

## Paper 3 [Posted as supplied by the author]

### The effect of patients with cancer holding their own records on communication and quality of life

#### ABSTRACT

**Objective.** The burden of cancer care in general practice is increasing. Patient-held records may facilitate effective, coordinated care. Our aim was to evaluate the use of a supplementary patient-held record in cancer care.

**Method.** A total of 1296 radiotherapy outpatients with any form of cancer were randomised either to hold a supplementary record or to receive normal care. It was explained to record holders that the supplementary record was intended to improve communication with health professionals and act as an *aide memoire*. After three months, patients' satisfaction with communication and with participation in their own care were assessed. Global health status, emotional functioning, and cognitive functioning were measured.

**Results.** Three months after the intervention, 450 (78%) patients responded. There were no significant differences between groups in any of the outcome measures. Patients in both groups expressed a high level of satisfaction with communication and participation in their care. Mean (SD) scores in the intervention and control groups were: global health status, 66.8 (24.2) and 65.3 (23.7); emotional functioning, 75.0 (24.6) and 77.4 (22.8); cognitive functioning 84.5 (21.0) and 84.0 (21.3).

**Conclusion.** A supplementary patient-held record appears to have no effect on satisfaction with communication, participation in care, or quality of life. Such an innovation should not be pursued in providing hospital-based care.

#### Introduction

The report of the Expert Advisory Committee on Cancer Services (Calman-Hine Report<sup>1</sup>) proposed a three-tier service with specialised cancer centres at the top and primary care at the foundation. The effect will be to increase specialisation in hospital practice, which, with an already expanded primary care team, will tend to fragment care. Allying this with recommendations in the report – that cancer services should be patient-centred and give clear information about treatment options – will be difficult.

Cancer patients and their families crave information<sup>2-6</sup> but are often uncertain what to ask<sup>4</sup> and unhappy with the information they receive.<sup>7,8</sup> Communication is of central importance to patients<sup>9</sup> and carers.<sup>10</sup> In this study we investigated whether a patient-held record for radiotherapy outpatients would affect their satisfaction with communication and participation in their own care, and their quality of life.

#### Method

A total of 850 patients were recruited from consecutive attenders at radiotherapy clinics. All patients with cancer (except curable dermatological cancers) and aged 16 years or over were eligible.

In the clinic patients were randomised to the intervention group (a patient-held record) or control group dependent on the day of the week. The record consisted of an A4-size plastic wallet containing communication/diary sheets for use by the patient, their family, health professionals

and carers, as well as pages for appointments, medication, and addresses and telephone numbers. The study nurse explained the use of the record as a means of communication and as an *aide memoire*. Patients were encouraged to read and write in it and to show it to anyone concerned with their care. The record explicitly invited carers to use it as an aid to communication. Patients in both groups received an information sheet about the trial. Six months after recruitment, all record-holding patients were asked to return the record.

To assess outcome, we used an instrument measuring quality of life. The main outcomes were global health status, emotional functioning, and cognitive functioning at three months. To examine outcomes more directly related to the trial intervention (i.e. patients' satisfaction with communication and with participation in their own care), a 7-item questionnaire was used. Items were scored on a five-point scale: strongly agree to strongly disagree.

Clinic lists were reviewed and letters sent to eligible patients informing them about the study one week before their appointments. At the clinic, the study was explained to each patient by a study nurse. An explanatory letter was sent to their GP. Participants were randomised by the study nurse either to the record-holding group (RH) or to normal care (NC).

Three months after recruitment, questionnaires relating to the main outcomes of the trial, the use of the record, and contact with health professionals were sent to all patients. Two reminders were sent to non-responders. The significance tests used were the *t*-test for comparing means, the chi-squared test for comparing proportions, and the Mann-Whitney test for comparing Likert scale scores.

