Patients with cancer holding their own records: a randomised controlled trial

MARK DRURY

PATRICIA YUDKIN

JEAN HARCOURT

RAY FITZPATRICK

LESLEY JONES

CHRIS ALCOCK

MICHAEL MINTON

SUMMARY

Background. *The burden of cancer care in general practice is increasing. Patient-held records may facilitate effective, coordinated care, but no randomised controlled trials of their use in cancer care have been conducted, and concerns about possible negative effects remain.*

Aim. *To evaluate the use of a supplementary patient-held record in cancer care.*

Method. *Six hundred and fifty 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 using the European Organization for Research and Treatment of Cancer QLQ-C30 questionnaire.*

Results. *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 for radiotherapy outpatients appears to have no effect on satisfaction with communication, participation in care, or quality of life.*

Keywords: *cancer patients; patient satisfaction; patient-held records; communication.*

Introduction

IN 1995, the report of the Expert Advisory Committee on Cancer Services (Calman–Hine Report[1]) 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[2-6] but are often uncertain what to ask[4] and unhappy with the information they receive.[7,8] Communication is of central importance to patients[9] and carers[10] and is a common source of dissatisfaction.[11,12]

Patient-held records have been used successfully in obstetric and paediatric care to improve communication and promote patients' involvement in their own care.[13-15] Patients viewing their own general practitioner (GP) records reported a positive effect on communication, without increasing anxiety.[16] A review of the ethical and practical aspects of patient-held records[17] concluded that there were few drawbacks and considerable benefits. However, patient-held records have not been evaluated in cancer care.

In 1994, a pilot study of outpatients receiving palliative care[18] suggested a patient-held record was used and acceptable. In this study we investigated whether such a record for radiotherapy outpatients would affect their satisfaction with communication and with participation in their own care or their quality of life.

Method

Subjects

A total of 650 patients were recruited between April 1994 and April 1996 from consecutive attenders at radiotherapy clinics run by the Oxford Radcliffe National Health Service (NHS) Trust. All patients with cancer (except curable dermatological cancers) and aged 16 years or over were eligible.

Intervention

After randomisation in the clinic, patients in the intervention group were given the supplementary record. It 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, if well enough, were asked to return the record.

Outcome measures

Psychometrically tested outcome measures directly relevant to the trial intervention are not available. We therefore used a vali-

M Drury, MRCGP, general practitioner, Wantage, Oxfordshire. P Yudkin, MA, DPhil, university research lecturer; J Harcourt, BA, research nurse; and L Jones, BA, computer scientist, Imperial Cancer Research Fund General Practice Research Group, Department of Primary Health Care, University of Oxford. R Fitzpatrick, BA, MSc, PhD, professor, Division of Public Health and Primary Health Care, University of Oxford. C Alcock, FRCP, FRCR, clinical director of clinical oncology; and M Minton, FRCP, consultant in palliative medicine, Oxford Radcliffe Hospital, Headington, Oxford.

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dated instrument measuring quality of life that was specifically developed for cancer patients: the European Organization for Research and Treatment of Cancer QLQ-C30 questionnaire (EORTC QLQ C30).[19] 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 19-item questionnaire (Box 1) was developed, based on evidence from the pilot study. Items were scored on a five-point scale: strongly agree to strongly disagree.

Sample size

To detect an effect size of 0.33 (considered a small but worthwhile effect)[20] in the mean EORTC QLQ C30 score between the two groups, with 90% power and at a significance level of 0.05, required 412 subjects (206 in each group). To allow for the high attrition rate expected in cancer patients, 650 were recruited.

Recruitment and randomisation

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 who requested consent to take part. An explanatory letter and copy of the patient's consent was sent to their GP.

Participants were randomised by the study nurse, either to the record-holding group (RH) or to normal care (NC). The allocations, generated using random numbers and in blocks of 10, were in sealed, numbered, opaque envelopes, which were opened sequentially.

Data collected

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 (if well enough). Two reminders were sent to non-responders.

At the end of the study, a questionnaire about attitudes to patients holding their own records was sent to all GPs of RH patients (*n* = 229).

