Interventions to improve risk communication in clinical genetics: systematic review


CRD summary
The review concluded that supportive or emotional elements of counselling provided more benefits to users than the informational or educational elements for communication models and decisional aids for risk communication in clinical genetics. Due to heterogeneity in outcome evaluation and study design, and uncertain study quality, the authors’ conclusion that the results should be interpreted with caution seems appropriate.

Authors' objectives
To evaluate the effectiveness of interventions to improve risk communication in clinical genetics.

Searching
MEDLINE, EMBASE, CINAHL, PsycINFO, NRR and The Cochrane Library were searched from 1985 to January 2006; search terms were reported. Citation indices were searched. Key journals and authors in the field and bibliographies of retrieved articles were handsearched.

Study selection
Experimental evaluations of interventions to improve risk communication in clinical genetics including randomised controlled trials (RCTs) and other designs where separate effects or outcomes attributable to the risk communication intervention could be identified were eligible for inclusion. Studies were excluded if the study design or details did not allow assessment of the risk communication effects. Participants could be people who attended consultations for themselves/their children or people who used supporting materials for clinical genetics consultations (decision aids). The authors distinguished between risk communication and genetic counselling and summarised risk communication as: conveying probabilistic information intended to support decision making; education that included the mechanism of disease, personal risk factors, inheritance of susceptibility, benefits and limitations of tests, risks of testing, limitations of prevention or surveillance; and counselling that included experience of disease, test result communication and impact, implications of not being tested and coping resources.

Most of the included studies were of risk communication for breast cancer or breast and ovarian cancer; smaller numbers considered other hereditary diseases (Down’s syndrome, cystic fibrosis, haemochromatosis, Alzheimer's disease, breast and colorectal cancer and hereditary cancer). Most studies were in women only. Relatively few studies were in pregnant women; one of these included male partners. Ages ranged from 18 to 75 years and mean age, where reported, ranged from 30 to 56.5 years. Most studies provided details of ethnicity and were predominately in Caucasians. All studies were conducted in developed countries.

Two independent reviewers performed the selection. Disagreements were resolved by reference to a third reviewer.

Assessment of study quality
Methodological quality was assessed by two reviewers independently; one reviewer performed all the assessment and two reviewers shared the duplicate methodology assessment. Criteria used were: concealment of allocation in RCTs; blinding of participants or researchers where appropriate; and validity of outcome measures.

Data extraction
Data was extracted by two reviewers; one reviewer extracted all data and two other reviewers shared the duplicate extraction. Data was collated into a table. Statistical significance was reported for some results and odds ratios (ORs) for others.

Methods of synthesis
A narrative synthesis was performed that took greater account of the higher levels of evidence and separated results for counselling and use of decision aids.
Results of the review
Twenty-eight studies were identified (n≥8,708): 17 RCTs (n≥5,349, range 53 to 2,165, numbers not reported for three RCTs); four quasi-experimental studies (n=2,729, range 27 to 2,000); two cohort studies (n=203 for one study); one before-after study (n=60); one case series (in development); two observational studies (n=295 and n=6); and one free text comments on questionnaire study (n=66). Only 25 studies evaluated their interventions. One observational study noted limited adherence to the full schedule proposed and one RCT had limited recruitment.

Counselling (16 studies that included 11 RCTs; two studies were evaluated):

The interventions were found to improve cognitive outcomes such as: perceived risk (four RCTs; significance only reported for a before-after study, p<0.01); knowledge (one RCT, p<0.001); comprehension/understanding (not significant for one RCT and significant for another RCT, OR 3.5, 95% CI 1.3 to 9.5, and a quasi-experimental study); and information seeking (one RCT, p<0.001).

At least five RCTs demonstrated that providing information contributed to the success of the interventions in improving cognitive outcomes. The authors believed that counselling and support were the more important elements of successful interventions.

Five RCTs evaluated affective and health outcomes such as anxiety, cancer-related worry and depression. All reported reductions (significance only reported for one RCT, where psychosocial counselling was more effective than genetic counselling). There was some positive evidence for the benefit of cointerventions and framing manipulations.

Decision aids (12 studies):

Decision aids were static video/leaflet-based (seven studies that included three RCTs) or interactive digital web/CD-ROM products (five studies that included three RCTs).

The interventions improved cognitive outcomes such as: perceived risk (three of six studies that included five RCTs; significance only reported for one RCT, p<0.001); knowledge (significantly in five of six studies that included four RCTs, range p<0.001 to p<0.05); one RCT found increased knowledge for feedback to a genetic counsellor versus a CD-ROM (OR 0.63, 95% CI 0.45 to 0.80); and understanding (one RCT, p<0.01).

Seven studies (four RCTs) evaluated anxiety, worries or distress. Only one RCT reported a difference in effect with reduced anxiety for counselling versus an interactive intervention (significance not given).

Other results and intervention details were reported and discussed.

Authors’ conclusions
For both communication models and decisional aids, the supportive or emotional elements of counselling provided more benefits to users than the informational or educational elements. Risk communication interventions mainly achieve benefits on cognitive outcomes and less clearly on affective, behavioural or health status measures.

CRD commentary
This publication summarised the results of one part of a large review (see Other Publications of Related Interest). The review addressed a well-defined question in terms of participants, interventions and study design; relevant outcomes were less clearly described. Relevant databases were searched. It was unclear whether or not language restrictions were applied and a minimal search was made for unpublished studies and so some relevant studies may have been missed. Publication bias was not assessed. Although study quality was assessed using suitable criteria, little relevant information was provided. Efforts were made to reduce error and bias in the review process, but it was not clear how disagreements were resolved in data extraction and quality assessment. Relevant study details were reported, but no details of loss to follow-up and few of length of follow-up data were given. A narrative synthesis was provided due to the heterogeneity of the interventions and patient/user groups. An overall comparison of the interventions was difficult due to the additional heterogeneity of the comparisons made. The authors recommended caution in the interpretation of results of studies in this area due to inconsistencies in outcome evaluation and study design.
In view of some potential limitations arising from the review process, uncertainties about the quality of included studies and the authors' own reservations, the review conclusions should be treated with caution.

**Implications of the review for practice and research**

**Practice:** The authors proposed that a balance was needed between the medical agenda and requirements to disclose/discuss issues and the need to address users’ concerns, need for support, issues of loss and relationship problems. The authors highlighted that professionals may be reluctant to promote communication or decision aids to users if they go beyond the professionals’ level of knowledge and familiarity.

**Research:** Further research was required on: how best to use tools such as decision aids as an adjunct to counselling for emotional support, often before discussion with a clinician, and to understand why they were effective; long-term effects of interventions on patients’ understanding and subsequent risk-reducing behaviour; interventions in underserved groups of the population, including ethnic minorities and people with lower levels of educational attainment; the influence of individualised risk information; and cost-effectiveness. Users should be involved in the design-stage of interventions. If the scope for clinical genetics branches into primary care then more innovative educational training initiatives may be required.

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