



A colorectal cancer patient focus group develops an information package

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ABSTRACT

INTRODUCTION In order to deliver high quality care and empower cancer patients in decision-making, good quality information and communication are essential. We describe the development of an information booklet.

PATIENTS AND METHODS A total of 22 colorectal cancer patients (12 male; median age, 72 years, range, 40–86 years) met on 3 occasions. Patients were asked to define their information needs and score them (1–4) according to importance. The information document was written. The second meeting involved feedback on the booklet. The modified booklet was reviewed/approved by the group before submission for local ethics committee approval prior to its distribution to other patients.

RESULTS All participants felt the project a good idea. Essential information included the surgeon's individual morbidity, mortality, survival, recurrence data and details of adjuvant therapies (score = 4). Also important were type of surgery, complications and postoperative recovery (score = 3). Simple anatomical drawings were also considered important.

CONCLUSIONS The booklet is now used to personalise information for all our patients and serves, in part, as a record of the key issues discussed during the consultation. The booklet has been evaluated in a randomised trial.

KEYWORDS

Colorectal cancer – Decision making – Information needs – Patient participation

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One of the commonest complaints made by patients with cancer is about poor communication and inadequate information.¹ The NHS *Cancer Plan*² and *The Cancer Information Strategy*⁵ emphasise the need for good communication, both for delivering high quality care and for empowering people to be involved in decisions about their own care. Good quality information is required for different purposes including the understanding of presenting symptoms, the disease's natural history, the services and treatments available and ultimately allow for informed patient participation in decisions about treatment.

Current generic published information often omits relevant data, fails to give a balanced view of the effectiveness of certain treatments and, in general, ignores uncertainties. By definition, they contain no data relevant to their local multidisciplinary team. Patients cannot express informed and appropriate preferences about their care unless they are given sufficient information. In addition, it is increasingly evident that the involvement of patients in the development of services means that those services become more appropriate and acceptable to their users. This may lead to

a less stressful and more rewarding interaction between healthcare professionals and future patients. Calman-Hine recommended that planning in cancer services should take account of the 'views and preferences of patients'.⁴ This requires research to ascertain what patients want and development of measures to ensure that these views are then reflected in practice.

We describe the processes whereby a colorectal cancer patient focus group was involved in the development of an information booklet.

Patients, Methods and Results

A total of 28 consecutive patients (16 males) were invited to participate in the development of an information booklet. All had recently completed their colorectal cancer journey; all were under the care of the senior author. The 28 patients were approached by the authors whilst attending follow-up out-patient clinics. They were subsequently telephoned to confirm their participation in the project and answer any questions that they had.

Table 1 Information needs as scored by the group

Information	Importance score (0–4; 0, least important; 4, most important)
Individual surgeon's morbidity and mortality data	4
Adjuvant chemotherapy/radiotherapy (how, why, risks versus benefits)	4
5-year survival (by Dukes' stage) and recurrence	4
Surgery (what and how)	3
Recovery period/postoperative complications	3
Stomas (rate/operation, complications, where to find help)	2
Investigations – radiology, colonoscopy (what, why, accuracy)	2
Family history; what about my children	2
Members of multidisciplinary team (contact numbers)	2
Colorectal cancer in general (including symptoms)	1
Glossary of terms	1
Further information/support (e.g. web sites)	1
Follow-up arrangements and long-term management (e.g. scans, diet)	1

Twenty-two patients met up as a group with the senior author. The project aim of producing an information package for future patients was discussed. The senior author explained that no restrictions were to be placed on any area that the group felt needed to be addressed. All felt that the project was a good idea. To avoid any question of bias, the group was then left to elect a chair (a 68-year-old, retired female teacher) and progress the project as they felt necessary. The group comprised 12 males and 10 females; age range, 40–86 years, with a median of 72 years. All were Caucasian. Each individual was given the opportunity to discuss their recent experiences and how they wanted to take the project forward. Existing methods of information provision were discussed. These in the main comprised leaflets provided by national bodies, a large part of which was directed towards the issue of stomas. The group met on three occasions. No clinician attended any of the meetings.

Areas of concern quickly identified by the group included the provision of comprehensive, easily understood, unbiased information about the condition, what to expect, the availability of treatments and options and their side effects. The group's chief concern related to questions on probability of survival, risks of recurrence and survival prospects once a recurrence is diagnosed. It thus became obvious that the information would require regular reviewing and updating. The patient group suggested scoring their information needs according to importance: 0 = least important, 4 = most important (Table 1).

