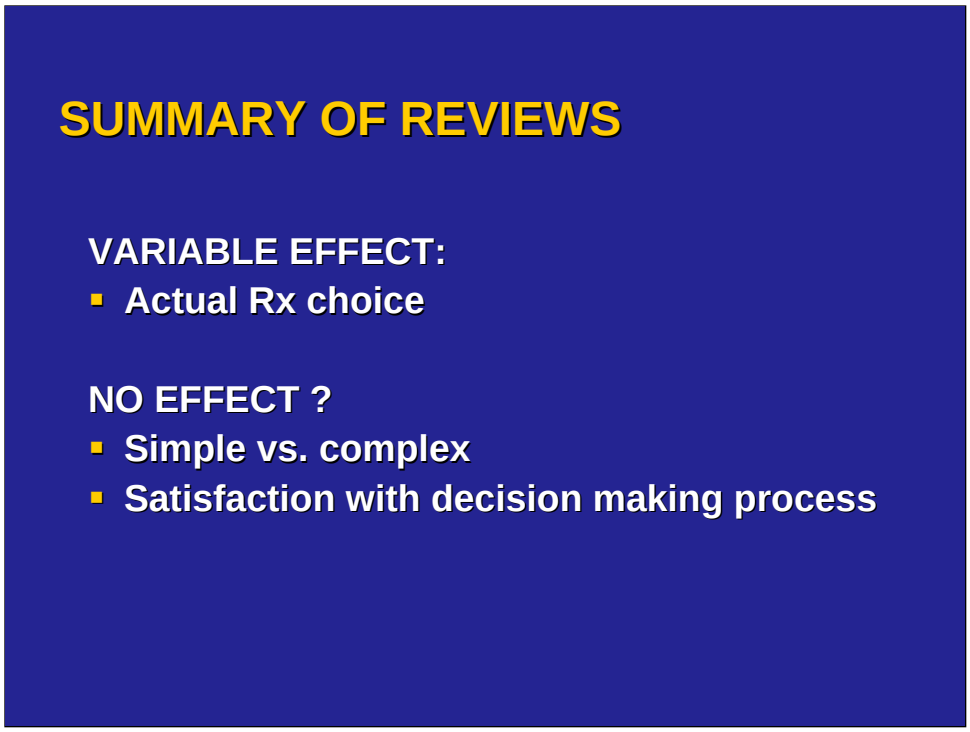
Some patterns are clearly emerging.

Decision support systems are acceptable to patients and can help those who are uncertain at baseline to make a deliberated choice.



SUMMARY OF REVIEWS

There is some evidence that they can increase the likelihood that choices are based on better knowledge, more realistic expectations of outcomes, clearer awareness of own personal “values”, and better communication with clinicians.

