

Randomised controlled trial of a shared care programme for newly referred cancer patients: bridging the gap between general practice and hospital

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Objective: To determine the effect of a shared care programme on the attitudes of newly referred cancer patients towards the healthcare system and their health related quality of life and performance status, and to assess patients' reports on contacts with their general practitioner (GP).

Setting: Department of Oncology at Aarhus University Hospital and general practices.

Design: Randomised controlled trial in which patients completed questionnaires at three time points. The shared care programme included transfer of knowledge from the oncologist to the GP, improved communication between the parties, and active patient involvement.

Participants: 248 consecutive cancer patients recently referred to the department.

Main outcome measures: Patients' attitudes towards the healthcare services, their health related quality of life, performance status, and reports on contacts with their GPs.

Results: The shared care programme had a positive effect on patient evaluation of cooperation between the primary and secondary healthcare sectors. The effect was particularly significant in men and in younger patients (18–49 years) who felt they received more care from the GP and were left less in limbo. Young patients in the intervention group rated the GP's knowledge of disease and treatment significantly higher than young patients in the control group. The number of contacts with the GP was significantly higher in the intervention group. The EORTC quality of life questionnaire and performance status showed no significant differences between the two groups.

Conclusions: An intersectoral shared care programme in which GPs and patients are actively involved has a positive influence on patients' attitudes towards the healthcare system. Young patients and men particularly benefit from the programme.

Patients with cancer may feel uncertain about what is going to happen when they are referred to hospital and they may experience psychological morbidity and dissatisfaction with the provision of information and care.¹ They have stressed the importance of the following aspects in their contact with the healthcare service: doctors' technical competence, communication skills, continuity of care, family care, and financial circumstances.² Most patients with cancer are treated as outpatients and may therefore feel left alone at crucial moments. At such times they often consult their general practitioner (GP) for further advice, information, and repetition of information. These contacts place the GP in a key position in which s/he may have problems due to lack of specific knowledge of cancer and lack of collaboration with the oncologists.^{3–5} This situation occurs frequently and may be remedied by sharing the care between GPs and oncologists.

Shared care has been defined as "care [which] applies when the responsibility for the health care of the patient is shared between individuals or teams who are part of separate organisations, or where substantial organisational boundaries exist".⁶ It implies personal communication and organised transfer of knowledge from hospital doctors to GPs and patient involvement. The dialogue between the oncologist and the GP is particularly important.^{7–9} James *et al*¹⁰ reported that a paediatric oncology information package for GPs helped them to manage their patients' disease and improved their communication with the oncologists.

This study was undertaken to assess the effect of a shared care programme on the attitudes of newly referred cancer patients towards the healthcare system, their health related quality of life and performance status, and to describe patients' reports on contacts with their GP. The effect of the

shared care programme was measured using questionnaires. Several questionnaires have been developed to assess patient satisfaction with care in either the primary setting or in the hospital. We wanted a questionnaire which could measure the interface between the two settings. The "patient career diary" is a questionnaire which measures patients' attitude to care across the primary/secondary interface.¹¹ It uses the expression attitude being defined as a psychological tendency that is expressed by evaluating a particular entity with some degree of favour or disfavour.¹² A quality of life questionnaire and a performance questionnaire were also used to determine whether the intervention had any influence (negative or positive) on patients' functioning, symptoms, and overall quality of life.^{13 14}

METHODS

Study population

The study population consisted of cancer patients newly referred to the Department of Oncology at the Aarhus University Hospital, Denmark. The catchment area has a population of 1.3 million, of whom 248 were consecutively included during a 3 month period from August to December 1998. Inclusion and exclusion criteria are shown in box 1.

Intervention

The intervention was compared with the normal procedure in the department. In the Department of Oncology there were no standard procedures for informing the GPs about newly diagnosed cancer patients. Generally, a discharge summary letter was sent to the GP at the end of the treatment period; some sections in the department would send a short letter at the

Box 1 Inclusion and exclusion criteria**Inclusion criteria**

- Informed consent
- 18 years and over
- Danish citizens, able to understand and speak Danish
- Mentally able to cooperate
- Newly referred and diagnosed cancer patients who were scheduled for treatment or attendance for control at the Department of Oncology during a given period
- Patients with recurrent disease could be included if their last visit took place later than 3 years previously

Exclusion criteria

- Short palliative radiation therapy without subsequent check up
- Patients enrolled in a special ambulatory with doctors from other departments (dermatologists and otologists)
- Patients with a diagnosis of lymphoma (this group was transferred to another hospital during the inclusion period)
- Patient not listed with a GP, health insurance group II patients (patient co-payment, 2–3% of the Danish population)

beginning of the treatment. Sometimes several months could pass before the GP received any information. The discharge summary letters did not follow any guideline.

The shared care programme had three elements (box 2): (1) knowledge transfer; (2) communication channels; and (3) active patient involvement.

Knowledge transfer

Discharge summary letters were written according to the study guideline and contained details of the investigation, treatment, and information the patient had received. The letters also described in detail which physical, psychological, and social problems the patients had or might expect to get, and contained information about what the oncologists expected the GP to do. In addition, the GP received specific information about the patient's type of cancer, treatment plans, and prognosis as well as general information about treatment of common side effects and pain.⁷

Communication channels

Names and telephone numbers of doctors and nurses responsible for the patient were provided.

