

Decision aids for patients facing health treatment or screening decisions: systematic review

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Abstract

Objective To conduct a systematic review of randomised trials of patient decision aids in improving decision making and outcomes.

Design We included randomised trials of interventions providing structured, detailed, and specific information on treatment or screening options and outcomes to aid decision making. Two reviewers independently screened and extracted data on several evaluation criteria. Results were pooled by using weighted mean differences and relative risks.

Results 17 studies met the inclusion criteria. Compared with the controls, decision aids produced higher knowledge scores (weighted mean difference = 19/100, 95% confidence interval 14 to 25); lower decisional conflict scores (weighted mean difference = -0.3/5, -0.4 to -0.1); more active patient participation in decision making (relative risk = 2.27, 95% confidence interval 1.3 to 4); and no differences in anxiety, satisfaction with decisions (weighted mean difference = 0.6/100, -3 to 4), or satisfaction with the decision making process (2/100, -3 to 7). Decision aids had a variable effect on decisions. When complex decision aids were compared with simpler versions, they were better at reducing decisional conflict, improved knowledge marginally, but did not affect satisfaction.

Conclusions Decision aids improve knowledge, reduce decisional conflict, and stimulate patients to be more active in decision making without increasing their anxiety. Decision aids have little effect on satisfaction and a variable effect on decisions. The effects on outcomes of decisions (persistence with choice, quality of life) remain uncertain.

Introduction

Some medical decisions are complex because the evidence on outcomes is uncertain or the options have different risk-benefit profiles that patients value differently.^{1,2} Practice guidelines for these difficult decisions recommend that patients understand the probable outcomes of options; consider the personal value they place on benefits versus risks; and participate with their practitioners in deciding about treatment.³ Decision aids or shared decision making programmes have been developed as adjuncts to counselling from practi-

tioners. Their efficacy has been described in general reports and reviews.⁴⁻⁶ We conducted a systematic overview of the trials of decision aids to determine whether they improved decision making and outcomes for patients facing treatment or screening decisions.

Methods

The search strategy is described in detail elsewhere.⁷ We searched the following electronic databases: Medline (1966-April 98); Embase (1980-November 98); PsycINFO (1979-March 98); CINAHL (1983-February 98); Aidsline (1980-98); CancerLit (1983-April 98); and the Cochrane Controlled Trials Register (1998, Issue 4). Additional studies were searched for in our personal files and the contents lists of *Health Expectations* (1998), *Medical Decision Making* (January-March 1986-January-March 1998), and *Patient Education and Counselling* (January 1995-February 1998).

We included randomised controlled trials comparing decision aids to controls or alternative interventions. Participants were 14 years and over deciding about screening or treatment options. Decision aids were defined as interventions designed to help people make specific and deliberative choices among options (including the status quo) by providing (at the minimum) information on the options and outcomes relevant to a patient's health. The aid may also have included information on the disease or condition; probabilities of outcomes tailored to personal health risk factors; an explicit exercise to clarify values; information on others' opinions; and guidance or coaching in the steps of decision making and communicating with others. We excluded studies involving hypothetical choices; decisions regarding lifestyle changes, entry to a clinical trial, or general advance directives; education programmes not geared to a specific decision; and interventions designed to promote compliance or to elicit informed consent for a recommended option.

Evaluation of outcomes depends on the framework used to develop the decision aids.^{5,8-13} To ascertain whether the decision aids achieved their objectives, we examined a broad range of positive or negative effects on decision making processes and outcomes of decisions. Although the decision aids focused on diverse clinical decisions, many had similar objectives such as improving knowledge, satisfaction, and participation in

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A table giving details of the studies included in the review is available on the BMJ's website

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decision making and reducing decisional conflict. Other outcomes included the choices patients selected, anxiety, and health related quality of life.

Two reviewers (VF, AR, or JT) screened each study and extracted data independently using standardised forms. Inconsistencies were resolved by discussion and consensus. Missing data were obtained from the authors when possible.

The results of the studies were described individually and pooled when similar measures were used. We used RevMan V3.1¹⁴ to estimate a weighted treatment effect (with 95% confidence intervals). We used weighted mean differences for continuous measures and Mantel-Haenszel methods to calculate pooled relative risks for dichotomous outcomes. Heterogeneity was tested with a χ^2 test ($\alpha = 0.10$). If clinically and statistically appropriate, heterogeneous data were analysed with a random effects model.