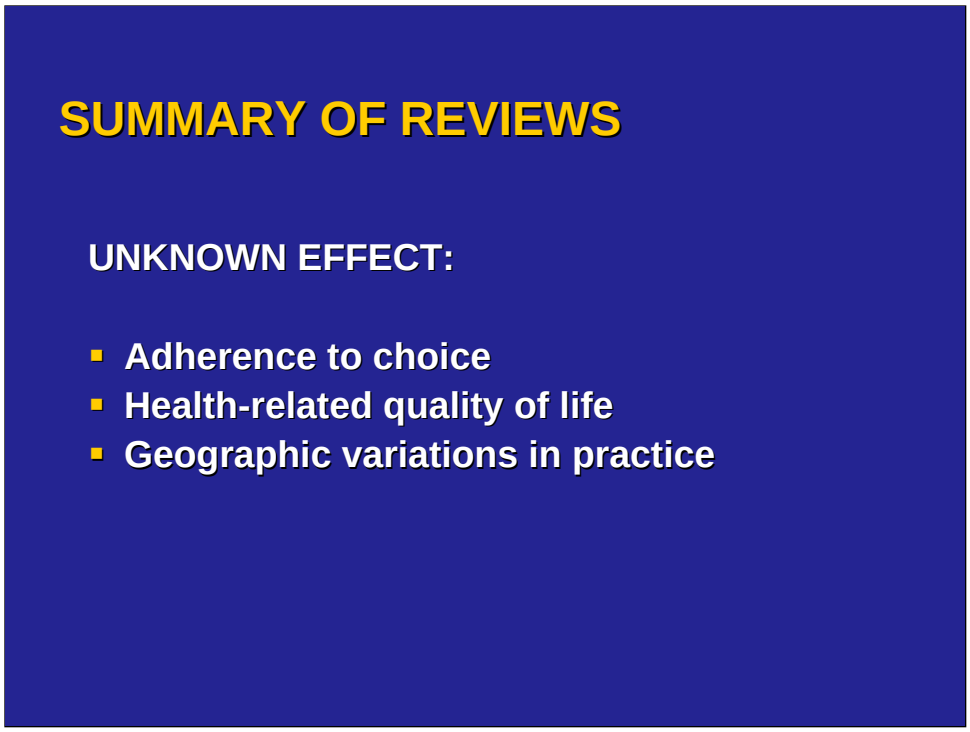


SUMMARY OF REVIEWS

There is also some outcome evidence that DAs – in, for example, surgery for BPH – can affect actual treatment choice.

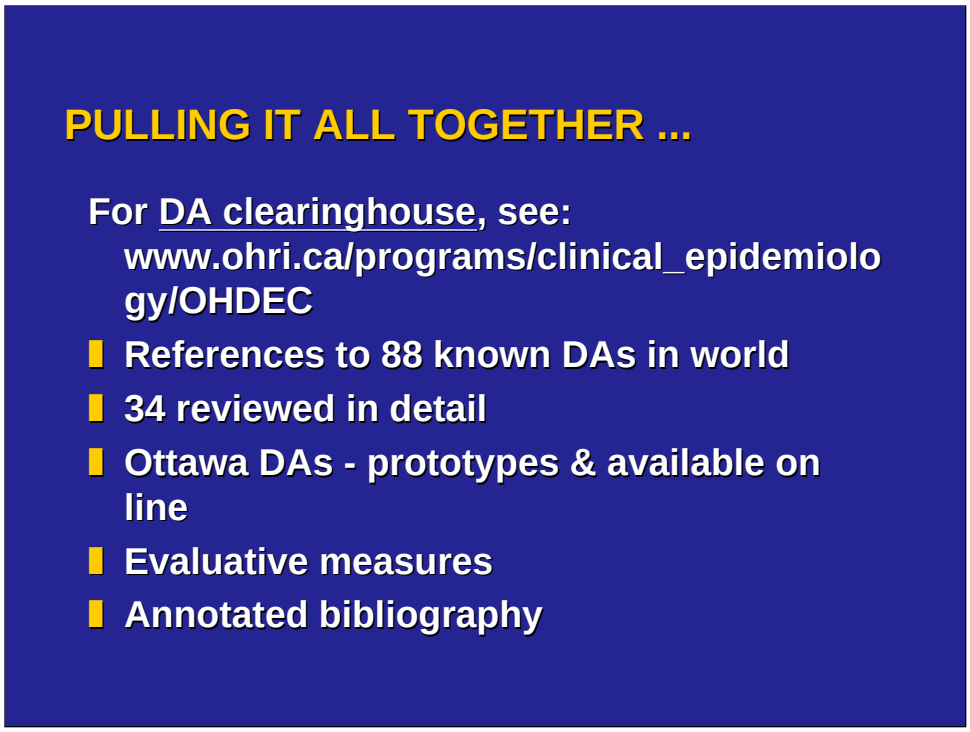
There appear to be minimal differential effects from using relatively complex vs. simpler DAs.

And DAs seem not to have a strong effect on satisfaction with the actual DM process – which may actually be the case, or may be due to insensitivity in our current measures of satisfaction with the DM process.



SUMMARY OF REVIEWS

At the moment, the evaluative studies for DAs have not been comprehensive enough for us to draw any conclusions about their effects on adherence to a selected treatment plan, health-related quality of life, and practice variation – although there is some outcome evidence that DAs – in, for example, surgery for BPH, for angina and for back pain – can modify inordinately variant levels of health service utilization.



One “spin-off” from these reviews has been the creation of a “clearinghouse” of information about decision aids for patients.