Box 2 Shared care programme**Knowledge transfer**

- Discharge summary letters following predefined guidelines
- Specific information on the disease and its treatment
- General information about chemotherapy
- General information about radiotherapy
- General information about pain treatment
- Information about treatment of induced nausea and sickness
- Information about some acute oncological conditions

Communication channels

- Names and phone numbers of doctors and nurses responsible for the patient were attached to the discharge summary letter to the GPs

Active patient involvement

- In the intervention group the patients received oral as well as written information about the information package to their GP
- The patients were encouraged to contact their GP when facing problems they assumed could be solved in this setting

Active patient involvement

Patients were recommended to contact their GP when facing problems they assumed could be solved in this setting and they were told that the GP would receive an information package.

The shared care programme was launched when the patient left the Department of Oncology or the outpatient department—that is, when the patient left hospital. The information was sent by ordinary mail to the GPs who were receiving patients from the intervention group. The information was expected to arrive the following day.

Outcome measures

The outcome measures focused on the patients' attitude to the healthcare services, reports on contacts with the GP, and health related quality of life and performance status. Evaluations were performed three times: soon after the introduction of the shared care programme and 3 and 6 months thereafter. The first questionnaire at time 0 was therefore answered after the introduction of the shared care programme. Outcome measures were monitored using three instruments:

(1) The patient's attitude towards the health care system. Part of an English questionnaire was used together with new questions based on results from interviews with cancer patients and caregivers.⁷ The new questions were developed on the basis of a template similar to the English questions.¹¹ Two successive pilot tests were performed, each with 10 patients. Firstly, the English questions were translated and tested together with the new questions to reveal linguistic difficulties.¹⁵ The second test focused on aspects of content validity.^{13 16 17} Construct validity was tested on data from the 6 months score, applying principal component analysis, non-parametric correlation Spearman's rho, and Cronbach's coefficient α tests.¹⁸ The final indexes are shown in the appendix.

(2) The European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire Core 30 (EORTC QLQ-C30) (version 3.0). This questionnaire consists of 30 core questions about physical function, global scores, and symptoms. A Danish translation was available and the scoring manual was followed.¹⁹ Summarised scales were unweighted in our study.

(3) Eastern Cooperative Oncology Group (ECOG) Scale of Performance Status adopted by the WHO. Questions about performance status were applied to assess the patients' level of function and capability of self-care.^{14 20}

Sample size

A sample of 194 (2 × 97) randomised patients was theoretically enough to achieve statistically significant differences with a minimal relevant difference of 20%, a 0.050 two sided significance level, and a 10% risk of type II error. Based on an expected withdrawal rate of about 25%, a total of 250 (2 × 125) patients had to be included.

Statistical analysis

Non-parametric analysis was performed as the data did not show a normal distribution. Comparisons between groups were made using the Mann-Whitney U test. Dichotomous data were compared with Fisher's exact tests. A two sided significance level of 0.05 was chosen.

Results from the questionnaires concerning patients' attitude towards the healthcare system were dealt with according to the manual.¹¹ The questionnaire scores were linearly transformed to a range of 0–100 where a high score represents a more positive attitude towards the subject. The EORTC-QLQ C-30 questionnaire scores were also linearly transformed to a range of 0–100. A high scale score on a functional scale represents a high healthy level of functioning; a high global health status score represents a high quality of life;

Table 1 Characteristics of patients at study entry according to group and sex (n=248)

	Control group (n=127)		Intervention group (n=121)	
	Women (n=87)	Men (n=40)	Women (n=72)	Men (n=49)
Age				
18–29	1 (1.1)	4 (10.0)	1 (1.4)	5 (10.2)
30–39	5 (5.7)	5 (12.5)	7 (9.7)	7 (14.3)
40–49	11 (12.6)	6 (15.0)	15 (20.8)	12 (24.5)
50–59	23 (26.4)	10 (25.0)	20 (27.8)	7 (14.3)
60–69	30 (34.5)	11 (27.5)	17 (23.6)	8 (16.3)
70+	17 (19.5)	4 (10.0)	12 (16.7)	10 (20.4)
Marital status				
Single (never married)	1 (1.1)	3 (7.5)	5 (6.9)	8 (16.3)
Married	44 (50.6)	19 (47.5)	40 (55.6)	24 (49.0)
Living with partner	8 (9.2)	5 (12.5)	2 (2.8)	1 (2.0)
Single (divorced)	9 (10.3)	2 (5.0)	5 (6.9)	4 (8.2)
Single (widowed)	15 (17.2)	5 (12.5)	6 (8.3)	3 (6.1)
Missing	10 (11.5)	6 (15.0)	14 (19.4)	9 (18.4)
Stage of disease				
Local/locoregional	70 (80.5)	22 (55.0)	61 (84.7)	30 (61.2)
Distant	13 (14.9)	13 (32.5)	10 (13.9)	15 (30.6)
Missing	4 (4.6)	5 (12.5)	1 (1.4)	4 (8.2)
Cancer diagnosis				
Breast	53 (60.9)	0	43 (59.7)	0
Gastrointestinal	7 (8.0)	10 (25.0)	6 (8.3)	9 (18.4)
Germinal cell	0	10 (25.0)	0	14 (28.6)
Head and neck	3 (3.4)	4 (10.0)	6 (8.3)	7 (14.3)
Bladder and kidney	0	7 (17.5)	4 (5.6)	7 (14.3)
Ovarian and cervix	15 (17.2)	0	8 (11.1)	0
Sarcoma	4 (4.6)	5 (12.5)	2 (2.8)	5 (10.2)
Malignant melanoma	1 (1.1)	1 (2.5)	1 (1.4)	5 (10.2)
Brain	2 (2.3)	0	1 (1.4)	0
Lung	1 (1.1)	2 (5.0)	1 (1.4)	2 (4.1)
Miscellaneous	1 (1.1)	1 (2.5)	0	0
Treatment intention				
Curative	71 (81.6)	23 (57.5)	64 (88.9)	35 (71.4)
Palliative	9 (10.3)	11 (27.5)	6 (8.3)	10 (20.4)
Missing	7 (8.0)	6 (15.0)	2 (2.8)	4 (8.2)
Allocation of patients to GP practices				
Practices with one patient (n=162)	74		88	
Practices with two patients (n=28)	32		24	
Practices with three patients (n=7)	12		9	
Practice with four patients (n=1)	4		0	
Practice with five patients (n=1)	5		0	