Identified in factor analysis:

Satisfaction with communication and with participation in care

- I have found it difficult to remember when to take my medicines and tablets
- Doctors and nurses keep me fully informed about my illness
- My doctors and nurses appear to be fully aware of all aspects of my illness and treatment
- I often forget what I want to say to my nurses and doctors
- I sometimes feel confused by the number of different doctors and nurses that I see
- I do not feel I have any control over the way my illness is treated
- My doctors and nurses often seem unaware of the problems I am facing
- I find it easy to remember everything my nurses and doctors say to me
- Those involved in my care do not seem to know what others are doing
- I feel I can take an active part in decisions about my treatment

Desire for information

- I would like to be fully informed about all matters that relate to my illness
- I would like to see all my medical records

Remaining statements

- I am unsure what my medicines and tablets are for
- I find it difficult to talk to my doctors
- I feel my family has not been told everything they would like to know about my illness
- I find it easy to ask for the help that I need from my doctors and nurses
- It has been easy to remember my appointments
- I find it easy to talk to my family about my illness
- I feel able to face all future aspects of my illness

Box 1. The 19 statements relating to communication and participation in care.

Statistical methods

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.

To improve reliability of measurement and to reduce the number of statistical comparisons, the 19-item questionnaire was analysed using principal component analysis and a single varimax rotation of data. The raw scores were transposed, if necessary, so that higher scores always represented a greater sense of participation in care or a greater desire for information. Five factors with an Eigen value of greater than one were identified. On intuitive grounds and after examination of a scree plot, the two factors with the largest eigen values of 1.9 (desire for information) and 4.9 (satisfaction with communication and participation in care) were selected. They accounted for 35.9% of the variance. Items were selected that loaded on factors greater than 0.5. Clustering of items supported the use of two scales: satisfaction with communication and with participation in care (10 items), and desire for information (two items) (Box 1). Internal reliability for both scales was satisfactory (Cronbach's alpha = 0.81 and 0.74 respectively). The Central Oxford Research Ethics Committee granted approval for the study.

Results

Study population

The progress of patients through the study is shown in Figure 1. Of the 896 eligible patients presenting at the clinic, 246 (27.5%) refused to participate; 120 (13.4%) because the record would make them too anxious, 59 (6.6%) because they felt too well to need one, 40 (4.5 %) because they felt too ill, and 27 (3.0%) for other reasons. There was no difference in the pattern of diagnoses or in sex between refusers and participants, but the former were older (*P* = 0.003): mean (SD) ages were 65.0 (13.4) years and 62.1 (13.3) years respectively.

Of the 650 patients who entered the trial, 76 died or withdrew before three months. Thus, 574 patients were sent the three-month questionnaire, of whom 450 responded: 206/284 (72.5%) in the RH group and 244/290 (84.1%) in the NC group, a difference of 11.6% (95% confidence interval = 4.9 to 18.3; *P* = 0.001). Responses to individual questions were sometimes missing; details are given in the text.

Table 1 shows the age, sex, and diagnoses of patients enrolled in the study. Patients who died or withdrew before three months had a different pattern of diagnoses from those who remained (*P*<0.001): more had carcinoma of the bronchus (38.2% of those who died or withdrew compared with 14.1%) and fewer had carcinoma of the breast (18.4% compared with 35.2%). The remaining patients were similar in both groups. There were no statistically significant differences in age, sex, or diagnosis between those who responded to the questionnaire and those who did not, and these characteristics were comparable in the two groups of responders (Table 2).

Clinic attendance and contacts with professional carers

Very few patients (10/206, 4.9% in the RH group, and 13/244, 5.3% in the NC group) reported that they had not attended any

