Evaluation of the Psychological Effects of an Intensive Follow-up Program 'From a Distance' as Compared to Care as Usual in Colorectal Cancer Patients

A Pilot Study

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Abstract

Objectives. This pilot study examines the attitude, satisfaction, effects and preferences related to a new type of intensive follow-up among colorectal cancer patients after curative treatment. The aim of the study was to examine whether an intensive follow-up program with serum Carcino Embryonic Antigen (CEA) measurements, but with less scheduled outpatient clinic visits, is feasible in terms of patients' evaluation and perception.

Design and Method. This study had a between-subjects design with a total of 109 patients completed a questionnaire. The questionnaire contained questions about patients' attitude towards the follow-up program, about the existence of depression, anxiety and cancer worries and about the satisfaction with the follow-up program. Beyond that we evaluated patients' preferences for an eventual further follow-up program. The trial group of patients underwent a monthly serum CEA blood test and a visited the the physician once every 6 months to a year. The comparison group brought a visit each 3 to 6 months to the physician in addition to an ultrasound once per half year.

Results. No significant differences were found between the trial group and the comparison group according to the attitude towards follow-up, anxiety, depression and cancer worries. The trial group was even more satisfied with their follow-up program ($p = 0.02$). Most patients in both groups preferred their current follow-up program, though the majority of the trial patients had a second preferred option for the monthly blood tests without contact with the physician. Patients in the comparison group who suffered from more anxiety, depression and cancer worries preferred a more intensive follow-up program including the monthly serum CEA blood test.

Conclusion. The positive evaluation of the intensive follow-up program and the preference of the trial group for the monthly serum CEA blood test rather than visiting the physician makes intensive follow-up without increase in outpatient clinic visits feasible.

Introduction

Colorectal cancer is the third most-common type of cancer in the Netherlands, with an occurence of 10.000 new patients each year in the Netherlands (Association of Comprehensive Cancer Centres, 2005). After curative resection patients are subjected to a follow-up program that constitutes of outpatient clinic visits each 3 to 6 months during 5 years, complemented with Carcino Embryonic Antigen (CEA) measurements and imaging techniques. The first objective of follow-up programs is the early detection of metastases for intended curative treatment and to observe the result of medical treatment. Secondly, a follow-up program can offer mitigation of the social and psychological load of the disease. In the year 2002 approximately 30.000 colorectal cancer patients participated in a follow-up program (Health Council of the Netherlands, 2007). In about 30% of these patients recurrent disease during follow-up is found (Tjandra & Chan, 2007). Currently in only 10% of patients with recurrent symptoms a curative treatment is possible (Tjandra et al., 2007).

Extensive research has identified various types of follow-up programs for choosing the most effective strategy in the early detection of recurrent disease and its effect on patients' survival. A limited gain in survival was found for the more intensive follow-up programs. However, the ultimate strategy could not be determined up until now (Kievit, 2000; Jeffery, Hickey & Hider, 2002; Renehan, Egger, Saunders & O'Dwyer, 2002; Tjandra & Chan, 2007). Only the serum CEA has proved to increase the percentage of curative resection of metachronous metastases and final patient survival (Grossman, de Bock, Klaase & Wiggers, 2009). All intensive follow-up schedules tested up to now entailed an increase in the frequency of outpatient clinic visits.

Colorectal cancer is a frequent disease unfortunately. Follow-up programs cause a large logistic pressure on the outpatient clinic capacity and are costly (Kievit & Bruinvels, 1995; Macafee, Whynes & Scholefield, 2007; Papagrigoriadis, 2007). Therefore there is an urgent need for developing a follow-up program that is effective but still cost-efficient without causing a logistic load. A new type of intensive follow-up aimed at early detection of recurrent disease with the use of frequent serum CEA measurements and a decrease of remote check-ups (follow-up 'from a distance'), is currently under investigation in a phase II clinical trial at the Medical Spectrum Twente. This type of follow-up is only feasible when patients do not experience negative side effects however. The underlying study compares and evaluates the psychological effects, experiences and preferences of the patients in the trial group to patients who have care as usual.