Results

We identified 10 387 unique citations from the electronic databases and nine studies from personal files and contacts. Of these, 500 citations focused on patient decision making and 17 met our inclusion criteria.¹⁵⁻³¹

The decision aids focused on 11 screening or treatment decisions (see *BMJ*'s website for details). All aids included information on the clinical problem in addition to information on the options and outcomes. Over half included outcome probabilities, examples of others, and guidance in the steps of decision making. A quarter included a values clarification exercise.

Compared with usual care (table 1), decision aids improved average knowledge scores for the options and outcomes by 13 to 25 points out of 100 (weighted mean difference = 19, 95% confidence interval 14 to 25). Compared with simpler interventions, more intensive decision aids improved average knowledge scores by 0.9 to 6 points (weighted mean difference 3, 0.7 to 5).

Decision aids had a positive impact on decisional conflict in three of four studies (table 2) with reductions ranging from 0.2 to 0.4 out of 5 (weighted mean difference = 0.3, 0.1 to 0.4). When the subscales of decisional conflict were examined (data not shown), all studies showed that decision aids were better than usual care or simpler aids in improving patients' perceptions of "feeling informed."^{19 25 26} In two of three studies, decision aids also made patients feel clear about personal values and supported in decision making.^{19 26} The uncertainty subscale improved decisional conflict in the short term but not the long term in one study,²⁸ and in another the perceived effective decision subscale improved.¹⁹

Three studies evaluated satisfaction with the decision making process and satisfaction with the decision using similar interventions, designs, and measures.^{15 16 25} One study found that decision aids improved satisfaction with the decision making process,¹⁵ but the pooled difference was not significant (weighted mean difference = 2, -3 to 7). There were no significant differences between usual care and decision aids in satisfaction with the decision in either the individual trials or in the pooled studies (weighted mean difference = 0.6, -3 to 4). Two other studies that used different measures also found no significant differences in satisfaction with the decision.^{24 28}

Fourteen studies assessed the effect of decision aids on the decision made by the participants (table 3). In trials examining decisions about major surgery, decision aids reduced the preference for the more intensive treatment by 21-42% (relative risk = 0.74, 95% confidence interval 0.6 to 0.9). In contrast, decision aids did not influence preferences for circumcision of newborn babies (0.96, 0.85 to 1.07).

Decision aids significantly reduced preferences for prostate specific antigen testing (by 21-48%) in two studies but had no effect in another. There was significant heterogeneity when results were pooled, and the relative risk with a random effects model was not significant (0.83, 0.6 to 1.3). Preferences for screening for breast cancer genes and prenatal testing were not affected by decision aids in individual or pooled studies (1.08, 0.95 to 1.22).

Decision aids increased preferences for hepatitis B vaccine by 76% but did not affect decisions about dental surgery. Decisions regarding hormone therapy were not affected when more intensive methods were compared with simpler methods to aid decisions.

In three studies decision aids showed a consistent trend in increasing the proportion of participants assuming a more active role in decision making

Table 1 Effect of decision aids on patient's knowledge of options and outcomes

Decision	Decision aid		Comparison group		Weight	Mean difference (95% CI)
	No of patients	Mean (SD) knowledge score	No of patients	Mean (SD) knowledge score		
Compared with usual care						
Benign prostate disease ¹⁵	104	75 (45)	123	54 (45)	14.1	21 (9 to 33)
Ischaemic heart disease ²⁵	86	75 (17)	94	62 (17)	29.4	13 (8 to 18)
Ischaemic heart disease ¹⁶	61	83 (16)	48	58 (16)	26.4	25 (19 to 31)
BRCA1 gene test ²²	122	69 (19)	164	49 (21.7)	30.1	20 (15 to 25)
Total (random effects $\chi^2=9.6$ (df =3), Z=6.85)	373		429		100	19 (14 to 25)
Compared with less intensive decision aid						
Hormone therapy ²⁸	83	87 (11)	87	84 (12)	47.4	3 (-0.4 to 6)
Hormone therapy ²⁶	81	75 (20)	84	71 (21)	14.3	4 (-2 to 10)
Prenatal screen ²⁴	67	88 (15)	88	87 (16)	24.7	0.9 (-4 to 6)
Mastectomy ²⁹	30	83 (12)	30	76 (14)	13.5	6 (-0.3 to 13)
Total (fixed effects $\chi^2=1.8$ (df =3), Z=2.54)	261		289		100	3 (0.7 to 5)

Knowledge tests regarding options and outcomes were specific to the decision and were scored from 0 (0% items correct) to 100 (100% items correct).