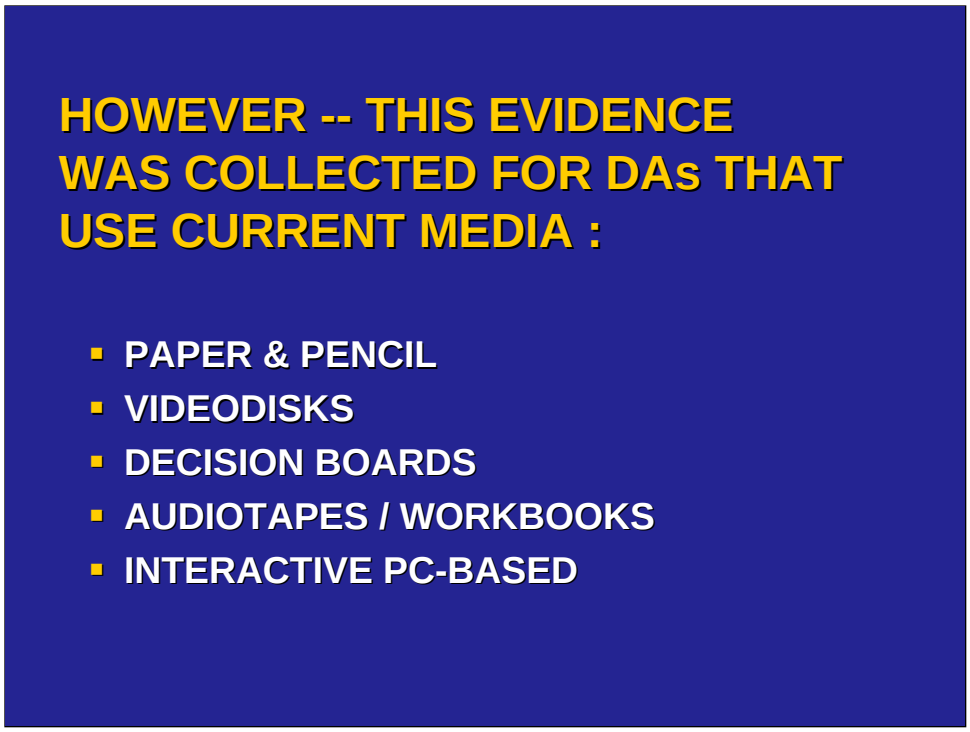
This clearinghouse is at the University of Ottawa, at the website address noted above. The clearinghouse provides

References to 88 known DAs in world -- 34 of these are reviewed in detail

The DAs that have been developed at the University of Ottawa can be viewed – either as prototypes or actually available on line

In addition, this website lists the kinds of evaluative measures that have been used to assess DAs for patients.

Finally, the website provides an extensive annotated bibliography about the design, development, and testing of DAs; this bibliography could be very helpful for beginning & seasoned investigators in health care decision making.



MEDIA FOR DECISION AIDS

OK – Now, with regard to those recent reviews of the effectiveness of DAs, it's important to note that this evidence was collected to DAs that use current media.

The media include – and this is by no means an exhaustive list –

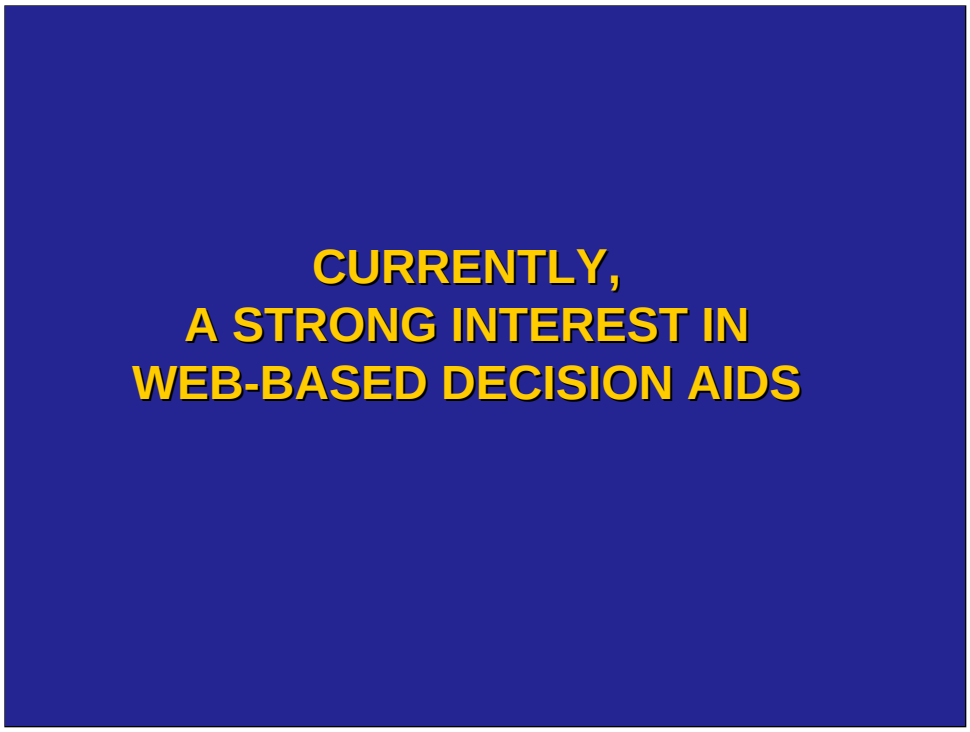
PAPER & PENCIL (multiple sites)