Values are n (%).

but a high score on the symptom scale/item represents a high level of symptoms/problems.¹⁹ The results of the questionnaire on performance status were analysed without transformation.

Ethics, randomisation, and masking

The study was approved by the local scientific ethics committee and written informed consent was obtained from the patients.

A project secretary outside the hospital premises kept a list of numbers from 1–250 randomly arranged into two groups. After obtaining written informed consent from the patients, the investigator opened an envelope with a random number of 1–250. This number was communicated to the project secretary who informed the investigator of the group to which this number (patient) belonged. Once a patient was randomised to a particular group, any further patients from the same general practice were automatically assigned to the same group. The study was unblinded. Patients in both groups were informed of the group to which they had been assigned as active involvement of the patients in the intervention group was part of the strategy. The GPs receiving the information packages were asked not to distribute the material among colleagues in order to prevent bias of the control group. The oncologists only had the list to perform discharge summary letters when they had a patient in the intervention group. They were asked not to make any copy of the list to ensure they would not use it in the control group.

RESULTS

Patient characteristics

A total of 588 patients were registered between August and December 1998, of whom 274 met the inclusion criteria shown in box 1 and 250 agreed to participate. Sixteen patients refused to participate because they felt they could not manage to fill in the questionnaires and we failed to include eight patients. Two patients were excluded after randomisation because they did not meet the inclusion criteria. The characteristics of the remaining 248 patients are shown in table 1.

Randomisation

Randomisation yielded an almost equal number of patients and an almost equal distribution according to disease and sociodemographic parameters in each group (table 1). However, the randomisation produced an imbalance in age with more young patients (18–49 years) in the intervention group.

Flow of participants and follow up

The progress of the patients through the trial is shown in fig 1. The first questionnaire was given to all 248 patients after introduction of the shared care programme. The response rates and the number of patients who dropped out during the 6 months are shown. A total of 48 patients (24 from each group) dropped out of the study, 17 because they died.

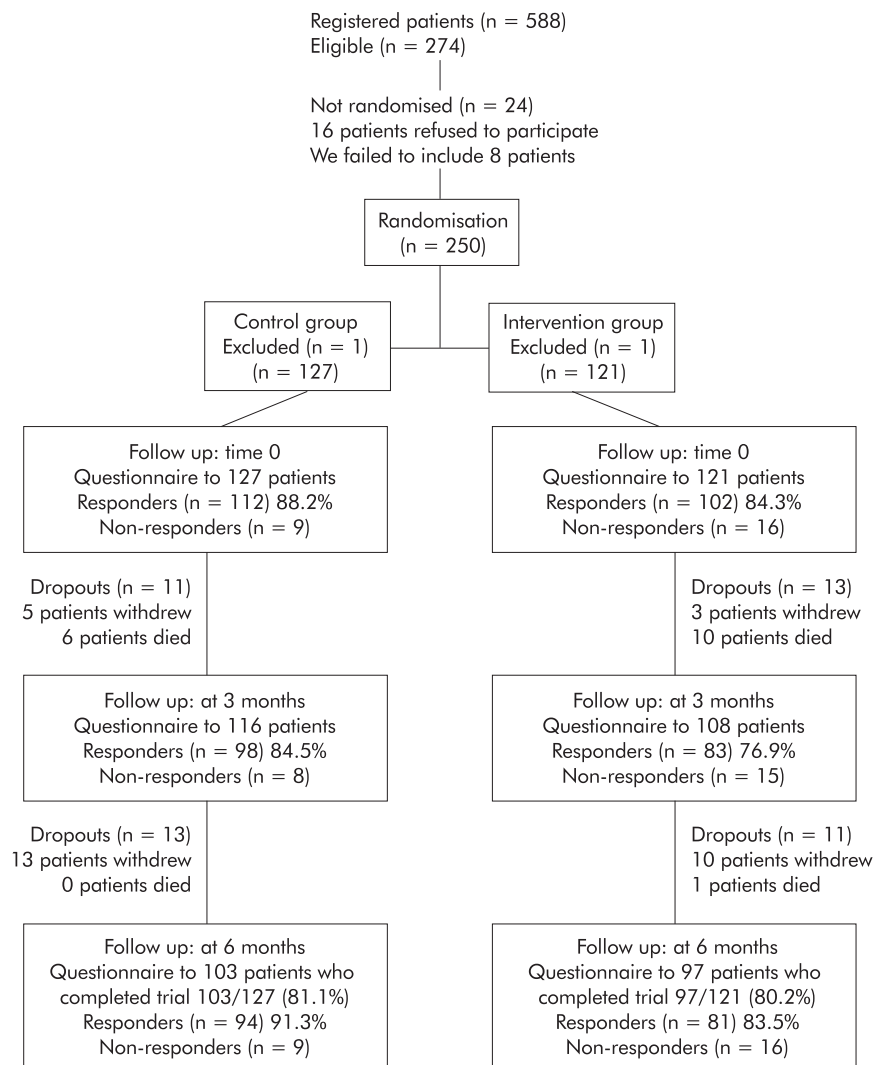


Figure 1 Progress of patients through the trial showing number of responders at the three stages of assessment (0, 3 and 6 months). Dropouts between the assessments are shown.