Table 2 Effect of decision aids on decisional conflict

Decision	Decision aid		Comparison group		Weight	Mean difference (95% CI)
	No of patients	Mean (SD) conflict score	No of patients	Mean (SD) conflict score		
Compared with usual care						
Prostate specific antigen test ¹⁹	50	1.8 (0.5)	50	2.2 (0.7)	27.5	-0.4 (-0.7 to -0.2)
Ischaemic heart disease ²⁵	86	2.1 (1.5)	94	2.1 (1.5)	8.1	0.0 (-0.4 to 0.4)
Compared with less intensive decision aid						
Hormone therapy ²⁸	83	2.6 (1.0)	89	3.0 (1.0)	17.8	-0.4 (-0.7 to -0.1)
Hormone therapy ²⁶	81	2.1 (0.6)	84	2.3 (0.6)	46.6	-0.2 (-0.4 to -0.02)
Total (fixed effects $\chi^2=3.89$ (df =3), Z=4.3)	300		317		100	-0.3 (-0.4 to -0.1)

Decisional conflict ranges theoretically from 1 (strong agreement that one is certain, informed, clear about values, and supported in decision making) and 5 (strong disagreement). Scores above 2.5 are associated with decision delay and those below 2 are associated with decision implementation. A negative mean difference means the decision aid had a positive benefit.

compared with usual case controls (pooled relative risk = 2.27, 1.3 to 4).^{18 19 25}

We were unable to combine the results of some studies because of lack of information on standard deviations. One study found that decision aids significantly reduced the decline in quality of life after treatments for benign prostatic hypertrophy,¹⁵ but a study focusing on treatments for ischaemic heart disease showed no difference.¹⁶ Four studies showed that the use of decision aids did not affect patients' anxiety.^{18 19 24 30} One study found that patients receiving a decision aid with detailed outcome descriptions and probabilities had more realistic expectations (accurate perceptions of the probabilities of outcomes) than those who did not have this information included.²⁶

Discussion

Despite the variability in decisions, interventions, and measurement, the trials were consistent in showing that decision aids do a better job than usual care in improving patients' knowledge about options, reducing their decisional conflict, and stimulating patients to take a more active role in decision making without increasing their anxiety. Decision aids had a variable effect on decisions and virtually no effect on satisfaction. The effects on the outcomes of decisions (such as quality of life) are still uncertain. When compared with simpler versions, more intensive decision aids reduced decisional conflict, improved knowledge marginally, and had no different effect on satisfaction.

Knowledge, comfort, and empowerment

The largest and most consistent benefit of decision aids over usual care is better knowledge of options and outcomes. The 19% improvement in scores is clinically important because the scores of people in the usual care group were inadequate for informed decision making and they often made different decisions. These results suggest that doctors' usual methods may not be good enough for informing patients about these complex, value laden decisions. Patients need to comprehend the options and outcomes in order to consider and communicate the personal value they place on the benefits versus the harms.

Decision aids help patients feel more comfortable with their choices, as shown by the reduced decisional conflict scores. Patients uniformly feel more informed about options, and in some cases (notably primary care settings) feel clearer regarding personal values and supported in decision making. The improvement is one to two thirds of a standard deviation. Cross sectional studies suggest that this shift places more patients in the zone where they are more likely to follow through their decisions. However, the effect of reduced decisional conflict on persistence with choices needs to be established prospectively.

Decision aids increased active participation in decision making. The relative and absolute size of the effect was much greater in the Davison studies,^{18 19} possibly because coaching was part of the interventions.

