

## ORIGINAL ARTICLE

# Patients' views on follow up of colorectal cancer: implications for risk communication and decision making

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**Background:** Medical views about the clinical value and potential detrimental effect on quality of life of postoperative follow up are divided. There is no literature on the views of British patients with colorectal cancer towards the follow up process.

**Aim:** To investigate patients' views and experiences of follow up of colorectal cancer, and to assess their attitudes towards suggested changes to follow up policy.

**Patients and methods:** A total of 156 asymptomatic and disease-free patients with colorectal cancer were identified from the follow up clinic. Recurrence-free status was confirmed through retrieval of computerised clinic letters. A postal survey using a 39 item piloted questionnaire was undertaken. Data analysis generated descriptive statistics and logistic regression models.

**Results:** A response rate of 61% (95) was obtained. Among these respondents, 63% (60) had undergone initial surgery within three years of the time of the survey, and 86% (82) patients expected a further follow up appointment. Majorities of the sample, ranging from 71% (67) to 96% (91), expressed satisfaction with respect to clinic delays, staff conduct and knowledge about their case, consultation time, and being able to discuss personal problems freely. However some patients reported difficulty in discussing sexual problems at the clinic. Appointment imminence caused anxiety, sleep problems, and decreased appetite in 35% (35), 27% (26), and 8% (8) of patients respectively. However, 78% (74) patients felt reassured and optimistic for the future after receiving results. Such optimism is not necessarily justified in terms of estimated mortality risks. A majority (78%, 66) stated that they would value finding out about the presence of recurrence even if there would be no survival benefit. Nearly half of the sample (48%, 43) felt that they would disagree with the cessation of follow up in any circumstances. Only 47% (42) and 27% (24) indicated that they would accept follow up by a specialist nurse or their general practitioner, respectively. Attitude to follow up was unrelated to reported anxiety before appointments. Only 22% (19) of the sample could identify risk indicators for recurrence, but 64% (61) agreed that they would like to be told what to look for.

**Discussion:** A sample of patients with colorectal cancer expressed a high degree of satisfaction with hospital follow up. Although a substantial minority reported suffering from pre-visit anxiety, most felt that this disadvantage was compensated for by reassuring results, and believed that investigations did not have a significant negative impact on their quality of life. Respondents valued hospital follow up, and half would reject complete discharge or alternative forms of follow up. These findings demonstrate that patients have a different perception of the risk of recurrence than clinicians who would consider the survival prospects for most patients to be more or less unaffected by follow up interventions. Attempted modifications to follow up policies should be introduced with caution, and should take account of patient understanding of medical reasoning. The findings also raise questions about risk communication with patients.

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The clinical value of colorectal cancer follow up has been debated for many years. Doubts have been expressed as to whether it results in increased survival.<sup>1</sup> Complete abandonment of follow up,<sup>2</sup> and adoption of a "non-intensive" follow up policy<sup>3</sup> have been proposed. Audits in the UK and other countries have shown that follow up practices vary considerably.<sup>4,5</sup> Surgeons who follow up their patients intensively aim to detect early liver secondaries, which can be treated surgically with good results.<sup>6</sup> A recent meta-analysis demonstrated a survival benefit for those patients who had intensive follow up in which abdominal imaging and carcinoembryonic antigen measurements were used.<sup>7</sup>

The argument of those who advocate abandonment of follow up is twofold. Firstly, they argue that the often extensive medical resources spent on follow up investigations could be deployed more cost effectively in other areas of colorectal cancer diagnosis and treatment.<sup>8</sup> Secondly, they suggest that secondary investigations may adversely affect patients' quality of life, either through inducing anxiety or as a result of the side effects of procedures such as colonoscopy, without

providing any compensating benefit in terms of reduced mortality risks.

However the latter argument depends upon assumptions about patient perspectives, about which little is known. The one study found by the present authors, undertaken in Holland,<sup>9</sup> found no evidence that follow up reduced patients' perceived quality of life. No studies of the views of British patients have been published.