Psychological effects of follow-up

Patients vary substantially in how they experience follow-up programs. In general, patients have a positive attitude towards follow-up schedules (Graupe, Schwenk, Bracht, Kröner-Herwig & Stock, 1996; Stiggelbout et al., 1997). Patients prefer routine follow-ups above ignoring follow-up (Kiebert, Welvaart & Kievit, 1993), even if the visit leads to anxiety and there is no guarantee recurrences will be detected (Fernie & Mackean, 2002; Papagrigoriadis & Heyman, 2003; Steele, Haigh & Knowles, 2007). De Bock et al. (2004) found that breast cancer patients had high expectations of follow-ups. The respondents believed that an early detection of recurrence will lead to a higher chance to survive. In previous studies patients reported feeling reassured by the follow-up scheme (Papagrigoriadis et al., 2003). The communication with the physician in earlier follow-up programs was judged moderately positive (Stiggelbout et al., 1997; De Bock et al., 2004).

Besides the positive effects of follow-up, also negative consequences of follow-up visits exists. The follow-up process may cause anxiety, depression and distress (Lampic et al.,1994; Graupe et al., 1996; Stiggelbout et al., 1997; Hutton & Williams, 2001; Fernie & Mackean, 2002; Humphris et al., 2003; Steele et al., 2007; Kew, Galaal & Manderville, 2009). Patients may be distressed in the week before a follow-up visit (Papagrigoriadis & Heyman, 2003), they may experience anxiety for the physical examinations (Graupe et al., 1996) and respondents may have some distress about the results of performed tests (Fernie & Mackean, 2002). Patients also worry about the recurrence of cancer (Lampic et al., 1994; McCaul, Branstetter, O'Donnell, Jacobsen & Qiunlan, 1998; Fernie & Mackean, 2002; De Bock et al., 2004). De Bock et al. (2004) found that patients didn't experience much nervous anticipation or many disadvantages in follow-up.

Previous studies have examined whether a higher frequency of follow-up visits lead to more distress. Graupe et al. (1996) found that patients with a more frequent follow-up scheme do not have more stress than patients with fewer follow-up visits. Patients who had more frequent check-up visits had more confidence in the follow-up process (Kjeldsen, Thorsen, Whalley & Kronborg, 1999). Stiggelbout et al. (1997) reported that the majority of the patients was satisfied with the number of follow-up visits.

In general, the above mentioned studies show that patients experience some distress from a follow-up, but the majority of people in earlier studies had a positive attitude towards their follow-up program. It seems that the advantages of a follow-up program outweigh the disadvantages (Stiggelbout et al., 1997).

Attitudes towards follow-up can be influenced by the features of the follow-up program, like the burden of medical investigations or the frequency of follow-up visits. It may be influenced by aspects other than the follow-up program itself. In order to understand and clarify patients' attitudes it is important to know which elements influence patients' attitude. Therefore the

results of this study will be evaluated with the help of a theoretical model about attitude.

According to the 'three component model of attitudes' (Zanna & Rempel, 1988), attitudes are based on the three aspects; beliefs, feelings and past behaviours. With the help of this model, the results of this study will be viewed in the context of this model aiding the understanding of the results.

The intensive follow-up as carried out in the trial at the Medical Spectrum Twente (MST) differs on substantial aspects from previous studies. More intensive follow-up is realized through monthly testing of serum CEA, after which the test results are reported by letter. This high intensity has not been evaluated before. Follow-up visits to the outpatient clinic and thus contact with the physician is limited to visits every 6 months to a year, and is thus less frequent than care as usual.

In this study the influence of this intensive follow-up program was examined in comparison with care as usual. The attitude, anxiety, depression, cancer worries and satisfaction among patients was examined, related to patient characteristics. Secondly, the preference for the type of follow-up, the influence of the effects of follow-up and the attitude on the preferred choice of patients in follow-up was analyzed.

Methods

Setting

The MST and the University Medical Center Groningen (UMCG) are currently examining the efficacy of frequent (every month) testing of serum CEAs on early detection of recurrent disease in a phase II clinical trial (OptCEAtrial). This trial is carried out in the Medical Spectrum Twente. The trial group has a 6 to 12 monthly follow-up at the hospital with the physician and monthly testing of serum CEA. Patients with an increase in CEA-level in two consecutive months are invited by telephone for further examinations in the hospital. In case of a normal CEA-level patients receive the result by letter. In this study design the contact with the physician on the outpatient clinic is less frequent as compared to care as usual.

Patients

For this study, questionnaires were sent to two groups of patients who all had a curative treatment of colorectal cancer in the previous year. The trial group (n = 60) was submitted to a monthly serum CEA blood test, a 6 to 12 monthly outpatient clinic visit and a yearly CT scan at year 1 and 2. In case of questions or worries, patients have access to the hospital for intermittent appointments with a physician. The trial group patients were asked to take part in the study by a physician and all but one of the patients agreed to participate.