Patients' attitudes towards cooperation and their feeling of not being left in limbo

The patients' assessments at 3 and 6 months of four different variables concerning cooperation and their feeling of not being left in limbo are shown in table 2. The questions were not asked at time 0 because the patients had no experience of cooperation between the sectors at this time.

The index and the single item for cooperation showed statistically significant improvements at 3 months ($p=0.025$ and $p=0.004$, respectively) but the effect decreased after 6 months. Subgroup analyses on sex and age showed a positive effect for women ($p=0.011$) and for the younger age group ($p=0.001$ and $p<0.001$, respectively) at 3 months.

The index related to patients' feelings of not being left in limbo indicated a difference at 6 months which was almost statistically significant ($p=0.055$). At 6 months men in the shared care programme felt less left in limbo ($p=0.031$), as did the younger age group at both 3 and 6 months ($p=0.024$ and $p=0.031$, respectively).

Patients' attitudes towards their GP

The results for the four variables concerning the GP are shown in table 3. Questions regarding patients' attitudes towards their GP were asked at time 0 and 3 and 6 months later. At time 0 the intervention group had a more positive assessment of the information they received from their GP than the

control group; the difference was almost statistically significant ($p=0.051$). Men, in particular, assessed the information from the GP more positively at time 0 ($p=0.007$) and at 6 months ($p=0.028$). All intervention group patients gave evaluation of care a higher score at time 0 than the controls ($p=0.032$). In particular, men gave significantly more prominence to this parameter both at time 0 ($p=0.003$) and at 6 months ($p=0.036$). The younger age group (18–49 years) also scored higher on care at time 0 ($p=0.028$). The GP's knowledge of the disease and treatment was rated more positively by the younger age group at 3 months ($p=0.029$) than by the controls. The global assessment of the GP was significantly better in the intervention group ($p=0.036$), particularly for men at time 0 ($p=0.010$).

Patients' contacts with their GP during the study

Table 4 shows the patients' reports on contacts with their GPs. The two groups showed no differences at time 0 when all patients were considered together. However, patients in the intervention group had significantly more contacts with their GPs than the controls, both after 3 months ($p=0.049$) and 6 months ($p=0.046$). Analysis by sex showed that men in the control group had the highest number of contacts with their GP at time 0 ($p=0.042$), but the reverse was the case at 3 and 6 months when men in the intervention group had most contacts with their GPs ($p=0.007$ and $p=0.014$, respectively). No

Table 2 Patients' attitudes towards the cooperation between the primary sector and the Department of Oncology and patients' assessments of their feeling of not being left in limbo

	3 months					6 months				
	Control		Intervention			Control		Intervention		
	N	Mean	N	Mean	p value*	N	Mean	N	Mean	p value*
Intersector cooperation (all patients)†	62	55.04	57	64.80	0.025	62	51.71	59	59.22	0.055
Global assessment of intersector cooperation‡	76	56.58	69	69.57	0.004	76	58.55	71	63.73	0.142
Feeling of not being left in limbo§	77	62.80	67	67.70	0.111	77	55.58	65	65.49	0.055
Global assessment of the feeling of not being left in limbo¶	83	55.12	76	61.84	0.168	83	52.71	72	57.64	0.324
Intersector cooperation†										
Women	44	57.81	34	66.91	0.095	42	54.61	35	61.07	0.208
Men	18	48.26	23	61.68	0.091	20	45.63	24	56.51	0.076
Global assessment of intersector cooperation‡										
Women	55	58.18	42	73.21	0.011	52	62.02	43	65.12	0.565
Men	21	52.38	27	63.89	0.137	24	51.04	28	61.61	0.078
Feeling of not being left in limbo§										
Women	57	63.28	42	69.22	0.118	54	59.13	38	65.04	0.246
Men	20	61.43	25	65.14	0.429	23	57.30	27	66.14	0.031
Global assessment of the feeling of not being left in limbo¶										
Women	61	56.15	47	64.36	0.127	59	51.69	42	55.36	0.595
Men	22	52.27	29	57.76	0.541	24	55.21	30	60.83	0.345
Intersector cooperation†										
Age 18–49	20	45.94	26	63.70	0.001	23	48.10	27	58.10	0.121
Age 50–85	42	59.38	31	65.73	0.328	39	53.85	32	60.16	0.173
Global assessment of intersector cooperation‡										
Age 18–49	23	43.48	28	70.54	0.001	26	54.81	30	58.33	0.469
Age 50–85	53	62.26	41	68.90	0.200	50	60.50	41	67.68	0.119
Feeling of not being left in limbo§										
Age 18–49	23	56.68	31	67.05	0.024	25	54.29	30	65.48	0.031
Age 50–85	54	65.41	36	68.25	0.337	52	60.65	35	65.51	0.367
Global assessment of the feeling of not being left in limbo¶										
Age 18–49	25	50.00	32	62.50	0.098	28	45.54	34	55.15	0.204
Age 50–85	58	57.33	44	61.36	0.450	55	56.36	38	59.87	0.606

Subgroup analyses for sex and age differences. Assessments 3 and 6 months after the introduction of the shared care programme.