The present study had two aims: firstly, to investigate the views and experiences of British patients with colorectal cancer about the follow up process; and, secondly, to assess their attitudes towards abandoning hospital follow up, or substituting less medically intensive policies.

## PATIENTS AND METHODS

### Identification of the sample

Patients from the department of colorectal surgery were eligible to join the study if, at the time that data collection was being carried out, they were being followed up after surgery

for colorectal cancer and were considered free of recurrent disease. All patients with colorectal cancer who had visited the surgical outpatient department for follow up at least once between April 1998 and April 1999, and whose clinical records indicated that they were free of recurrence, were identified through the hospital's electronic records, and invited to participate in the survey.

### Questionnaire design

We decided to design our own questionnaire as there was no existing tool which would have been adequate for our purposes. Standardised quality of life measurement questionnaires were not considered appropriate as our patients were asymptomatic, and any effect on their quality of life was expected to occur intermittently, and soon after follow up visits.

A 39 item questionnaire focused on the views and experiences of patients about follow up visits and investigations. It was organised into six thematic sections covering, from the patient's perspective:

1. Clinical background.
2. Experience at the clinic.
3. Anxiety before the clinic visit.
4. Experience of investigations.
5. Attitude towards receiving information about the risk of cancer recurrence.
6. Attitude towards possible changes in follow up policy.

Ethics committee approval was obtained. The questionnaire was discussed with a focus group of experts (surgeons, doctors, and health professionals specialising in colorectal cancer treatment). It was then piloted with a small group of patients who were probed about their answers so that their comprehension of the questions could be checked.

### Postal survey

Anonymous questionnaires were posted to 156 eligible patients (see below) together with a covering letter and self addressed stamped envelope. No reminders were sent on the grounds that the questionnaire dealt with sensitive issues, and that the risk of causing distress to the patients had to be minimised.

Sampling and other methodological limitations of the study will be reviewed in the discussion section.

## RESULTS

The computer search identified 263 patients receiving follow up for colorectal cancer from the department of general surgery. Of those patients, 156 who were classified as currently disease free were invited to participate in the study. A further 107 patients who had known or suspected recurrence were excluded. The response rate was 60% (95). This relatively high response rate for a single mail shot may reflect the importance to patients of the services which they received. Only 7% (7) respondents reported finding the questionnaire distressing, and only one expressed regret at having completed it.

Descriptive statistics will be presented, unless indicated otherwise, without adjustment for missing data. The (non-significant) outcomes of logistic regression analyses will be mentioned where appropriate.

### Clinical background information

The majority of patients, 63% (60), had had surgery less than three years before the study, and only 4% (4) had received surgery more than five years before. Only 3% (3) of patients were receiving adjuvant therapy at the time of the study. However 45% (43) patients had received adjuvant therapy in the past. A stoma was present at the time of the study in 21% (20) of patients.

### Experience in the clinic

Thirty patients (32%) reported that they mainly saw the consultant at the clinic, while 10% (10) stated that they never saw the consultant, and 35% (31) patients that they mainly saw the junior doctors. Only 23% (21) patients saw the colorectal nurse on follow up visits. A majority of the sample (82%, 76) were confident that the doctors either knew all the details or the essential facts of their case. However, 15% (14) patients expressed disappointment that the doctors did not know enough about their case.

Most respondents accepted having to wait at the clinic, as 61% (55) said that they did not mind delays, while 33% (30) accepted them. The time spent with them during the consultation was considered as long as they expected by 74% (68), while another 19% (18) thought it was shorter than expected but still adequate. Only 2% (2) patients thought that consultations were too short.

Almost all of the patients sampled (97%, 91) felt that the approach of staff in the clinic helped them to discuss their problems, and 82% (76) considered themselves able to discuss any problem at the clinic. However 12% (11) patients reported difficulty in discussing problems, particularly those associated with sexual dysfunction. Only 3% (3) indicated that they would prefer to discuss such problems with their general practitioner (GP) or a nurse rather than a hospital doctor.

### Pre-visit anxiety and experience from investigations

Over half the sample (57%, 54) reported feeling no more anxious than usual in the week before the follow up visit, and the same proportion said that they did not have sleep problems. However, 35% (35) admitted to feeling worried at this time. Within the worried group, 91% (32) faced sleep problems and 23% (8) reduced appetite before an investigation.