## **Results**

### *Study population*

The progress of patients through the study is shown in Figure 1. Of the 1296 eligible patients presenting at the clinic, 850 entered the trial, and completed follow-up questionnaires were received from 450 (53%). Responses to individual questions were sometimes missing. Table 1 shows the age, sex, and diagnoses of patients enrolled in the study. There were no statistically significant differences between the two groups (Table 2).

### *Clinic attendance and contacts with professional carers*

Very few patients (4.9% in the RH group and 5.3% in the NC group) reported that they had not attended any clinics in the three months since recruitment. The most commonly attended clinics were radiotherapy/oncology (82.7% of RH group and 84.6% of NC group), surgical (29.7% and 22.6% respectively), chest (8.5% and 10.0% respectively), and medical (8.1% and 10.9% respectively). Most patients (78.3% in the RH group and 85.2% in the NC group) had visited their GP. Other carers most often seen were vicars/priests (16.7% and 10.6% respectively) and Macmillan nurses (13.1% and 11.5% respectively). There were no significant differences in attendance or contacts between the two groups.

### *Patients' reported use of the record*

Three months after recruitment, 96.8% of those in the RH group still had their record. Of these, 91.8% said that they understood how to use it, 88.9% reported reading it, and 61.7% said that they wrote in it themselves. 82.2% showed it to their hospital doctors when seen and 66.7% to their GP. Other people who patients commonly reported as reading or writing in the record included family members (33.5%), radiotherapists (29.3%), and hospital nurses (27.9%).

### *Quality of life and symptoms*

There were no differences between the groups in the study's main outcomes: global health status, emotional functioning, or cognitive functioning (Table 3). Overall, mean scores were similar in the two groups. Of the six symptoms, the record holding group suffered more from nausea and vomiting and from constipation.

#### *Patients' satisfaction with communication and with participation in their own care*

Patients in both groups expressed a similarly high level of satisfaction. Mean (SD) scores for the 7 items (each scored on a scale of 1 to 5) relating to satisfaction with communication and with participation in care were 3.83 (0.59) in the RH group and 3.80 (0.59) in the NC group (mean difference = 0.03; 95% CI = 0.09 to 0.15). Mean (SD) scores for the 5 items relating to desire for information were 4.27 (0.79) and 4.14 (0.79) respectively (mean difference = 0.13; 95% CI = 0.02 to 0.28).

### **Discussion**

In this large study, we did not find any significant benefit arising from cancer patients holding their own supplementary record, nor did we find any significant negative effect. There were, however, indications that record holding may have been a burden to some patients. After three months, the response rate to the questionnaire was much lower among the record holders than the normal care group, and record holders more often failed to complete all the questions, particularly those concerning the record itself. Such discrepant response rates are unusual and suggest that something about the intervention itself affected the probability of response. It may be that patients felt a degree of guilt if they had failed to use the record, or that the record forced them to confront aspects of their illness that they did not wish to explore – a possibility supported by the finding that record holders appeared less able than non-record holders to face all future aspects of their illness. Only two-thirds of the record holders who had seen their GP said they had shown the GP their record. Recruitment in hospital outpatients may have led some patients to see it as belonging in secondary care.

One problem we encountered was the large number of patients who were deemed to be too unwell to be followed-up after three months. Given that, we did not feel that analysing on the basis of 'intention to treat' was appropriate.

The momentum to develop tools that inform and empower patients with cancer is driven by an articulate voluntary sector, growing evidence of unmet need, and the search for mechanisms that facilitate shared care. Counter to this has been the concern that, indiscriminately used, such tools may have a negative effect on care. Our evidence shows that use of a supplementary patient-held record does not produce measurable benefit. However, given the additional cost involved, there is no justification for using supplementary patient-held records in the NHS for cancer care or, indeed, in other areas of care.