VIDEODISKS & WEB-BASED (Dartmouth)

DECISION BOARDS (McMaster)

AUDIOTAPES / WORKBOOKS (Ottawa; U. of Toronto)

INTERACTIVE PC-BASED (Dartmouth; U. of Ottawa; U. of T.; other N. American; U. of Leiden; U. of Amsterdam, London School of Hygiene & Tropical Medicine)



More recently, there is also a strong interest in web-based DAs.

HOW TO EVALUATE WHETHER THESE NEW TYPES OF DAS "WORK" ?

Some measurement aspects of "decision quality" may be "media-free"...

These new types of web-based DAs will raise new questions about how to go about evaluating their effectiveness.

In some ways, measuring improvement in "decision quality" may be "media-free"...

Media - Free ?

- Patient knowledge
- Understanding uncertainty
- Satisfaction with decision
- Match participation preferences
- Treatment choice concordant with preferences
- Confident about choice, actual adherence to treatment, competence
- Disease-specific & general health status

Some media-free aspects of evaluation include:

Whether a DA increases patients' understanding about what's at stake and the uncertainties involved.

Whether DA use increases their satisfaction with the decision making process.

The extent to which a particular approach to decision support really matches the patient's preferences for participating in DM in the first place.

Whether using a DA leads to choosing a treatment that is most consistent with actual preferences, to greater confidence about the treatment selected, to greater adherence to treatment, and to a greater sense of decisional competence about future health care decision making.

And whether the use of decision aids in SDM is associated with subsequent differences in disease-specific &/or general health status.

UNIQUE EVALUATIVE ISSUES WITH THE WEB …

- Triaging to correct DA ?
- Accessibility, attractiveness, navigability ?
- Interactive capabilities?
  - Tailor to unique risk profiles ?
  - Reveal unique values ?

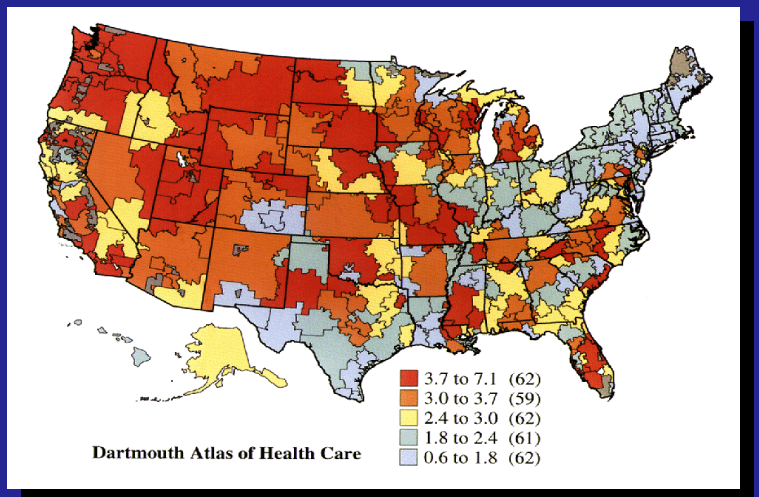
However, some unique evaluative issues for DAs available on the Web include….

Whether or not patients have been able to “triage” themselves to the right DA for them.

If the Web-based DA is accessible, attractive, and can be easily navigated.

Does the Web-based DA provide the best kind of interactivity – for example, to permit tailoring the DA to the individual’s unique risk profile, and to permit working with engaging values clarification exercises?

Practice Variation: Is Geography Destiny?



And finally – What might be the effects of systematically providing evidence about variations in practice as one of the core informational elements in the construction of Web-based DAs – as well as DAs designed for other kinds of media?

This brings us back full circle to one of the original motivations for recognizing the experience of decisional conflict in patients, for considering the idea of decision support as a clinical skill, and for working with formal decision aids as tools for providing that decision support.