Altering choices

The variable effect of decision aids on patients' decisions may be due to several reasons. Firstly, most

Table 3 Effect of decision aids on patients' decisions

Decision	Decision aid		Comparison intervention		Weight	Relative risk (95% CI)
	No of patients	% choosing option	No of patients	% choosing option		
Major surgery						
Coronary revascularisation ¹⁶	61	41	48	58	26.4	0.7 (0.5 to 1.0)
Coronary revascularisation ²⁵	86	59	94	76	57.2	0.79 (0.6 to 1.0)
Prostatectomy ¹⁵	104	5	123	8	6.2	0.74 (0.3 to 2)
Mastectomy ²⁹	30	24	30	42	10.1	0.58 (0.3 to 1.0)
Total (fixed effects $\chi^2=0.73$ (df=3), $Z=3.18$)	281		295		100	0.74 (0.6 to 0.9)
Circumcision of newborn boys						
Maisels et al ²³	23	91.3	28	96.4	67.3	0.95 (0.8 to 1.1)
Herrera et al ²¹	56	84	47	87	32.7	1.07 (0.9 to 1.3)
Total ($\chi^2=0.02$ (df=1), $Z=0.76$)	79		75			0.96 (0.85 to 1.07)
Testing for prostate specific antigen						
Davison and Degner ¹⁹	50	48	50	38	31.1	1.26 (0.8 to 2)
Flood et al ²⁰	103	11.7	93	22.6	21.8	0.52 (0.3 to 1.0)
Wolf et al ³¹	103	60.2	102	76.5	47.2	0.79 (0.6 to 0.9)
Total (random effects $\chi^2=5.56$ (df=2), $Z=0.91$)	256		245		100	0.83 (0.6 to 1.3)
Other screening						
BRCA1 gene test ²²	122	69.7	164	65.2	38	1.07 (0.9 to 1.3)
Amniocentesis ³⁰	441	37	431	34.1	62	1.08 (0.9 to 1.3)
Total (fixed effects $\chi^2=0.02$ (df=1), $Z=1.15$)	563		595		100	1.08 (0.95 to 1.22)
Other						
Hepatitis B vaccine ¹⁷	753	23.4	263	13.3		1.76 (1.3 to 2.5)
Dental surgery ²⁷	37	85	37	70.3		1.19 (0.9 to 1.5)
Hormone therapy ^{26*}	81	13.6	84	15.5		0.88 (0.4 to 1.8)

*Comparison between more intensive and less intensive decision aids.

studies were underpowered to detect important differences. Secondly, some of the 11 options may have been underused at baseline and others overused. This would influence the direction of effect once patients become informed and involved in decision making. Thirdly, patients may react differently to the outcomes being considered in the different decisions. Some decisions may be driven predominantly by the probabilities of outcomes and others by the values for outcomes. For example, the aids seem to have a small effect on decisions about major surgical procedures. This may be because patients have inflated perceptions of the probability of benefit and do not understand the probabilities of risks and uncertainties in evidence of effectiveness. When given better knowledge of the outcomes and their associated probabilities, fewer patients may decide that the benefits outweigh the risks. In contrast, decision aids had little effect on circumcisions. This decision may be driven more by values and norms than by perceived probabilities of medical outcomes, as is suggested by the high rates of use in both arms of the trials.

Satisfaction

The studies showed no effect on satisfaction with decision making. This may be because it is difficult to show improvements in satisfaction when control ratings are already quite high and when choices are inherently difficult because of competing benefits and risks. Furthermore, once the decision is made, people may find it more psychologically comforting to say that they

What is already known on this topic

Patient decision aids or shared decision making programmes aim to help patients come to informed decisions

Studies of their effectiveness have often been small and have focused on a wide range of medical conditions

What this study adds

Decision aids are better than usual care in improving patients' knowledge, comfort, and participation in decision making without increasing anxiety

They have little effect on satisfaction and variable effect on patients' decisions

Compared with simpler versions, more detailed aids improve patients' comfort with decision making and marginally improve knowledge

are satisfied with it than to entertain doubts about what they chose.³²

Further research

The small differences between simpler and more complex versions of decision aids indicate a need to establish the essential ingredients in decision aids and to identify the patients who are most likely to benefit from more complex versions.

There are several gaps in research. Few studies examined the effects on persistence with choices or health outcomes. We also know little about doctors' views about decision aids, the effect on patient-doctor interactions, and cost effectiveness. More trials are needed to gain a better understanding of what types of decision support work with which types of patients. Baseline predisposition toward choices, preference for participation in decision making, age, sex, ethnicity, and education may all have a bearing on the effectiveness of decision aids. Future reviews would be aided if investigators used standard search terms (such as "shared decision making") and gave structured reports of the composition of decision aids and comparison interventions. Moreover, people who develop and use decision aids need to reach a consensus on a minimum set of criteria for evaluating their effects.

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