In the comparison group (n = 80) the usual follow-up was carried out, consisting of an outpatient clinic visit every 3 to 6 months, often complemented with an ultrasound every six months. The trial group was randomly selected.

Questionnaires

The design exists of questionnaires which were sent to the patients' homes. The questionnaires that were specifically designed for this study have been pretested. First it was tested on random respondents (not specifically patients). After that the questionnaire was tested and evaluated with the aid of an interview with 2 colorectal cancer patients who were part of the trial group and three patients who were part of the comparison group. After that the questions were adjusted and sent to the trial and the comparison group. The questionnaires were sent at a random time, not at a specific moment before or after a follow-up appointment. The time after curative treatment varied from 1 month to 1,5 year.

Attitude

Attitude towards the follow-up program was measured by the Dutch version of a validated attitude questionnaire (De Bock et al., 2004). The questionnaire of the current study existed of four different subscales: reassurance (Cronbach's α = 0,47), nervous anticipation (α = 0,75), general disadvantages (α= 0,61) and communication (α = 0,74). For the exact wording of the items, see the appendix.

In order to measure the experiences with the monthly serum CEA blood test of the trial group patients, a similar attitude questionnaire was developed specifically for this study. The same subscales were used: reassurance (α = 0,57), nervous anticipation (α = 0,87), general disadvantages (α= 0,67) and communication (α = 0,21). Both questionnaires were coded from 0 to 3. Because of the low reliability score of the communication scale, only the separate items of this subscale were used. For both questionnaires applied that a higher score meant a more positive communication and reassurance while a higher score at nervous anticipation and general disadvantages meant a more negative result.

Effects on Anxiety depression and cancer worries

Anxiety and depression were examined by the Dutch version of the Hospital Anxiety and Depression Scale (HADS) (Spinhoven et al., 1997). Within this questionnaire higher scores meant more anxiety (α = 0,89) and more depression (α = 0,88).

Lerman (1994) developed a scale to measure cancer worries. In this study we used the Dutch version of this Cancer Worry Scale (Bleiker, 2008). Within this questionnaire (α = 0,92) patients with higher scores had more cancer worries. The anxiety, depression and cancer worries scale were all coded from 0 to 3.

Satisfaction and preferences

Satisfaction was measured by a questionnaire specifically designed for this study. This 5-item questionnaire (α = 0,90) was measured by a 10-point scale (Table 4). The higher the score, the more satisfied the patient was.

In order to measure patients' preferred follow-up program patients had to declare which program they preferred the most and which program they preferred the least. The patients had the choice between 4 options; (1) no follow-up, (2) visits to the physician every 3 to 6 months (the current mode of the comparison group), (3) every month a blood test or (4) every month a blood test with every 6 months to every year a visit to the physician (current mode of the trial group). A higher score meant a less preferred option for follow-up (most preferred = 1 to less preferred = 4).

Additionally, we asked the patients if they would like to know when they have recurrences even if they are asymptomatic but cannot be treated. The higher the score, the more the patients would like to know if they have recurrent disease.

The exact questions about the satisfaction and preferences of patients are shown in the appendix.

Data analysis

All data were analyzed using SPSS (Statistical Package of the Social Science) for Windows. Descriptive statistics were performed for all variables. The differences in patient characteristics between the two study groups were measured by the Chi square test and the Mann Whitney U test. To asses the scale-differences in attitude towards follow-up, satisfaction and effects, the statistical procedure for one way ANCOVA was used.

Associations between patients' preferred follow-up and attitudes towards follow-up, satisfaction and effects were tested using Spearman's rank-order correlation. The associations with patient characteristics were also measured by the Spearman's rank-order correlation procedure.

Results

A set of 138 questionnaires was sent to the patients, of which 58 to the patients of the trial group and 80 to respondents of the comparison group. Among the patients of the trial group, 49 (84%) completed the questionnaire. A total of 60 (75%) patients of the comparison group returned the questionnaire.

The patient characteristics are presented in Table 1. The comparison group had significantly more males than the trial group. On all other demographic variables no significant differences between the groups were found. It was decided to include gender as a covariate in all subsequent analyses.