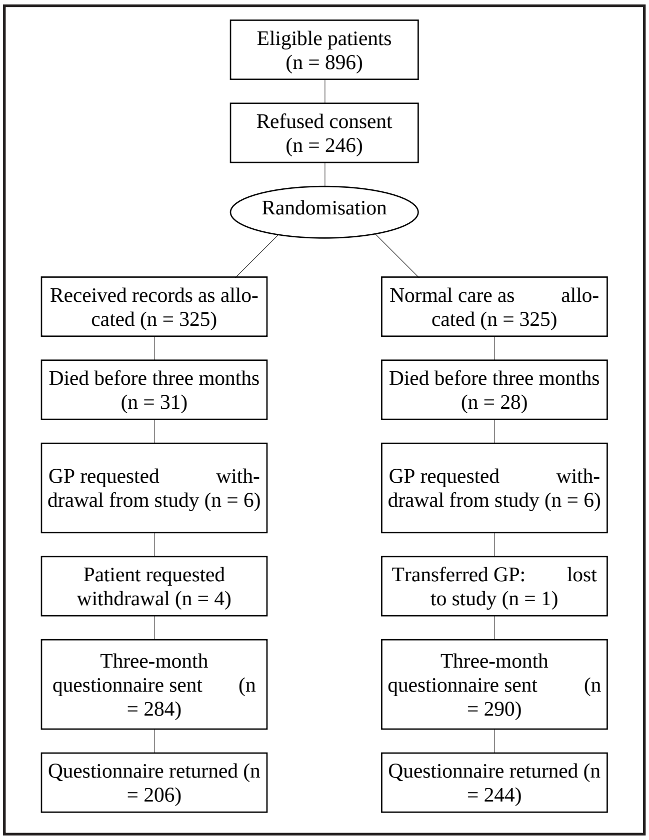

Figure 1. Progress of patients through the trial.

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

	RH group (n = 325)	NC group (n = 325)
Mean (SD) age in 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)

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 (159/203, 78.3% in the RH group, and 156/183, 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 who responded (184/190) still had their record. Of these, 91.8% (168/183) said that they understood how to use it, 88.9% (160/180) reported reading it, and 61.7% (113/183) said that they wrote in it themselves. A total of 82.2% (143/174) showed it to their hospital doctors when seen, and 66.7% (106/159) to their GP. Other people who patients commonly reported as reading or writing in the record included family members (33.5%; 59/176), radiotherapists (29.3%; 49/167), and hospital nurses (27.9%; 46/165).

Quality of life measured by EORTC QLQ C-30

There were no differences between 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.

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 10 statements (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 two statements 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). There was little difference between groups in the responses to the seven statements not identified in the factor analysis (Table 4); however, patients in the RH group felt significantly less able to face all future aspects of their illness (*P* = 0.05).

GPs' views about the patient-held record

Of the 229 GPs of RH patients who received the questionnaire, 202 (88.2%) responded; only 27.3% (54/198) said they had seen the record. There were no significant differences between GPs who had and had not seen the record in views about patients with cancer having access to their medical records (*P* = 0.90) or being fully informed on all matters that relate to their illness (*P* = 0.52) (Table 5). Not all GPs who answered the questionnaire responded to these questions.

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 indications that record holding may have been a burden to some patients. Twenty-seven per cent of the eligible patients declined to participate; nearly half because they thought the record would generate anxiety. 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. A sensitivity analysis suggested that the excess non-response among record holders might possibly have underestimated the negative effects of the records.

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

	Responders RH group (n = 206)	Non-responders NC group (n = 244)	n = 124
Mean (SD) age (years)	61.6 (13.2)	62.1 (12.8)	61.1(15.3)
Sex			
Female	64.6 (133)	59.0 (144)	58.9 (73)
Male	35.4 (73)	41.0 (100)	41.1 (51)
Diagnosis of cancer			
Breast	38.8 (80)	35.7 (87)	28.2 (35)
Bronchus	10.7 (22)	14.3 (35)	19.4 (24)
Bowel	12.1(25)	15.2 (37)	12.1 (15)
Gynaecological	9.2 (19)	8.2 (20)	8.1 (10)
Urogenital	7.3 (15)	5.3 (13)	10.5 (13)
Head and neck	4.9 (10)	4.5 (11)	4.0 (5)
Upper GI tract	3.4 (7)	2.5 (6)	7.3 (9)
Lymphoma	3.4 (7)	3.3 (8)	1.6 (2)
Unknown primary	-	3.7 (9)	0.8 (1)
Other	10.2 (21)	7.4 (18)	8.1 (10)

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

Table 3. Mean (SD) EORTC QLQ-C30 Quality of Life Scores.

