Does the patient-held record improve continuity and related outcomes in cancer care: a systematic review

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CRD summary
This generally well-conducted review evaluated the effectiveness of patient-held records (PHRs) in cancer care. The authors concluded that randomised controlled trials did not show any beneficial effect, whereas studies with less rigorous designs showed the more positive benefits of PHRs. The authors' conclusions are supported by the data presented and are likely to be reliable.

Authors' objectives
To evaluate the effectiveness of the patient-held record (PHR) in the care of cancer patients.

Searching
MEDLINE (1966 to 2004), EMBASE (1980 to 2004), CINAHL (1982 to 2004), the Cochrane Database of Systematic Reviews (Issue 1, 2004) and the Cochrane Controlled Trials Register (Issue 1, 2004) were searched; the search terms were reported. The reference lists of identified studies were screened for further relevant studies. An expert panel advised the authors about recently published articles and ongoing research.

Study selection
Study designs of evaluations included in the review
Any type of evaluation was eligible for inclusion.

Specific interventions included in the review
Studies of PHRs in cancer care, for improving communication and information exchange and promoting continuity of care and patients' involvement in care, were eligible for inclusion. The PHRs in the included studies were of various formats and contents. PHRs were either loose leaf or bound notebooks. The contents of the PHRs included: medical information, personal information, communication among health care professionals, communication between health care professionals and patients, instructions to patients, diary sheets for entry by patients or family members, pages for appointment, medication, important addresses and telephone numbers. The function of the PHRs in included studies was clinical as well as informal communication. The control groups in controlled trials were allocated to usual care or informal communication.

Participants included in the review
Studies of patients with cancer were eligible for inclusion. The patients in the included studies had one or more of the following cancers: lung, head and neck, colorectal, breast, haematological or any type of cancer. The patients were either newly diagnosed with cancer or at any stage of illness, or with palliative care needs.

Outcomes assessed in the review
Studies evaluating the effectiveness of the PHR and identifying impediments to its optimal functioning and evaluation were eligible for inclusion. In addition to these outcomes, the design of the record and the views of patients and health care professionals on the record's use were also evaluated in the review.

How were decisions on the relevance of primary studies made?
One reviewer selected the studies and a second reviewer independently checked the selection. Any disagreements were resolved through discussion.

Assessment of study quality
Two investigators independently assessed the quality of the included studies. The quality of randomised controlled trials (RCTs) was assessed according to a standard system using items on accrual, homogeneity, randomisation, attrition, intervention, outcome assessment and the reporting of results. Each study was allocated a score ranging from 0 (lowest)
to 7 (highest). Other types of evaluation were assessed using a different tool which incorporated items on the adequacy of description of the title, abstract, introduction, aims, methodology, data, sampling, data analysis, ethics and bias, results, transferability, and implications and practice. The maximum possible score was 36.

**Data extraction**
One reviewer extracted the data onto standardised forms and another reviewer independently checked the extraction. Any disagreements were resolved by discussion.

**Methods of synthesis**
How were the studies combined?
A narrative synthesis was provided.

How were differences between studies investigated?
The narrative addressed the RCTs first and then the observational studies. Summary study characteristics were tabulated.

**Results of the review**
Thirteen studies involving 1,975 patients, 830 health professionals and 59 carers were included. There were 7 RCTs (1,250 patients and 638 health professionals) and 6 non-randomised studies (725 patients, 192 health professionals and 59 carers).

The quality assessment scores among the 7 RCTs ranged from 3 to 6 out of a maximum possible score of 7; most scored 4 or 4.5. Among the non-randomised studies, the scores ranged from 20 to 36 out of a maximum possible score of 36; most scored 30 or more.

Six of the 7 RCTs did not find any significant beneficial effect of PHRs on the various outcomes of interest. Only one trial showed that patients with PHRs were better informed, had more support and experienced fewer psychosocial problems compared with controls.

Two RCTs which reported on improvement in communication showed no improvement in this outcome either between patients and health professionals or among health professionals. One RCT reported that both patients as well as professionals were better informed.

Three out of 4 RCTs found no difference in patient satisfaction with the information provided between the patients who received PHRs and those who did not. One RCT found that more patients in the usual care group were very satisfied with information than those in the PHR group (86% versus 58%). One RCT found a significant difference in preparing for appointments, monitoring own progress and feeling in control with the PHR.

In non-randomised studies, PHRs were shown consistently to be feasible, acceptable, improve communication between health professionals and patients, act as memory aids, and found to be useful by both patients and health professionals. The health professionals also found them to be a useful tool to exchange information between different parties.

**Cost information**
Three RCTs which reported on the use of health resources and expenditure did not find any differences in this outcome between the two groups. The only cost of the intervention was the cost incurred in producing the actual record.

**Authors’ conclusions**
RCTs did not find any benefit of PHRs on the intended outcomes, whereas non-randomised studies showed the more positive benefits of the PHRs. The non-randomised studies also shed light on some of the essential mechanisms and conditions for their successful use. Most of the patients welcomed the introduction of the PHR.

**CRD commentary**
The research question and inclusion criteria were clearly stated. Several relevant databases were searched, with dates and search terms reported. Efforts were made to find unpublished as well as published studies, thereby reducing the
potential for publication bias. It is not clear whether non-English language literature was sought, which might have introduced the possibility of language bias. The study selection, quality assessment and data extraction processes were performed in duplicate, or at least independently checked by a second reviewer, thereby reducing the potential for reviewer error and bias. The included studies were appropriately grouped according to the study design. Details of the included studies were summarised in tables, including results of the quality assessment exercise. The authors’ conclusions are supported by the data presented and are likely to be reliable.

Implications of the review for practice and research
Practice: The authors did not state any implications for practice.

Research: The authors stated the importance of further research to determine the conditions under which the PHR can realise its potential as a tool to promote continuity of care and patient participation.

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