Table 1: Patient Characteristics

	Trial group n = 49 (%)	Comparison group n= 60 (%)	p *
Average age	67	67	n.s.
Number of men	38 (79)	30 (53)	0.01
Composition of the family			n.s.
Living alone	8 (17)	7 (13)	
Living together	2 (4)	2 (6)	
Married	38 (79)	45 (82)	
Children			n.s.
None	5 (12)	12 (23)	
Yes < 20 years	4 (9)	3(6)	
Yes > 20 years	34 (79)	37(71)	
Highest education			n.s.
Primary school	10 (21)	10 (18)	
< Higher General Secondary Education	29 (62)	34 (62)	
> Pre-University Education	7 (15)	11 (20)	
Working	9(19)	8 (14)	n.s.
Co morbidity	18 (39)	32 (56)	n.s.

* Chi square and Mann Whitney U test

Attitudes towards the follow-up program

Table 2 shows the scale and item scores on the separate attitude scales of both study groups. No significant differences were found between the two study groups. From the outcomes in Table 2 it can be deduced that the majority of the patients in both study groups felt rather reassured by their own follow-up program. At almost every item in the nervous anticipation scale the trial group experienced less nervous anticipation in comparison to the comparison group patients. The comparison group reported more disadvantages in the follow-up program; they somewhat more considered a follow-up as a negative reminder of the disease in comparison to the trial group. Patients were moderately positive about the communication with the physician; they were able to talk about various things. In total both study groups reported a rather positive attitude towards the follow-up program.

Table 2: scale and item scores on the separate attitude items by trial group and comparison group

	Trial group N = 49					Comparison group N = 60					
	Not at all (%)	Somewhat (%)	Rather (%)	Very much (%)	Mean	Not at all (%)	Somewhat (%)	Rather (%)	Very much (%)	Mean	p*
Attitude											
Reassurance (scale)					**2.3**					**2.3**	n.s.
Perception of reassurance	-	3 (6)	24 (49)	22 (45)	2.4	(17)	5 (9)	26 (44)	27 (46)	2.3	
Reassurance after follow-up	-	4 (8)	28 (57)	17 (35)	2.3	-	8 (13)	26 (43)	26 (43)	2.3	
Advantages outweigh disadvantages	9 (18)	4 (8)	10 (20)	26 (53)	2.1	3 (5)	11 (18)	19 (32)	27 (45)	2.2	
More worries without follow-up	1 (2)	7 (14)	19 (39)	22 (45)	2.3	-	7 (12)	18 (30)	35 (58)	2.5	
Nervous Anticipation (scale)					**0.4**					**0.6**	n.s.
Nervous for follow-up	21 (43)	22 (45)	4 (8)	2 (4)	0.7	20 (33)	26 (43)	12 (20)	2 (3)	0.9	
Bad sleeping before follow-up	39 (80)	7 (14)	2 (4)	1 (2)	0.3	36 (60)	17 (28)	5 (8)	2 (3)	0.6	
Postpone plans after follow-up	36 (74)	7 (14)	3 (6)	3 (6)	0.5	34 (58)	13 (22)	8 (14)	4 (7)	0.7	
Dread follow-up	34 (71)	10 (21)	3 (6)	1 (2)	0.4	31 (52)	20 (33)	5 (8)	4 (7)	0.7	
Rather less frequently follow-up	39 (83)	4 (9)	4 (9)	-	0.3	50 (86)	4 (7)	3 (5)	1 (2)	0.2	
General Disadvantages (scale)					**0.3**					**0.5**	n.s.
Follow-up rather at General Practitioner	44 (92)	4 (8)	-	-	0.1	52 (87)	6 (10)	1 (2)	1 (2)	0.2	
Investigations burdensome	41 (84)	8 (16)	-	-	0.2	46 (77)	11 (18)	2 (3)	1 (2)	0.3	
Is follow-up a negative reminder	25 (52)	16 (33)	7 (15)	-	0.6	20 (33)	32 (53)	4 (7)	4 (7)	0.9	
Communication (scale)					**2.3**					**2.3**	n.s.
Ask about things at follow-up	2 (4)	5 (10)	29 (59)	13 (27)	2.1	-	10 (17)	31 (52)	19 (32)	2.2	
Discuss matters of concern	1 (2)	4 (8)	24 (50)	19 (40)	2.3	1 (2)	10 (17)	27 (45)	22 (37)	2.2	
Do people pay attention to you	1 (2)	-	22 (45)	26 (53)	2.5	-	1 (2)	28 (47)	31 (52)	2.5	
Do physicians have enough time	-	2 (4)	25 (53)	20 (43)	2.4	1 (2)	5 (8)	33 (55)	21 (35)	2.2	