	RH group (n = 206)	NC group (n = 244)	Difference (95% CI)
Functional Scales			
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)
Symptom Scales			
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[a]	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)
Financial impact	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. [a]Difference between groups: $P = 0.002$

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. Even fewer (only a quarter) of the GPs of record-holding patients reported having seen it. This latter figure may be an underestimate, since we did not know which of these GPs had actually seen the patients. However, since questionnaires were sent to GPs at the end of the study, many may have forgotten seeing the record, and the low figure suggests that the record made relatively little impact on GPs.

The apparent lack of benefit of the record may reflect the particular circumstances of our study. The pilot study and other reports on the feasibility of patient-held records in cancer care[21,22] were limited to those receiving palliative care. Many of our study participants were in relatively good health and in infrequent contact with doctors and nurses. Patients in our study had a much better level of functioning and fewer symptoms, as measured by the EORTC QLQ C-30 questionnaire, than those with non-resectable lung cancer.[19] They also felt that communication with doctors and nurses was good, and had a real sense of participation in their care. Moreover, the majority of patients had access to a Cancer Information Centre onsite. In these circumstances it may be difficult to demonstrate that a supplementary record, even if valued, measurably improves outcome.

In two randomised trials comparing antenatal patients holding their own main records with those holding supplementary co-operation cards, patients holding the main record felt significantly more able to talk to their doctors and midwives, more in control of care,[13] and better informed.[14] One explanation for the null result in our study may be the difference between ‘well’ and ‘sick’ person care; although, in our pilot study in palliative care, patients reported that a supplementary record was valuable in promoting communication with carers and involvement with care. It may be that both obstetric and palliative care are areas in which the primary care team feels closely involved and therefore well motivated to use the record as a tool, whereas care for patients attending radiotherapy clinics is perceived as the province of the hospital.

Table 4. Statements[a] relating to communication and participation in care.

Statement	Group	Agree[b] (%)	Unsure (%)	Disagree[b] (%)	Total
I am unsure what my medicines and tablets are for	RH	6.1	2.8	91.1	179
	NC	5.6	6.1	88.3	213
I find it difficult to talk to my doctors	RH	11.4	6.5	82.1	184
	NC	8.5	6.7	84.8	224
I feel my family have not been told everything they would like to know about my illness	RH	14.6	10.3	75.1	185
	NC	15.0	11.4	73.6	220
I find it easy to ask for the help I need from doctors and nurses	RH	79.6	8.9	11.5	191
	NC	80.7	7.3	12.0	233
It has been easy to remember my appointments	RH	92.2	3.1	4.7	192
	NC	93.6	1.7	4.7	236
I find it easy to talk to my family about my illness	RH	76.9	6.5	16.7	186
	NC	84.1	5.6	10.3	233
I feel able to face all future aspects of my illness[c]	RH	61.9	28.6	9.5	189
	NC	71.4	21.8	6.7	238

[a]Statements not included in scales relating to satisfaction with communication and participation in care, and desire for information (see text). [b]Agree or strongly agree/disagree or strongly disagree. [c]Difference between groups: P = 0.05, Mann–Whitney test based on five-point scale.

Table 5. General practitioners' attitudes towards record holders and patient access to information (%).[a]

Q.1. Patients with potentially life-threatening cancer should have access to their medical records

	Strongly agree	Agree	Unsure	Disagree	Strongly disagree
GP had seen record (n = 51)	7.8	49.0	33.3	7.8	2.0
GP had not seen record (n = 127)	10.2	47.2	31.5	7.9	3.1
Total	9.6	47.8	32.0	7.9	2.8

Q.2. Patients should be fully informed about all matters that relate to their illness

	Strongly agree	Agree	Unsure	Disagree	Strongly disagree
GP had seen record (n = 52)	21.2	61.5	11.5	5.8	0.0
GP had not seen record (n = 129)	29.5	51.9	14.0	3.9	0.8
Total	27.1	54.7	13.3	4.4	0.6

[a]Not all GPs who answered the questionnaire responded to these questions; no significant difference between GPs who had seen and had not seen the record (Q.1: P = 0.90; Q.2: P = 0.52).