N=number of patients who answered all index/item questions. Questions with missing values were excluded, so the numbers given here are lower than the numbers from the responders (fig 1).

Mean values range from 0 to 100. Questionnaire scores were linearly transformed to a range from 0 to 100. A high score represents a more positive attitude toward the subjects. Mean values are listed.

*The values did not correspond to a truly normal distribution but a mean value can illustrate the distribution. The Mann-Whitney U test was applied to detect statistical differences between the control and intervention group. Statistical level of significance 0.05. Asymptote significance (two tailed).

†The index consists of four questions concerning intersector cooperation.

‡The item consists of one question concerning the global assessment of intersector cooperation.

§The index consists of seven questions concerning the care during the period after coming out of hospital.¹¹

¶The item consists of one question concerning the global assessment of the care during the period after coming out of hospital.

differences were seen with regard to the contacts of the female patients. In the older intervention group (50–85 years) the highest contact frequency was seen at 6 months ($p=0.050$).

Patients' assessments of their health related quality of life (EORTC QLQ-C30)

The results are presented in table 5 and show no statistically significant differences between the two groups.

Performance status

There was no difference in performance status between the two groups (table 6).

DISCUSSION

The shared care programme used in this study had a significant effect on patients' evaluations of issues of cooperation, their feeling of not being left in limbo, and their attitudes towards and reported contacts with their GP. Patients in the intervention group overall had significantly more frequent contacts with their GPs than controls. Women in both groups had a positive attitude towards the questions, and Danish women in general contact their GP frequently. Men, on the other hand, are more reticent, but the intervention caused them to contact their GP as often as the women. Studies of sex differences in patterns of confiding among newly diagnosed cancer patients have shown that women turn to several

different persons for psychological and social support, whereas men are more likely to have only one confidante, usually their wives.^{21,22} This study apparently gave men the opportunity of having at least one more confidante—namely, their GP. Young patients in the intervention group ascribed improvements to factors like the GP's knowledge and care, intersectoral cooperation, and the feeling of not being left in limbo.

There were no differences in EORTC QLQ-C30 scores between the groups and no differences were found in health related quality of life. The intervention did not influence patients' health related quality of life in either a positive or negative direction, which means that we can tell cancer patients when including them in a shared care programme that it has been shown that it will at least not influence the health related quality of life in a negative direction. The performance status did not differ between the two groups. The shared care programme had no influence on patients' ability to perform simple physical activities.

The study had the advantage of being prospective and randomised. The participants were included consecutively with a participation rate of 91.2% (248/272), so the study population can be regarded as representative. Randomisation yielded an almost equal number of patients in each group, except that there were more young patients in the intervention group. However, we obtained our goal of equal numbers in each

Table 3 Patients' attitudes towards their general practitioner (GP)

	Time 0					3 months					6 months				
	Control		Intervention			Control		Intervention			Control		Intervention		
	N	Mean	N	Mean	p value*	N	Mean	N	Mean	p value*	N	Mean	N	Mean	p value*
Information from the GP (all patients)†	63	67.66	55	78.18	0.051	39	67.63	44	75.57	0.460	38	68.59	43	74.27	0.377
Care from the GP‡	68	74.34	66	83.64	0.032	42	76.79	50	83.50	0.144	36	77.50	45	79.22	0.542
GP's knowledge§	47	65.78	50	68.83	0.942	40	66.04	38	69.52	0.630	27	66.67	32	64.84	0.588
Global assessment of the GP¶	72	58.68	69	71.01	0.036	46	62.50	51	75.98	0.060	41	64.02	45	68.89	0.438
Information from the GP†															
Women	39	70.51	36	78.47	0.761	31	70.36	23	79.89	0.279	31	71.77	28	74.78	0.933
Men	24	63.02	19	77.63	0.007	8	57.03	21	70.83	0.374	7	54.46	15	73.33	0.028
Care from the GP‡															
Women	41	78.05	42	84.05	0.915	34	78.97	28	86.61	0.194	28	81.07	29	79.66	0.539
Men	27	68.70	24	82.92	0.003	8	67.50	22	79.55	0.069	8	65.00	16	78.44	0.036
GP's knowledge§															
Women	32	70.31	31	67.74	0.370	34	68.63	24	69.44	0.987	22	70.83	23	63.77	0.204
Men	15	56.11	19	70.61	0.218	6	51.39	14	69.64	0.123	5	48.33	9	67.59	0.135
Global assessment of the GP¶															
Women	44	61.93	44	68.75	0.492	38	63.16	29	78.45	0.058	33	68.94	28	72.32	0.952
Men	28	53.57	25	75.00	0.010	8	59.37	22	72.73	0.318	8	43.75	17	63.24	0.127
Information from the GP†															
18–49	16	69.92	24	76.56	0.343	11	61.36	19	70.72	0.663	11	68.89	18	68.40	0.910
50–85	47	66.89	31	79.44	0.062	28	70.09	25	79.25	0.371	27	68.06	25	78.50	0.166
Care from the GP‡															
18–49	17	70.59	28	81.61	0.028	11	68.64	20	80.25	0.071	12	80.42	18	77.22	0.966
50–85	51	75.59	38	85.13	0.158	31	79.68	30	85.67	0.513	24	76.04	27	80.56	0.448
GP's knowledge§															
18–49	9	54.63	21	60.71	0.872	11	43.94	14	66.67	0.029	6	58.33	10	64.17	0.780
50–85	38	68.42	29	74.71	0.576	29	74.43	24	71.18	0.638	21	69.05	22	65.15	0.666
Global assessment of the GP¶															
18–49	17	52.94	31	68.55	0.094	13	57.69	21	70.24	0.246	12	60.42	18	56.94	0.879
50–85	55	60.45	38	73.03	0.119	33	64.39	30	80.00	0.104	29	65.52	27	76.85	0.169

Assessments were made at time 0 and 3 and 6 months after the introduction of the shared care programme. Subgroup analyses were performed for sex and age differences.