*(p) = scale difference measured by One way ANOVA with gender as a covariate

Table 3: scale and item scores on the separate items by trial group

	Not at all (%)	Somewhat (%)	Rather (%)	Very much (%)	Mean
Attitude					
Reassurance					2.6
Perception of reassurance		1 (2)	19 (39)	29 (59)	
Reassurance after follow-up	7 (14)	2 (4)	17 (35)	30 (61)	
Nervous Anticipation					0.4
Nervous for follow-up	37 (76)	9 (18)	2 (4)	1 (2)	
Nervous while waiting for the results	27 (55)	18 (37)	3 (6)	1 (2)	
General Disadvantages					0.2
Blood test burdensome	43 (88)	5 (10)	1 (2)		
Once a month blood test burdensome	43 (88)	5 (10)	1 (2)		
One week waiting for result too long?	35 (73)	9 (19)	2 (4)	2 (4)	
Communication					
Results by letter	6 (12)	2 (4)	16 (32)	25 (51)	
Important to know when to get the result	4 (8)	9 (19)	16 (33)	19 (40)	
Enough possibility's to contact the physician	2 (4)	2 (4)	33 (67)	12 (25)	

Attitude's towards the blood test

Since only the trial group patients have monthly blood tests, the following results (Table 3) only apply for the trial group. Overall the results of these questions corresponded to the results of the attitude questions which were asked in the comparison group as well. The trial group patients reported a positive evaluation of the blood test. The majority of the patients didn't consider the blood test burdensome at all. In general, patients would like to receive a good result of the blood test by letter and the majority of the trial group patients didn't think one week waiting for the blood test result was too long. Knowing when to receive the result by letter was important to patients and to a large extend the patients reported having enough possibilities to contact the physician.

Table 4: scale and item scores of satisfaction (mean scores)

	Trial group n = 47	Comparison group n = 56	p*
Satisfaction (scale)	**8.8**	**8.3**	**0.02**
Satisfaction with follow-up	8.8	8.4	
Satisfaction frequency follow-up	8.9	8.1	
Satisfaction with doctor-patient contact	9.0	8.6	
Sufficient information about follow-up procedure	8.6	8.1	
Sufficient information during follow-up	8.5	8.2	
Preference			
Do patients want to know if they have recurrences?	**2.4**	**2.0**	**0.03**

*(p) = scale difference measured by One way ANOVA with gender as a covariate

Satisfaction and preferences

A significant difference was found between the trial and comparison group concerning satisfaction. The trial group had higher scores in every separate item of the satisfaction scale. In total, all patients were rather positive about their follow-up program.

To the question whether patients would like to know to have recurrent disease, even if there would be no curative treatment options, a significant difference was found between the two groups. Trial group patients would rather have the knowledge of the presence of recurrent disease in comparison to the comparison group patients.

We also asked patients to indicate their preferred option for follow-up (Table 5). In the trial group the majority chose for their current mode (monthly blood tests and visits to the doctor every 6 to 12 months). In the comparison group about half of the respondents preferred their present mode (3-6 monthly visits to the physician). Patients had the possibility to point out their second preferred choice for a follow-up program. Some of the patients only declared their first choice; therefore the number of cases differed within the first and second choice. More than half of the trial group of patients chose the option with the monthly blood test without visits to the physician. The patients in the comparison group chose very diversely for their second choice. The least attractive option for follow-up was without an established follow-up program.

Table 5: preferred options for follow-up

	Trial group		Comparison group	
	First choice n = 49 (%)	Second Choice n = 37 (%)	First choice n = 59 (%)	Second choice n = 42 (%)
Most intensive follow-up (Monthly blood+ 6-monthly visits to the physician)	33 (67)	5 (14)	20 (34)	13 (22)
Intensive follow-up (Monthly blood tests)	6 (12)	23 (62)	4 (7)	14 (24)
Less intensive follow-up (3 to 6-monthly visits to the physician)	8 (16)	8 (22)	32 (54)	10 (17)
No follow-up	2 (4)	1 (3)	3 (5)	5 (8)

Effects

Table 6 shows the anxiety depression and cancer worries in follow-up. No significant differences were found between trial and comparison group concerning these effects. The majority of the patient groups reported somewhat or no anxiety. Depression was present in only a minority of the patients with a difference in occurrence favouring the trial group. In the comparison group a quarter of the patients reported often to almost always having cancer worries, while in the trial group one eighth experienced more cancer worries.

Table 6: Scale scores of effects

	Trial group n = 49	Comparison Group n = 60	
	mean	mean	p*
Effects			
Anxiety	**0.5**	**0.7**	n.s.
Depression	**0.4**	**0.5**	n.s.
Cancer Worries	**0.7**	**1.0**	n.s.