The group chair then reported to the senior author who then wrote the first draft of the information document to

include all information, including information with an apparent low priority score. The senior author's surgical practice, morbidity and mortality data were then validated and analysed by the hospital's information systems analyst before inclusion in the booklet.

The second meeting involved feedback on the newly written document, including its design, readability, appropriateness and discussion of any concerns raised. Some patients felt that the high mortality (national figures) for elderly patients undergoing elective colorectal resections and those undergoing emergency surgery should be omitted. However, interestingly this was not an issue with the three octogenarians within the group and, therefore, it was decided by the group to retain this information. One patient suggested that details of the potential complications arising following anastomotic leakage should be omitted (*i.e.* sepsis, re-operation, ITU admission/ventilatory support and slow recovery). This patient had experienced such events. The remainder of the group elected to include this information. The issue of anatomical drawings of the various surgical resections was raised at this meeting. The solution, a simple line drawing of the vascular supply of the colon and rectum which could be modified as appropriate.

The modified document was reviewed and approved by the group at their final meeting. It was then submitted for ethics committee approval prior to being distributed to other patients. The ethics committee commented that the colour of the booklet (*i.e.* green) was calming, but felt that the black print on the front cover should be amended. The booklet was felt to be generally useful, but complex in

places. They suggested that the font size used should be enlarged, in view of the fact that some patient users would be elderly and may have visual impairment. The group elected to leave the booklet as it was.

The booklet, now including actuarial survival curves, has since been evaluated prospectively. Feedback has been positive. The data in the booklet are updated yearly and the booklet now includes data on over 500 consecutive patients with colorectal cancer treated by the senior author. We have found the booklet and line drawing particularly useful in personalising information for individual patients and serves, in part, as a recording of the key issues discussed during the consultation and a prompt for obtaining consent. It has also proved useful as a focus for discussions with our specialist colorectal cancer nurse.

Discussion

The provision of patient information and communication between patients and healthcare professionals are increasingly recognised as important aspects of patient care. This has been highlighted by the Cancer Services Collaborative, who produced a booklet listing possible solutions for improving the way in which services for cancer patients are delivered. The Cancer Services Collaborative emphasise the need for information to be developed by the multidisciplinary team in conjunction with patients and carers.

Previous research has shown a lack of congruence between patients and physicians when considering cancer patients' concerns,⁵ indicating the importance of discussion with the target group in the development of relevant information. It is difficult to assess how representative our participants were. Inconvenience, a desire to forget unpleasant events, ill-health and unsuitable dates all intervene; however, the degree of consistency in responses suggests that if non-participants had taken part this would not have significantly affected the results. Principles of consensus need to be adhered to, in order that the results are not distorted,⁶ but as the views of the group were generally very clear, little dispute arose. We were fortunate in the choice of the group's chair who ensured that no one individual dominated events and or the final opinion of the group. An example being the elderly patients insisting that the influence of patient age on peri-operative mortality and morbidity be kept in the booklet. Others too have found the focus group approach useful; Birchall *et al.*⁷ found such groups to be an effective and efficient means of assessing the views of patients and carers on professionally derived standards of care in oncology. Positive experiences, including our own of involving a patient focus group to develop a booklet that is sensitive, understood and accepted amongst its users, will

hopefully encourage others to use such methods, with the aim of improving the overall patient experience.

One of the potential problems of providing information to patients is to make it understandable, applicable to different age groups, intellectual backgrounds and cultures. In an attempt to address these questions, we have prospectively evaluated the effect this information booklet had on our patients understanding of their cancer journey as well as its effect on patient anxiety and depression levels.⁸⁻¹⁰ We have also investigated its effect on our patients' relatives.¹¹

A final consideration is the difficulty in providing validated individual surgeon's results and in sufficient numbers to the drawing of safe conclusions. Whilst accepting that it is impossible to provide data for surgeons at the start of their career, it is clearly of vital importance, particularly for the surgeon that these data are prospectively collected and validated. Whilst awaiting an individual's data, an alternative would be to provide patients with the unit's figures along with some additional reference as to acceptable national standards. Our database, established in 1996, fulfils the minimal data set requirements of the Association of Coloproctology and is validated on a weekly basis.

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