Respondents were offered a choice of terms describing the investigations to which they had already been submitted during their follow up. Nearly half (46%, 44) described them as "just necessary", while 22% (21) found them unpleasant, 4% (4) found them embarrassing, 6% (6) thought they were painful, and 2% (2) wondered whether they were necessary.

Respondents were asked to select the investigation/procedure they found most unpleasant. Almost half (45%, 43) indicated that they didn't mind any of the investigations. Only 27 responses to a specific question about the procedure that patients found most unpleasant were received. From the examinations/investigations listed, the most unpopular one was digital rectal examination with rigid sigmoidoscopy, which was thought to be the worst by 59% (16) of respondents who mentioned a procedure. Only 11 other specific answers were received. Colonoscopy was mentioned by four patients, barium enema by three patients, and computed tomography, faecal occult blood test, chest radiography, and examination by the doctor by one patient in each case. Patients found a procedure unpleasant either because it caused embarrassment, mentioned by 18% (18), or caused pain, referred to by 6% (6) of respondents. Only 13% (12) of patients reported that they worried while waiting for the results.

### Attitude towards knowledge about recurrence

When patients were asked whether they would like to know about the presence of recurrence even if there would be no treatment or survival benefit, 77% (66) answered affirmatively. Only 17% (15) patients indicated that they would prefer not to know if there would be no benefit from this knowledge.

Less than half of the sample (46%, 44) replied to a question asking them why they wanted to know about their risk of recurrence. Within this subsample, 41% (18) selected the response "it is my right to know the extent of my disease", 23% (10) wanted "to prepare psychologically", 11% (5) "to arrange family practical issues", and one respondent "to arrange work issues". "Religious or spiritual reasons" was

mentioned by one respondent. Non-specific responses were given by 23% (10) of respondents answering this question who agreed with the statement that they "just wanted to know".

#### Attitudes towards modifying follow up procedures

Respondents were asked how they might react in a hypothetical situation in which they would be discharged from follow up with an assurance that there is no evidence that follow up improves survival for patients with their condition. Almost half of the sample (47%, 43) indicated that they would disagree with the attempt to discharge them. A smaller group (24%, 22) stated that they would agree, and 23% (21) were willing to follow doctors' recommendations.

When asked about alternative types of follow up, 46% (42) stated that they would accept being followed up by a specialist nurse instead of a hospital doctor, while 32% (29) stated that they would prefer to be seen by a hospital doctor. A further 18% (17) expressed doubts about whether follow up by a nurse would be as good as follow up by a hospital doctor. A slightly lower proportion (26%, 24) expressed willingness to accept a GP based follow up scheme than were willing to be followed up by a specialist nurse, 13% (12) expressed doubts, and 56% (51) said that they would refuse to accept this form of follow up. However, when asked to choose between the three forms of follow up mentioned above, 55% (53) opted for the hospital doctor, 6% (6) the GP and 3% (3) the nurse, while 23% (22) said they were willing to follow the hospital doctor's recommendation, and 11% (12) did not answer the question.

Logistic regression was used to relate acceptance of discharge from follow up to other aspects of a patient's care, including having previously undergone chemotherapy or radiotherapy, the presence of a stoma, confidence in staff knowledge, having had unpleasant experiences in the clinic and anxiety before appointments. No statistically significant relationships were found.

#### Knowledge about risk factors for recurrence

Overall, respondents showed little knowledge about risk factors for recurrence. Only 21% (19) could name the symptoms associated with cancer reappearing. However, a majority would have liked to be informed about these matters, with 64% (61) stating that they would like to learn what those symptoms are.