Associations in preference for a follow-up program

Table 7 presents the associations between patients' preferences and attitudes towards follow-up and satisfaction and effects. A higher score for a type of follow-up program meant a less preferred option for follow-up. Patients from the trial group with more nervous anticipation towards the blood test had a stronger preference for the most intensive type of follow-up and less preference to care as usual. A stronger preference for the intensive follow-up was also found among the comparison group patients in case they had higher scores for nervous anticipation. Patients in the trial group who experienced more disadvantages in their follow-up program more often chose a less intensive follow-up program. Patients in the trial group with a lower score for satisfaction preferred the follow-up with the contact with the physician. In the comparison group a lower score on satisfaction meant a higher preference for their current mode.

In the trial group depression was related to the most intensive follow-up, patients with more depression less often chose for the traditional care. Patients in the comparison group with higher scores for depression and cancer worries had a stronger preference for the most intensive follow-up. Patients in the comparison group with higher scores for anxiety, depression and cancer worries even had a stronger preference for the monthly blood test, without visits to the physician. They opted less for their current consultancy mode.

Table 7: Spearman's Rho correlation between preferences and attitude towards follow-up, satisfaction and effects

	Trial group n = 49			Comparison Group n = 60		
	Most intensive	intensive	Less intensive	Most intensive	intensive	Less intensive
Attitude						
Reassurance	-0.28	-0.05	0.24	0.13	-0.20	0.08
Nervous Anticipation	-0.18	0.06	0.28	-0.14	**-0.32***	0.26
General Disadvantages	-0.05	0.09	-0.07	-0.15	-0.21	0.13
Communication	-0.12	0.21	0.12	0.18	0.28	-0.22
Attitude						
Reassurance (blood)	-0.24	0.10	0.23	-	-	-
Nervous Anticipation (blood)	**-0.37***	0.02	0.21	-	-	-
General Disadvantages (blood)	0.13	-0.03	**-0.37***	-	-	-
Satisfaction	-0.23	**0.32***	0.04	0.12	0.26	**0.31***
Anxiety	-0.08	-0.07	-0.16	-0.27	**-0.42****	**0.33***
Depression	0.13	0.10	**0.32***	**-0.35***	**-0.52****	**0.39****
Cancer Worries	-0.19	-0.08	0.05	**-0.31***	**-0.48****	**0.41****

*. Correlation is significant at the 0,05 level (2-tailed)

**. Correlation is significant at the 0,01 level (2-tailed)

Associations of preferences with patient characteristics

Some significant relations were found (Table 8) between the demographic characteristics and the attitude towards follow-up, the effects and the satisfaction. Patients in the trial group with younger children felt less reassured by their follow-up program. Patients who were married or were living together reported more disadvantages in follow-up than patients who were living alone in follow-up. Women experienced more cancer worries than men and patients with a higher education experienced less depression. A significant correlation was also found between co morbidity and satisfaction, patients who had other diseases overall were less satisfied with their follow-up program.

Table 8: Spearman's Rho correlation between patient characteristics and Attitudes, satisfaction and effects

	gender	age	Family	Age children	Highest education	Occupation	Co morbidity
Attitude							
Reassurance	0.03	0.01	-0.14	0.17	0.17	0.07	0.03
Nervous Anticipation	0.19	-0.16	-0.05	-0.04	-0.06	-0.13	-0.03
General Disadvantages	0.11	-0.15	**0.23***	0.05	0.04	-0.18	0.08
Communication	0.06	-0.08	-0.18	0.03	0.14	0.10	-0.01
Attitude							
Reassurance (blood)	-0.06	0.19	0.17	**0.36***	0.22	0.06	0.01
Nervous Anticipation (blood)	0.05	-0.27	0.01	-0.25	-0.10	-0.17	-0.02
General Disadvantages (blood)	0.15	-0.16	-0.03	-0.24	0.19	-0.10	-0.08
Satisfaction	0.05	0.13	-0.05	0.10	0.01	0.16	**-0.29****
Anxiety	0.08	0.05	-0.10	-0.07	-0.18	-0.03	0.08
Depression	-0.01	0.17	0.01	-0.21	**-0.26****	-0.01	0.17
Cancer Worries	**0.21***	-0.13	0.03	-0.04	-0.09	-0.06	0.09

*. Correlation is significant at the 0,05 level (2-tailed)

**. Correlation is significant at the 0,01 level (2-tailed)

Only a few significant associations were found between patient characteristics and Attitudes towards follow-up, satisfaction with the follow-up program and effects. No significant correlations were found with age and Occupation.