Selective use of supplementary patient-held records may be valuable in groups of patients at an active or critical stage in their disease, or in settings where there is an identified need for improved communication.

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 or harm.

References

1. Expert advisory Group on Cancer. *A policy framework for commissioning cancer services: Consultative Document.* London: EAGC, 1994.
2. Cassileth BR, Zupkis RV, Sutton-Smith K, March V. Information preferences among cancer patients. *Ann Intern Med* 1980; **92:** 832-836.
3. Derdiarian AK. Information needs of recently diagnosed cancer patients. *Nursing Res* 1986; **35:** 276-281.
4. National Cancer Alliance. *Patient centred cancer services: What patients say*. [Report of the National Cancer Alliance.] Oxford: National Cancer Alliance, 1996.
5. Blanchard CG, Labreque MS, Ruckdeschel JC, Balnchard EB. Information and decision making preferences of hospitalized adult cancer patients *Soc Sci Med* 1988; **27:** 1139-1145.
6. Meredith C, Symonds P, Webster L, *et al*. Information needs of cancer patients in west Scotland: cross sectional survey of patients' views. *BMJ* 1996; **313:** 724-726.
7. Fallowfield LJ. Giving sad and bad news. *Lancet* 1993; **341:** 476-470.
8. Seale C. Communication and awareness about death. A study of a random sample of dying people. *Soc Sci Med* 1991; **32:** 943-952.
9. Higginson I, Wade A, McCarthy M. Palliative care: Views of patients and their families. *BMJ* 1990; **301:** 277-281.
10. Robinson L, Stacy R. Palliative care in the community: setting guidelines for primary care teams. *Br J Gen Pract* 1994; **44:** 461-464.
11. Blythe A. Audit of terminal care in a general practice. *BMJ* 1990; **301:** 983-986.
12. Audit Comission. What seems to be the matter: communication between hospitals and patients. NHS Report 1993; no12 London. HMSO, 1993.
13. Elbourne D, Richardson M, Chalmers I, *et al*. The Newbury Maternity Care Study: a randomized controlled trial to assess a policy of women holding their own obstetric records. *Br J Obstet Gynaecol* 1987; **94:** 612-619.
14. Lovell A, Zander L, James C, *et al*. The St Thomas's Hospital maternity case notes study: a randomized controlled trial to assess the effects of giving expectant mothers their own maternity case notes. *Paediatr Perinat Epidemiol* 1987; **1:** 57-56.

15. Saffin K, Macfarlane A. How well are parent held records kept and completed? *Br J Gen Pract* 1991; **41:** 249-251.
16. Baldry M, Cheal C, Fisher B, *et al*. Giving patients their own records in general practice: experience of patients and staff. *BMJ* 1986; **292:** 596-598.
17. Gilhooly ML, McGhee SM. Medical records: practicalities and principles of patient posession. *J Med Ethics* 1991; **17(3):** 138-143.
18. Drury M, Harcourt J, Minton M. The acceptability of patients with cancer holding their own shared care record. *Psycho-oncology* 1996; **5:** 119-125.
19. Aaronson NK, Ahmedzi S, Bergman B, *et al*. The European Organization for the Treatment of Cancer QLQ-C30: A quality of life instrument for use in international clinical trials in oncology. *J Nat Cancer Inst* 1993; **85:** 365-376.
20. Wolf FM. Meta-analysis: *Quantitative Methods for Research Synthesis.* [Sage University Paper 59.] London: Sage Publications, 1986.
21. Latimer JL. A patient care travelling record for palliative care: A feasibility study. *J Palliat Care* 1991; **7:** 30-36.
22. Jones RVH. Dear Diary. *Nursing Times* 1990; **86:** 31-33.

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Dedication

Mardy Bartlett died on 28 November 1995. Her work as a research nurse on the study continued even during her final illness. Her enthusiasm and commitment were invaluable. She is greatly missed.

Address for correspondence

Dr Mark Drury, Department of Primary Health Care, Institute of Health Sciences, Headington, Oxford OX3 7LF. E-mail: mdrury@server.dphpc.ox.ac.uk