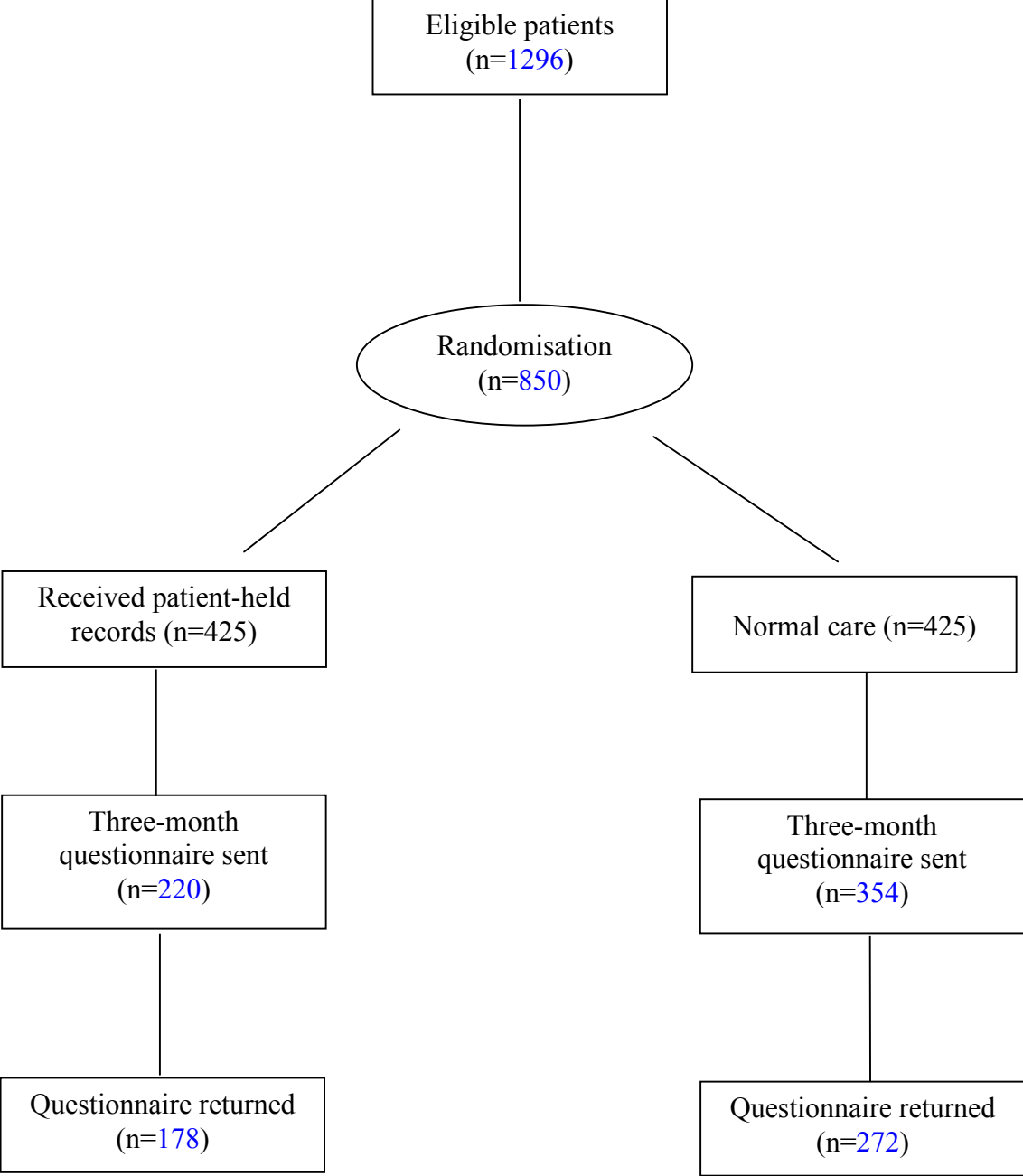
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**Figure 1: Progress of patients through the trial.**