Discussion

This study examined the attitude towards follow-up, the effects of the follow-up programme and the satisfaction and preferences of colorectal cancer patients. The trial and comparison group dealt with patients who suffered form an earlier colorectal cancer symptom and its treatment. As an overall, patients' experiences with the follow-up program were seen as rather positive in both study groups.

The positive evaluation of the trial group implies that an intensive follow-up program without an increase of outpatient clinic visits is feasible. This opens the road towards applying a more intense-, more effective- and still cost-efficient follow-up program for the early treatment of recurrent disease at colorectal cancer patients in the next future. At least it allows a larger-scale study for evaluating the net predictive power of the monthly serum CEA blood test.

The main difference in the design between the two groups was the frequency of testing. The trial group had every month serum CEA blood tests with 6 monthly to yearly visits to the physician, the comparison group usually didn't have this blood test and had 3 to 6 monthly visits to the physician.

This study was the first which measured the effects of a follow-up program with a once a month frequency, with less visits to the physician. No significant differences between the two study groups were found. The study even revealed a significant difference according to the level of satisfaction, favoring the trial group.

A limitation of the present study is the fact that patients were not assigned to one of the study groups in a randomized controlled trial. Instead of that they were asked if they allowed to be assigned to this follow-up rather than to the traditional check-up method. As a result, patients from the experimental group might have been slightly more positive due to fact that they were invited to participate in this study (Hawthorne effect). However there was no selection of patients asked for the trial, and all but one of the asked patients agreed to participate in the trial, resulting in a random inclusion. The more positive experience of the trial group may also have been due to the explicit reassurance that patients can contact the physician in between visits when questions or worries exist. This reassurance was not always explicitly given to the patients in the comparison group, possibly causing bias. However, the possibility of intermittent outpatient clinic visits in case of questions or clinical complaints is available to all patients.

A significant difference was found between the two groups related to the question if patients would like to know the presence of recurrent disease. Trial group patients more often reported a preference for knowing. This may have been caused by the focus on the detection of recurrences of the monthly blood test in the trial group. It should be admitted that the trial group patients were aware of the experimental design of the study and therefore aware of the lack of certainty of effectiveness and reliability of the monthly blood tests. Almost all patients were satisfied with their follow-up program; in case of the possibility of choosing their own follow-up program, over half of the patients preferred their current mode. It was striking that the majority of the trial group patients for their second preferred

program chose the follow-up program including the blood test, but without any visits to the physician. It seems that the monthly blood test was even more important than the appointments with the physician. This means intensive follow-up without increase of follow-up visits to the physician is possible. Important issues in this type of follow-up are 'adequate information' and the 'accessibility of the outpatient clinic'. This explicit accessibility has barely been used by the trial group during the trial and is logistically feasible.

The trial group received some additional questions about the blood test and the results. In general, patients didn't mind taking a blood test every month. Only 16,3% of the patients didn't like receiving the result by letter. The results show that the majority of the patients don't mind the lack of contact with the physician. This implies that the importance of scheduled outpatient clinic visits and contact with the physician is limited and is not essential in an intensive follow-up schedule.

Patients stated the importance of knowing when to receive the results. Patients should be informed about this. Also the processing of results and reporting to the patient should be tightly organized, preferably with the aid of automated processing. For instance awaiting the outcome of the test over the weekend could then be avoided.

The attitudes towards the follow-up program in both groups were rather positive. The advantages outweigh the disadvantages, which were also reported in the study of Stiggelbout et al. (1997). As in other studies (Papagrigoriadis & Heyman, 2003; Stiggelbout et al., 1997; De Bock et al, 2004), they felt reassured by the follow-up program, and patients reported the communication with the physician as moderately positive. The patients didn't experience many negative aspects of the follow-up program.

This positive attitude of patients towards their follow-up program can be clarified with the help of the 'three component model' (Zana & Rempel, 1988). It is reasonable that patients have positive feelings towards the follow-up program, because they are grateful for the curative treatment and have positive beliefs in the follow-up program. This is even more so because all patients were treated with curative intent and the majority of the patients received a positive result of the medical tests up until now. Because of these positive results of the past ('past behaviours'), patients are expected to be positive about their follow-up program. This effect also causes difficulty in finding more optimal strategies in follow-up programs because the evaluated differences are less pronounced.