N=number of patients who answered all index/item questions. Questions with missing values were excluded, so the numbers given here are lower than the numbers from the responders (fig 1).

Mean values range from 0 to 100. Questionnaire scores were linearly transformed to a range from 0 to 100. A high score represents a more positive attitude towards the subjects.

*The Mann-Whitney U test was applied to detect statistical differences between the control and intervention groups. Statistical level of significance 0.05. Asymptote significance (two tailed).

†The index consists of four questions concerning information from GPs.¹¹

‡The index consists of five questions concerning care from the GP.

§The index consists of three questions concerning the GP's knowledge of disease and treatment.

¶The item consists of one question concerning the global assessment of the GP.

group. Only a few general practices had more than three study patients, which reduced the problem of cluster randomisation as it is known that the design effect is small when the number of patients per general practice is less than 10. Furthermore, assessments were made with validated instruments. Only a few patients were reluctant to participate and high response rates were achieved in both groups, which may indicate that the patients considered the study important. On the other hand, the study may have been too small. The study was designed so that inclusion of 248 patients would be enough to reveal an effect with a minimal relevant difference between the groups of 20%. This may be optimistic, and a type II error may consequently be possible.

We used random allocation without blinding because we wanted to involve the patients by informing them about their possibilities. This implies a risk of information bias by the GP which may have influenced the time 0 scores. Patients in the intervention group may have had more positive expectations of their GP, knowing that they would be better informed about the disease and its treatment, and this may explain why the next two assessments by the GP were relatively less positive. The scores at time 0 should therefore be treated with some caution. However, patients in the control group were also informed about the study and the group to which they belonged, and this information may have caused them to see their GP more than they would otherwise have done. The

absence of regular baseline data is a problem as the patients actually received information about the intervention before answering the first questionnaire. They had 14 days to answer the questions at time 0. We had not foreseen this bias due to positive expectations in the intervention group. It would have been a real baseline if the patients had answered the time 0 questionnaires before randomisation, but we had a practical problem with time. The present project took time from the patients' scheduled time in the hospital. If we had also asked the patients to complete a questionnaire, the logistics in the department would have been disturbed and some patients might have refused to fill in questionnaires in their stressed situation. This might have resulted in only a specific group of patients wanting to participate with the risk of producing a non-representative group of patients. In spite of these problems, we wanted to present the data, knowing that they do not represent a true baseline, so interpretation is not really possible.

Patients' assessments of the shared care programme were evaluated by questionnaires in which we used part of the "patient career diary" together with new questions. The absence of validation in a large similar study group constitutes a methodological weakness, but the questionnaire was validated with the number of patients we had and we thus obtained a primary validated instrument.^{11 12}

Table 4 Patients' reports on contacts with their general practitioner (GP)

	Time 0†		3 months‡		6 months‡	
	Control	Intervention	Control	Intervention	Control	Intervention
All						
Yes	95 (74.8)	82 (67.8)	49 (38.6)	53 (43.8)	40 (31.5)	46 (38.0)
No	17 (13.4)	19 (15.7)	48 (37.8)	28 (23.1)	51 (40.2)	31 (25.6)
Missing	15 (11.8)	20 (16.5)	30 (23.6)	40 (33.1)	36 (28.3)	44 (36.4)
p value*		0.583		0.049		0.046
Women						
Yes	63 (72.4)	53 (73.6)	41 (47.1)	30 (48.4)	34 (39.1)	28 (38.9)
No	14 (16.1)	8 (11.1)	31 (35.6)	18 (29.0)	33 (37.9)	19 (26.4)
Missing	10 (11.5)	11 (15.3)	15 (17.2)	14 (22.6)	20 (23.0)	25 (34.7)
p value*		0.488		0.575		0.445
Men						
Yes	32 (80.0)	29 (59.2)	8 (20.0)	23 (46.9)	6 (15.0)	18 (36.7)
No	3 (7.5)	11 (22.4)	17 (42.5)	10 (20.4)	18 (45.0)	12 (24.5)
Missing	5 (12.5)	9 (18.4)	15 (37.5)	16 (36.7)	16 (40.0)	19 (38.8)
p value*	0.042			0.007		0.014
18–49 years						
Yes	24 (75.0)	33 (70.2)	13 (40.6)	20 (43.5)	11 (34.4)	17 (36.2)
No	6 (18.8)	8 (17.0)	15 (46.9)	13 (28.3)	17 (53.1)	16 (34.0)
Missing	2 (6.3)	6 (12.8)	4 (12.5)	13 (28.3)	4 (12.5)	14 (29.8)
p value*		1.000		0.310		0.441
50–85 years						
Yes	71 (74.7)	49 (66.2)	36 (37.9)	33 (44.0)	29 (30.5)	29 (39.2)
No	11 (11.6)	11 (14.9)	33 (34.7)	15 (20.0)	34 (35.8)	15 (20.3)
Missing	13 (13.7)	14 (18.9)	26 (27.4)	27 (36.0)	32 (33.7)	30 (40.5)
p value*		0.485		0.087		0.050

Data are presented as n (%).