**Table 1: Age, sex, and diagnosis of patients. Figures are % (n) except where otherwise stated.**

	<b>RH group (n=425)</b>	<b>NC group (n=425)</b>
Mean (SD) age (years)	61.9 (13.7)	62.2 (12.9)
Sex		
Female	60.6 (197)	58.5 (190)
Male	39.4 (128)	41.5 (135)
Diagnosis of cancer		
Breast	32.9 (107)	33.5 (109)
Bronchus	16.9 (55)	16.9 (55)
Bowel	12.9 (42)	13.5 (44)
Gynaecological	9.5 (31)	7.4 (24)
Urogenital	7.1 (23)	5.5 (18)
Head and neck	4.0 (13)	4.6 (15)
Upper GI tract	4.0 (13)	4.3 (14)
Lymphoma	3.1 (10)	3.1 (10)
Unknown primary	0.6 (2)	3.4 (11)
Other	8.9 (29)	7.7 (25)

**Table 2: Responders to three-month questionnaire: age, sex, and diagnosis of patients. Figures are % (n) except where otherwise stated.**

	<b>RH group (n=178)</b>	<b>NC group (n=272)</b>
Mean (SD) age in years	61.6 (13.2)	62.1 (12.8)
Sex		
Female	64.6 (133)	59.0 (144)
Male	35.4 (73)	41.0 (100)
Diagnosis of cancer		
Breast	38.8 (80)	35.7 (87)
Bronchus	10.7 (22)	14.3 (35)
Bowel	12.1 (25)	15.2 (37)
Gynaecological	9.2 (19)	8.2 (20)
Urogenital	7.3 (15)	5.3 (13)
Head and neck	4.9 (10)	4.5 (11)
Upper GI tract	3.4 (7)	2.5 (6)
Lymphoma	3.4 (7)	3.3 (8)
Unknown primary	-	3.7 (9)
Other	10.2 (21)	7.4 (18)

Note: There are no statistically significant differences in age, sex, or diagnosis between responders in the two groups.

**Table 3: Mean (SD) Quality of Life Scores.**

	<b>RH group (n=178)</b>	<b>NC group (n=272)</b>	<b>Difference (95% CI)</b>
<b>Functional Scales</b>			
Physical	72.3 (26.7)	71.8 (27.1)	0.5 (-4.7 to 5.7)
Role	73.2 (34.4)	72.7 (35.2)	0.5 (-6.1 to 7.1)
Emotional	75.0 (24.6)	77.4 (22.8)	-2.4 (-6.9 to 2.1)
Cognitive	84.5 (21.0)	84.0 (21.3)	0.5 (-3.5 to 4.5)
Social	76.0 (28.9)	74.6 (29.9)	1.4 (-4.3 to 7.1)
Global health status	66.8 (24.2)	65.3 (23.7)	1.5 (-3.0 to 6.0)
<b>Symptom Scales</b>			
Fatigue	34.2 (27.9)	35.6 (27.3)	-1.4 (-6.6 to 3.8)
Nausea, vomiting	5.4 (11.6)	8.0 (15.9)	-2.6 (-5.2 to -0.1)
Pain	21.0 (26.3)	21.9 (26.6)	-0.9 (-6.0 to 4.2)
Dyspnoea	20.0 (26.5)	19.1 (24.7)	0.9 (-3.9 to 5.7)
Sleep disturbance	30.2 (33.0)	28.4 (31.0)	1.8 (-4.3 to 7.9)
Appetite loss	14.0 (27.2)	16.4 (27.0)	-2.4 (-7.5 to 2.7)
Constipation <sup>a</sup>	11.7 (21.8)	19.8 (29.9)	-8.1 (-13.1 to -3.1)
Diarrhoea	7.5 (18.8)	9.3 (20.8)	-1.8 (-5.6 to 2.0)
<b>Financial impact</b>	12.7 (25.9)	14.4 (28.3)	-1.7 (-6.9 to 3.5)

Note: scores range from 0 to 100, with higher scores representing better function or more symptomatology. <sup>a</sup> Difference between groups: P=0.002