#### DISCUSSION

The relatively low response rate, 60%, can be explained in terms, firstly, of the decision not to send reminders to non-respondents, a decision taken on account of the sensitivity of the subject matter; and, secondly, in terms of the known pattern of low response rates to lengthy questionnaires<sup>10</sup> by older patients.<sup>11</sup> Sample representativeness with respect to the hospital population, therefore, cannot be assumed. For example, patients who were motivated to continue their relationship with the hospital may have been over-represented. In addition, the views of a sample drawn from one hospital cannot be taken as representative of wider populations on account of possible regional variations and the influence of experiences within one particular treatment milieu. Nevertheless, the survey provides some indication of the views held by a patient group who, for ethical reasons, must be approached with sensitivity. The suggestive findings about the attractiveness to patients of hospital based follow up, and about their lack of knowledge of their prospects or of risk factors are worthy of replications which would test their generalisability.

The validity of questionnaire data must always be treated with caution. Respondents may give responses that they believe are expected, or may simply not know how they would feel about a hypothetical situation—for example, about being invited to withdraw from follow up.

The findings revealed considerable variability in the pattern of follow up. According to our respondents, one third of follow up was undertaken by junior doctors rather than consultants. If hospitals are to provide a satisfactory service, they must ensure that departmental guidelines on follow up policy are in place for the junior doctors to follow. An unexpectedly low number of our patients (23%) saw the colorectal specialist nurse at their follow up visit in addition to a doctor. This low provision of specialist nursing care reflects the recent history of service organisation in the region, with colorectal cancer treated by all general surgeons, while specialist nurses worked mainly in colorectal clinics. There is still a shortage of colorectal nurses in the region. Specialist nurses can provide complementary advice that may contribute significantly to quality of life—for example, in relation to sexual functioning after cancer.<sup>12</sup>

Patient perception of the clinician's knowledge of their case significantly affects their trust in, and overall satisfaction with, the follow up process. Our survey found that 82% of patients were satisfied with this aspect of follow up.

Overbooking of clinics, with subsequent delays, unfortunately, occurs all too frequently in the NHS, and often causes patient dissatisfaction. Although patients who participated in the present study commonly suffered such delays, most expressed an accepting attitude towards them. This tolerance may reflect the importance that patients place on follow up. Patients attending clinics for less medically significant reasons may be less accepting of delays than are those who have life threatening conditions. A high degree of satisfaction may in fact reflect low patient expectations. It is inappropriate for cancer patients to be routinely referred to junior doctors for assessment regardless of patients' acceptance, particularly in the absence of well defined protocols for assessment and investigations. In our hospital a detailed protocol for follow up of colorectal cancer is in practice in order to ensure that all patients get equal quality of assessment regardless of the grade of the clinician they see. Clinic delays are audited and an effort is made to minimise them.

Follow up should address quality of life as well as survival, and staff need to facilitate discussion of sensitive issues. Most respondents (82%, 78) felt that they could discuss any problem, although a few had found it difficult to discuss sexual dysfunction. Clinicians should probe specifically for sexual dysfunction problems, particularly after radical pelvic surgery and radiotherapy. Impotence problems may be reversed through the use of sildenafil.<sup>13</sup> However, the social, interpersonal, and psychological aspects of sexual recovery after cancer surgery, as well as the impact on spouse relationships, should also be considered, for example through counselling by a specialist nurse, as noted above.

One of the arguments against intensive follow up for colorectal cancer is that investigations have a negative impact on the patient's quality of life. However, as also found by Stiggelbout *et al* in Holland, patients being followed up do not report a negative impact of investigations on their quality of life.<sup>9</sup> Although about a third of respondents mentioned pre-visit anxiety, this stress was compensated for by the reassuring effect of negative investigations. The majority of patients accept investigations stoically, perhaps believing that, although sometimes embarrassing or unpleasant, they are necessary. These findings suggest that a major benefit for patients of intensive follow up procedures is the communication of reassurance, a message which does not reflect the high mortality risks they faced.

Another argument against intensive follow up is that there is no point in knowing about recurrence if this knowledge will not result in increased survival. Such knowledge may reduce quality of life for patients whose mortality risk cannot be significantly reduced by further medical interventions. Although 18% (15) of our respondents agreed with this argument, 77% (66) desired to know about their condition and prospects, as

found elsewhere.<sup>14</sup> It is worth noting that some patients believed that they had a right to know the extent of their disease. On a more practical note, some patients wish to know about their prospects in order to make family or work arrangements, or to prepare psychologically.