* χ^2 tests, Fisher's exact test. Statistical level of significance 0.05. Asymptote significance (two tailed).

†Patients were asked to report whether they had had contact with their GP from the first sign of the disease and until the first contact with the Department of Oncology.

‡Patients were asked to report whether they had had contact with their GP during the previous 3 months.

The health related quality of life questionnaire has been validated in Danish cancer patients and we applied the instrument without further validation. The purpose of the EORTC QLQ-C30 questionnaire was to develop an integrated measurement system for evaluating the quality of life of patients participating in international clinical trials to determine whether their quality of life had become better, stayed the same, or become worse while participating in the trial.^{13, 19}

The performance status was not validated further in our study as this is a well known and validated instrument. It has also been used to determine whether the use of medication (shared care programme) influences the patient's ability to carry on his or her normal activities.^{14, 20}

Other studies have stressed the importance of providing patients with information as a way of reducing their sense of helplessness.²³ Patients with chronic diseases like cancer, who are often treated in different parts of the healthcare system, have a clear opinion about what they demand of the system—namely, access to appropriate care, information about care, knowledge of what is going on, and continuity. Failure in any of these dimensions causes patients to feel left in limbo.²⁴ The present study sought to improve system performance on these dimensions by enhancing patients' abilities to receive additional information and to have information received in the secondary healthcare sector repeated by their GP. Our results indicate that this approach decreases their feeling of being left in limbo.

Studies on shared care at the primary/secondary care interface show that successful disease management requires communication, role division, and sharing between the healthcare sectors involved.⁹ Studies on communication across sector boundaries in paediatric oncology have shown that an information package may effectively improve communication between the oncology unit and the GP.¹⁰ Our results support these findings. A clinical review of recent advances in

oncology emphasises the important role of the GP as cancer treatment is largely an outpatient activity where patients may therefore seek their GP's advice when presented with treatment options.³ This review stresses the need for GPs to be better educated in cancer care and the importance of communication and discharge summary letters as educational tools for GPs. It also admitted, however, that the best way of achieving good communication between oncologists and GPs has not yet been found.³

The shared care programme used in this study is simple. The oncologists provided the specific information on the different diseases and their treatment. The discharge summary letters were the most difficult part of the programme as they interfered with the daily routine of the doctors. These letters were written according to a predefined guideline and had to be sent on the day the patient left the department or outpatients. However, the department was used to conducting randomised controlled trials so the doctors were willing to follow the guideline for the discharge summary letters. Part of the success was because the department felt an ownership of the project. The head group of consultants accepted the project and told the doctors in the department to follow it. A further reason for its success was that the researcher (JDN) followed the project daily. It is essential to have an innovator when performing shared care programmes across borders in a healthcare system who has connections with both the primary and the secondary sectors. Studies like this could be "rolled out" into routine practice, but not until an innovator for the project is in place. The innovator must be prepared to invest time and energy in getting the project accepted in both settings. In the Danish healthcare system some GPs work a few hours a week in hospital departments as coordinators. These coordinators could be innovators for different shared care programmes.

The challenge to improve interpersonal communication between doctors in different settings remains, however.

Table 5 Newly referred cancer patients' assessments of the EORTC-QLQ-C30 quality of life questionnaire at time 0 and 3 and 6 months after the introduction of the shared care programme

	Time 0					3 months					6 months				
	Control		Intervention			Control		Intervention			Control		Intervention		
	N	Mean	N	Mean	p value*	N	Mean	N	Mean	p value*	N	Mean	N	Mean	p value*
<i>Functional scales</i>															
Physical functioning	111	78.35	101	77.33	0.971	96	82.03	83	80.72	0.804	91	81.32	80	80.92	0.620
Role functioning	109	53.82	100	60.17	0.141	97	69.76	81	72.02	0.554	91	72.71	79	73.42	0.781
Emotional functioning	110	68.26	100	69.00	0.776	97	77.12	83	80.22	0.308	91	78.14	80	75.42	0.665
Cognitive functioning	110	83.94	100	82.00	0.649	97	84.02	83	86.14	0.690	91	84.98	80	81.88	0.357
Social functioning	110	86.36	99	85.69	0.951	97	84.54	83	87.15	0.318	91	83.70	80	84.17	0.744
<i>Global health status</i>															
Global health status	109	63.46	98	65.99	0.236	97	69.93	83	70.08	0.782	92	69.11	80	69.79	0.933
<i>Symptom scales/items</i>															
Fatigue	111	36.94	101	34.43	0.272	97	35.62	83	30.79	0.177	91	31.14	80	29.31	0.874
Nausea and vomiting	111	7.06	101	7.43	0.987	97	8.59	83	10.44	0.886	92	8.15	80	8.13	0.843
Pain	110	29.24	101	23.43	0.076	97	24.74	83	19.28	0.069	91	21.80	80	19.38	0.345
Dyspnoea	111	9.61	100	15.33	0.040	96	14.58	83	13.25	0.930	92	14.49	80	15.00	0.921
Insomnia	111	32.43	101	26.40	0.113	96	27.43	83	23.29	0.168	92	24.28	80	22.50	0.729
Appetite loss	111	18.92	100	19.00	0.855	97	14.09	83	16.47	0.761	92	15.22	80	15.00	0.591
Constipation	109	12.23	99	12.12	0.677	97	9.97	83	12.05	0.922	91	10.26	80	12.50	0.502
Diarrhoea	108	12.35	98	11.22	0.458	96	13.54	83	12.45	0.587	91	13.55	80	11.25	0.564
Financial difficulties	110	13.94	98	8.84	0.145	97	12.37	82	12.20	0.591	91	16.85	79	11.39	0.110

N=number of patients who answered all index/item questions. Questions with missing values were excluded, so the numbers given here are lower than the numbers from the responders (fig 1).

