Information giving and decision-making in patients with advanced cancer: a systematic review

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CRD summary
The review concluded that some simple interventions including question prompt sheets, audio-taping of consultations and patient decision aids facilitated information provision and participation in the decision-making process for patients with advanced cancer. However, in view of the poor reporting of review methods, study details and results, and uncertain validity of the included studies, the authors' conclusions may not be reliable.

Authors' objectives
To evaluate methods of improving information provision and patient participation in decision-making for patients with advanced cancer.

Searching
PubMed (from 1966), PsycINFO (from 1967) and CINAHL (from 1982) were searched to end of 2003. Search terms were reported. Bibliographies of recent articles including review articles were also searched. Only English language studies were included in the review.

Study selection
Studies that evaluated methods of improving patient participation in decision-making and information giving to adult patients with advanced life limiting cancer were eligible for inclusion. Advanced cancer was defined as locally recurrent or metastatic where palliation rather than cure was the goal. Interventions evaluated to improve information giving in the included studies included consultation recordings, individual summary letter, patient held records, videos and booklets. Interventions to encourage participation in decision-making in the included studies included question prompt sheets, computer programme to aid participation, audio tape and decision making scenario exercises. Randomised controlled trials (RCTs), uncontrolled trials and descriptive studies were eligible for inclusion. Participants in the included studies were patients with varying cancer diagnoses and also included healthy volunteers and staff.

Two reviewers independently selected studies. Disagreements were resolved by consensus.

Assessment of study quality
It appears that the Jadad scale was used to assess validity of RCTs. Studies scoring less than 2 on the Jadad scale were excluded from the review. The authors did not state if they assessed validity of uncontrolled trials. The authors did not state how the validity assessment was performed or how many reviewers performed the assessment.

Data extraction
The authors did not state how data were extracted or how many reviewers performed the data extraction.

Methods of synthesis
The studies were combined in a narrative synthesis.

Results of the review
Forty seven studies were included in the review. However, 22 studies assessed patient preferences about decision making and information provision, therefore this abstract only reports results on the 25 studies assessing interventions to improve information provision and patient participation in decision making (n=3,731 patients, 339 staff and 107 volunteers/non-cancer controls). Twelve studies were RCTs, two were described as uncontrolled randomised trials and 11 were uncontrolled trials.

Methodological quality
Authors reported that most RCTs used valid randomisation methods (data not reported) and that not all trials stated whether the sample size was adequate to detect an increase. In addition two controlled trials had losses to follow-up of over 30%.

Interventions to improve information giving

Four studies reported that consultation tapes were well received by patients, with some studies finding improvements in knowledge and satisfaction. One study found that patients receiving an individual summary letter were more satisfied than those who did not receive the letter. However, in a survey of physicians, many expressed reservations in giving audiotapes or copy letters to patients. In a study asking patients to rate patient information booklets, the simplest booklet was preferred. Information provision was not improved by the use of a patient held record with patient input. Studies of video tapes had contradictory results.

Interventions to encourage participation in decision-making

Five studies evaluating a question prompt sheet reported positive results, in terms of usefulness, number of questions asked and recall. In a study of a computer programme to identify information and participation preferences, the majority of patients assumed the preferred role. A study assessing the effect of previously receiving a consultation tape on the subsequent consultation showed that the group who had received the tape requested more clarifications, but asked for less information already given. Studies of decision aids generally reported that they were acceptable to patients; some also reported decreased uncertainty in decision making and improved understanding.

Authors’ conclusions

The review found that some simple interventions including question prompt sheets, audio-taping of consultations and patient decision aids facilitated provision of information and involvement in the active decision-making process for patients with advanced life-limiting cancer.

CRD commentary

Inclusion criteria were broadly defined in terms of study design, interventions and participants, but were not defined for outcomes. Some relevant sources were searched but no attempt was made to reduce publication bias. Restriction to English language studies may have resulted in the loss of some relevant data. Methods were used to minimise reviewer errors and bias in the selection of studies but it is unclear whether similar steps were taken in assessment of validity and extraction of data. The validity of RCTs was assessed using an appropriate validity assessment scale, but results of the assessment were not fully reported. In addition, no validity assessment seems to have been undertaken for the uncontrolled studies. Therefore it is difficult to determine the reliability of the evidence presented. A narrative synthesis was appropriate given the differences between studies. The authors reported that most included participants' first language was English; therefore the results might not be generalisable to other cultures. The authors did not report study designs for uncontrolled studies and intervention details of included studies were not fully reported. There was also selective reporting of study results, with no effect sizes reported. In view of the poor reporting of review methodology, study details and results, and the uncertain validity of the included studies, the authors’ conclusions may not be reliable.

Implications of the review for practice and research

Practice: The authors did not state any implications for practice.

Research: The authors stated that controlled trials of interventions for improving information provision and participation in decision making are needed. These should focus on patients considering non-curative treatment to measure intervention effects on outcome measures such as satisfaction or anxiety levels. In addition, it should be established which interventions are practicable in a general clinical setting as opposed to a trial setting.

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Record Status
This is a critical abstract of a systematic review that meets the criteria for inclusion on DARE. Each critical abstract contains a brief summary of the review methods, results and conclusions followed by a detailed critical assessment on the reliability of the review and the conclusions drawn.