Patients may approach health risk in a fundamentally different way to health professionals who are attempting to operationalise evidence based practice.<sup>15</sup> Professionals focus on probabilities induced from observation of aggregated categories—for example, mortality risks in clinical subgroups and the average reduction in these risks associated with follow up. Patients and carers, in contrast, are primarily concerned with the personal future of an individual whom epidemiology treats as an average member of a category. They will, therefore, seek any information which might indicate a favourable individual trajectory.

The provision of investigations that may increase patients' knowledge about their future enhances their autonomy<sup>16</sup> even where it does not improve their chance of survival. Health economists who evaluate the cost of procedures against reduced mortality risk may not take account of such intangible gains. The present findings support those of a previous study which found that 92% of cancer patients want to have access to all available information about their condition.<sup>17</sup>

The reactions to the hypothetical scenario of discharge from follow up varied. Almost half (48%, 45) rejected this idea, 24% (23) accepted it, and 23% (22) wanted clinicians to make the decision. Logistic regression analysis failed to identify any factors associated with this difference in attitude. During the last 30 years, health services have become increasingly organised around screening programmes for cervical and breast cancer, diabetes, chromosomal disorders, hypercholesterolaemia, and many other conditions. These programmes have given rise to debates about whether screening may in some cases be "over-sold", as it is often not easy to demonstrate that the benefits outweigh the costs, including risks associated with the procedures themselves.<sup>18-20</sup> Just as patients may hold unrealistic expectations about the general benefits of screening, so colorectal cancer patients may not have been informed about, or appreciated, the limited benefit, in terms of increased survival chance, of follow up interventions. Our findings suggest, however, that patients would still seek intensive follow up even if they understood their limited average benefit.

When offered a direct choice between traditional hospital based, specialist nurse and GP follow up, 56%, a clear majority, opted for the existing system. Alternative follow up schemes were more likely to be accepted if they were also hospital based, with 46% (42) stating that they would accept follow up by a specialist nurse, and only 26% (24) responding positively to the idea of follow up by the GP. Although a GP based follow up scheme has been tried for another cancer,<sup>21</sup> and we have previously found that 50% of GPs expressed willingness to participate,<sup>22</sup> the findings of this survey do not support this policy. Patients may feel that GPs, because of their generalist orientation, cannot maintain expert knowledge about particular conditions.

Nurse-led follow up clinics have already been established for colorectal and other cancers,<sup>23</sup> in other UK regions, since they are viewed as more economical in terms of resources. Although participants in the present study favoured the system of hospital based follow up which they were familiar with, they might respond favourably to a nurse-led system if its rationale was explained to them in a way that addressed their concerns and reasons for valuing follow up. Further research exploring these issues in more depth from the perspectives of patients and carers is needed.

The study found that 64% (61) of respondents stated that they would like to know about symptoms suggestive of recurrence. In our hospital we have not followed a policy of providing detailed information to patients on symptoms of recurrence. This is because symptoms of recurrence are

non-specific, and information might cause anxiety. However, it can be argued that if we provided written information about suspicious symptoms, a small number of recurrences occurring during long intervals between annual appointments could be detected as a result of patient self reporting. This potential theoretical benefit should be balanced against the risk of generating excessive anxiety and unnecessary appointments.

Logistic regression analysis did not reveal any clinical factors that affect the patients's views. Patients of all stages that had a curative resection also had the same protocol of investigations. Previous chemotherapy and radiotherapy (associated with Duke's C stage of disease) did not affect the attitude towards follow up.

In conclusion our findings confirm that British patients with colorectal cancer show a positive attitude, if not an attachment, towards the follow up process. Our study supports the findings of other studies that, although a small degree of pre-visit anxiety is generated, follow up provides reassurance for patients and generates optimism that may, however, not be justified by the existing evidence. Investigations are well tolerated and there is a high degree of satisfaction from the whole process. There is considerable resistance to proposals about either abandoning or modifying the existing follow up policy. Any attempts to do so should be based on better understanding of the perspectives of patients.

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