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Review

Executive summary

Informed decision making: an annotated bibliography and systematic review

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Health Technology Assessment
NHS R&D HTA Programme

Executive summary

Background

Everyone makes decisions about their health, and many healthcare interventions aim to encourage this. An informed decision is one where a reasoned choice is made by a reasonable individual using relevant information about the advantages and disadvantages of all the possible courses of action, in accord with the individual's beliefs.

Objectives

- To provide an unbiased bibliography of controlled studies evaluating interventions that may affect informed patient decision making.
- To classify studies by research design, decision-making theory, type of intervention and health setting.
- To describe the measures of informed patient decision making and other outcomes reported.
- To identify under-reported areas and direct future research.

Methods

Data sources

The electronic databases MEDLINE, BIDS (social science), and PsycLIT were searched for 1991–96. The journals *Medical Decision Making, Patient Education and Counseling,* and *Preventive Medicine* were handsearched for 1986–96.

Inclusion criteria

Studies were included if they reported the results of a controlled study of any intervention using real patients making a health decision. Specifically, randomised controlled trials (RCTs), non-randomised concurrent studies, historical studies, and same subject 'before and after' studies were included. Health decisions were defined to include any reported health behaviour change as well as explicit decisions. Interventions were defined broadly to include any that could reasonably be expected to affect informed decision making, such as changes in information provision, cost, or service provision. Patients were defined as any individual making a decision about health care. Experimental studies on healthy student volunteers, studies of health professionals making decisions about another individual's care, and articles not published in English were excluded.

Data extraction

This was performed using coding forms by a member of the project group and checked by a team member, with disagreements resolved by discussion. Abstracts were assessed and the articles retrieved if the review criteria were met. Final inclusion decisions were made by the first author of this report and verified by another member of the project group.

Articles were classified by study quality according to the hierarchy of evidence, underlying theory, the domain of health care, and the health decision. The comparison groups, other factors associated with the decision-making process, reported measures, and a summary of the findings were recorded.

Data synthesis

Descriptive summaries and qualitative analysis were performed. The health domains and decisions were too diverse for meaningful quantitative meta-analysis.

Results

Following handsearching and abstract evaluation 825 articles were distributed to the project group members and 547 were subsequently included within the bibliography.

Study quality

There were 336 RCTs, 114 non-randomised concurrent studies, 34 historical, and 63 'before and after' same-sample studies. Only 51 of the RCTs were classified as having a low risk of bias. A total of 267 studies claimed to have approached a representative sample of participants, but only 243 reported the number invited to take part. Few studies provided adequate descriptions of the intervention materials.

Theoretical context

A total of 206 studies referred to an underlying theory. Of these, 101 referred to theories explain-

ing decision making such as expected utility theory, prospect theory or social cognition models.

Health domain and the decision

A total of 251 studies were in general medicine, 114 cancer, 108 genitourinary medicine, 61 primary care, 31 paediatrics; 15 mental health, 10 dentistry, 11 surgery, seven genetics, and 31 obstetrics and gynaecology, and midwifery. The decision was classified as a life-style change in 357 studies, a screening decision in 114, a treatment decision in 107, a decision to participate in the consultation in 51, and as another type of decision in 26 studies.

Interventions

A total of 301 interventions were of information provision itself, 273 varied the delivery of information, 208 provided patient feedback, 94 manipulated information in some other way, 55 prompted active patient participation, and 89 of another intervention altogether.

Decision-making factors

A total of 512 studies assessed actual rather than hypothetical decisions, 476 involved decisions affecting the participant rather than a third party and in 525 studies the decision was made without time pressure. Only 26 studies explicitly made patients aware of their involvement in the decision-making process.

Measures assessed

Demographic details were recorded in 515 studies, knowledge in 181, decision-making measures in 169, measures of affect in 69, satisfaction in 60, self-efficacy in 75, personality trait in 20 and other variables in 111 studies.

Summary result

Only five studies were **theory** driven, assessed measures associated with **informed** decision making, **and** used a low risk of bias design. Although of disparate design these five studies suggest that information and education are relatively ineffective ways of facilitating informed decision making, compared with the context and social influences. Studies reporting manipulation of information, and provision of feedback, were the most likely to report an effect.

Conclusions

There is a paucity of well-designed, theoretically driven and adequately operationalised research assessing informed patient decision making. Given the small number of high-quality studies and the relatively slow increase in research in this area there is no need for the NHS to revisit this topic as a review for 5 years. Resources should be concentrated on better primary research.

Recommendations for research

Future primary research should work under an explicit theory of decision making, record process measures to permit evaluation of whether the decision was informed, and if evaluating experimental interventions use randomised trials with a low risk of bias.

A booklet describing the main decision-making theories, and an inventory of suitable outcome measures could be developed to help clinical researchers design appropriate studies.

Complementary systematic reviews would be valuable.

- The effect of interventions on patient preferences. (At least 50 trials were excluded from the present bibliography because no behaviour change was recorded.)
- Observational studies of real patient decision making. Studies using tape-recorded consultations, verbal thinking aloud protocols, and other written or computer-based process-tracing methods will predominate.
- Assessing the effect of additional information, manipulation of information, provision of feedback, and group delivery of information on informed patient decision making.

Primary research is a priority in areas such as genetics, prenatal diagnosis and where decisions are often made by proxy, such as paediatrics and mental health.

Primary research is required to evaluate the following types of interventions:

- decision aids, such as graphical and computer-based devices
- information manipulation, such as decision analysis, prompts, and feedback.

Publication

Bekker H, Thornton JG, Airey CM, Connelly JB, Hewison J, Robinson MB, *et al.* Informed decision making: an annotated bibliography and systematic review. *Health Technol Assess* 1999;**3**(1).

NHS R&D HTA Programme

The overall aim of the NHS R&D Health Technology Assessment (HTA) programme is to ensure that high-quality research information on the costs, effectiveness and broader impact of health technologies is produced in the most efficient way for those who use, manage and work in the NHS. Research is undertaken in those areas where the evidence will lead to the greatest benefits to patients, either through improved patient outcomes or the most efficient use of NHS resources.

The Standing Group on Health Technology advises on national priorities for health technology assessment. Six advisory panels assist the Standing Group in identifying and prioritising projects. These priorities are then considered by the HTA Commissioning Board supported by the National Coordinating Centre for HTA (NCCHTA).

This report is one of a series covering acute care, diagnostics and imaging, methodology, pharmaceuticals, population screening, and primary and community care. It was identified as a priority by the Screening Panel and funded as project number 94/27/03.

The views expressed in this publication are those of the authors and not necessarily those of the Standing Group, the Commissioning Board, the Panel members or the Department of Health. The editors wish to emphasise that funding and publication of this research by the NHS should not be taken as implicit support for the recommendations for policy contained herein. In particular, policy options in the area of screening will be considered by the National Screening Committee. This Committee, chaired by the Chief Medical Officer, will take into account the views expressed here, further available evidence and other relevant considerations.

Reviews in *Health Technology Assessment* are termed 'systematic' when the account of the search, appraisal and synthesis methods (to minimise biases and random errors) would, in theory, permit the replication of the review by others.

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The editors have tried to ensure the accuracy of this report but cannot accept responsibility for any errors or omissions. They would like to thank the referees for their constructive comments on the draft document.

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