Mean values are listed. The values did not follow a normal distribution. The first five items show a distribution towards higher numbers (right skewed). The global and fatigue items show a tendency towards a normal distribution. The last indexes/items show a distribution towards lower numbers (left skewed). The mean measure scores range from 0 to 100. A high score on a functional scale represents a high/healthy level of functioning, a high score on the global health status represents a high quality of life, but a high score on a symptom scale represents a high level of symptoms.

*The Mann-Whitney U test was applied to detect statistical differences between the control and the intervention group. Statistical level of significance 0.05. Asymptote significance (two tailed).

Physical functioning (5 items), role functioning (2 items), emotional functioning (4 items), cognitive functioning (2 items), social functioning (2 items), global health status (2 items), fatigue symptom (3 items), nausea and vomiting (2 items), pain symptom (2 items), dyspnoea (1 item), insomnia (1 item), appetite loss (1 item), constipation (1 item), diarrhoea (1 item). Financial difficulties (1 item).

Table 6 Performance status in control (n=127) and intervention (n=121) groups at time 0 and 3 and 6 months after the introduction of the shared care programme

	Time 0		3 months		6 months	
	Control	Intervention	Control	Intervention	Control	Intervention
(0) Fully active, able to carry out all normal activity without restrictions	37	37	32	35	35	30
(1) Restricted in physically strenuous activity but ambulatory and able to carry out light work	76	74	50	41	40	35
(2) Ambulatory and capable of self-care but unable to carry out any work. Up and about more than 50% of waking hours	8	8	11	9	12	10
(3) Capable of only limited self-care, confined to bed or chair more than 50% of waking hours	5	2	2	3	1	1
(4) Completely disabled. Cannot carry on any self-care. Totally confined to bed or chair	1	0	0	0	0	1
Missing	0	0	21	20	15	20
Drop outs (total)	0	0	11	13	24	24

Further research is required into cultural barriers to communication in the healthcare system because improved communication and patient involvement may give relief to cancer patients and perhaps also improve the overall treatment results and care management. The demand for further research at the interface between the primary and secondary sector is particularly important because the population is growing and its life expectancy increasing, more cancer patients are being diagnosed, and more complex treatment options are being developed. This requires a system in which the organisation of cancer care is well designed, with oncologists sharing their responsibility with GPs.

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Key messages

- Patients with cancer may feel uncertain about what is going to happen when they are referred to hospital and may experience psychological morbidity and dissatisfaction with the provision of information and care.
- An intersectoral shared care programme had a positive effect on patient evaluation of:
 - attitudes towards the healthcare system;
 - intersectoral cooperation;
 - the feeling of not being left in limbo;
 - contacts with the general practitioner.
- The effect was particularly significant in men and in younger patients.

APPENDIX

Origin	Index/item	Statements
New	Intersectoral cooperation	I wished there would be a better cooperation between the hospital doctors and my GP I felt confident about the cooperation between my GP and the hospital doctors I got the impression that the hospital doctors left my GP out The hospital doctors have kept my GP informed of my progress ^{11*}
New	Global assessment of intersectoral cooperation	Altogether I have been satisfied with the cooperation between my GP and the hospital doctors.
Baker <i>et al</i> ¹¹ (section 5)†	Feeling of not being left in limbo	After I came out of hospital I sometimes felt as though I had been left "in limbo" After I came out of hospital I knew who to go to for help and advice I wish I had been given a little more help in coping with the medical side of my condition when I came out of hospital I wish I had been given a little more help in coping with my worries when I came out of hospital I would have liked to have been given more information about what to expect when I came out of hospital The hospital staff could have done more to make sure that I would be able to cope when I went home I have had enough information about my progress since I came out of hospital
New	Global assessment of not being left in limbo	Altogether I have found things concerning my care that could be improved since I came out of hospital.
Baker <i>et al</i> ¹¹ (section 2)‡	Information from the GP	Sometimes I felt that the GP did not see my condition as being very important I came away from the GP visits with some of my questions unanswered I did not get enough advice on my conditions Some of the GP's advice has been different from the advice that I got from the hospital
New	Care from the GP	I felt the GP told me everything that I wanted to know ^{11*} My GP has supported me during my illness I felt confident about my GP's knowledge of my disease My GP is very good at listening to me ^{11*} My GP takes the time to listen to me
New	GP's knowledge	My GP has enough knowledge of my disease My GP has enough knowledge of the treatment of my disease My GP has enough knowledge of side effects of my treatment
New	Global assessment of the GP	Altogether my GP could have supported me better during my illness

*Questions developed by Baker *et al*¹¹ but here mixed with new questions into new indexes.
†Section 5: Your hospital stay: Your care during the month after you came out of hospital.¹¹
‡Section 2: Other visits to the GP surgery (in connection with your hospital/clinic visits), component 1, information.¹¹

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