Patients in the comparison group with more nervous anticipation chose for a more intensive follow-up program. More depressed patients and patients with more cancer worries (both comparison group) also chose for one of the two more intensive follow-up programs. It seems that patients who have more distress in a follow-up program need more reassurance (Beaver & Luker, 2005). For this group of patients a monthly blood test may result in less distress in follow-up programs.

Patient characteristics did influence some of the results of the questionnaires. Graupe et al. (1996) stated that single, female and older patients experienced more psychological distress. Our results correspond with the study of Graupe et al. (1996) in that women experienced more cancer worries

than men. But in contrast with that study, patients who are living alone experienced less disadvantages in follow-up. This may have been due to the pleasure of social interaction that people have who are living alone. Patients in the trial group with younger children experienced less reassurance in follow-up. Steele et al. (2007) reported that patients with younger children experienced more concern about the recurrence of cancer. These aspects should be taken into account in the individual adaptations in the follow-up programs.

Follow-up checkups in itself have a positive effect on reassurance and remain important for patients after curative treatment of cancer. This should be based on real patients' needs and medical effectiveness however. New types of follow-up should therefore be evaluated for medical effectiveness, optimal communication and patients' needs. The positive evaluation of the intensive follow-up and the preference of the trial group for the monthly serum CEA blood test over visits to the physician makes intensive follow-up without increase of outpatient clinic visits and thus follow-up 'from a distance' feasible.

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Appendix

Attitude questions about the follow-up program

Reassurance

Do the follow-up visits convey you a sense of security?

Are you reassured after the follow-up visit?

Do the advantages outweigh the disadvantages?

Would you worry more about your disease if there were no follow-up?

Nervous Anticipation

Are you nervous about a follow-up visit?

Do you sleep less well in the week before the follow-up?

Do you postpone plans till after the follow-up visits?

Do you normally dread the follow-up visits?

Would you rather have follow-up visits less frequently?

General disadvantages

Would you prefer your family physician to perform the follow-up?

Do you think the investigations at follow-up burdensome?

Does the follow-up remind you each time of your disease, while you'd rather think less often about it?

Communication

Can you ask things at follow-up?

At follow-up, can you discuss with your doctor matters that are of concern to you or about which you worry?

Do people in the hospital pay attention to what you say?

Do the physicians at follow-up in the hospital have enough time for you?

Attitude of the trial group towards the blood test

Reassurance

Do the monthly blood tests convey you a sense of security?

Are you reassured after you have received a good result of the blood test?

Do the advantages of the monthly blood test outweigh the disadvantages?

Nervous anticipation

Are you nervous about the blood test?

Are you nervous when you are waiting for the blood test result?

Do you postpone plans till after the result of the blood test?

General disadvantages

Do you shrink from taking a blood test?

Do you think the monthly blood test burdensome?

Do you think waiting a week for the blood test result is too long?

Does the monthly blood test remind you each time of your disease?

Communication

Do you like receiving a good result by letter?

Knowing when to receive the blood test result is important.

Are there enough possibilities to contact the physician, if necessary?

Satisfaction questions

Would you indicate through giving a report mark from 1 to 10 how satisfied you are about the follow-up program you follow?

Would you indicate through giving a report mark from 1 to 10 how satisfied you are about the number of follow-up visits you get?

Would you indicate through giving a report mark from 1 to 10 how satisfied you are about the contact you have with the physician?

Do you think you get enough information about the follow-up program after your treatment for colorectal cancer?

Would you indicate through giving a report mark from 1 to 10 how satisfied you are about the information you receive of the physician during the follow-up visit?

Patients' preferences

I would like to know when I have recurrent disease, even if I would know it can't be treated in any way and I wouldn't have complaints for months.

☐ not at all ☐ somewhat ☐ Rather ☐ Very much

Patients' preferred option for a follow-up program

What if you could choose your preferred option for a follow-up program. Which follow-up program would you prefer? **Extend marks from 1 to 4**:

1 for the follow-up program you mostly prefer
2 for the follow-up program you rather prefer
3 for the follow-up program you less prefer
4 for the follow-up program you least prefer

(please fill in all four different marks on the dotted lines)

….. Intensive follow-up program with visits to the physician every 6 months to once a year and every month a blood test

….. Intensive follow-up program with a blood test every month and only contact with the physician in case of question or problems

….. Less intensive follow-up program with a visit to the physician every 3 to 6 months including a blood test

….. No fixed follow-up program. I would contact the physician myself if I think it's necessary