Eliciting views of patients with head and neck cancer and carers on professionally derived standards for care

M Birchall, A Richardson, L Lee on behalf of South and West Regional Cancer Organisation Tumour Panel for Head and Neck Cancer

Abstract

Objectives To examine views of patients and carers on the process of care for people with head and neck cancer; to assess whether focus groups are useful in this setting; to compare priorities and standards identified with those published by healthcare professionals; and to incorporate the expressed views into existing national standards.

Design Multicentre study of nine regional focus groups.

Setting Area covered by two regional health authorities.

Participants 40 patients who had had head and neck cancer and 18 carers.

Main outcome measures Views of individuals and groups on standards. Applicability of the method for patients whose appearance and ability to communicate was altered and for recently bereaved carers. Ease of incorporation of views into national and regional standards.

Results Patients and carers participated in discussions on all the principal questions. Opinions were expressed on waiting times, information available to patients, coordination of care, and crisis management. Professionally derived standards were substantially improved by the incorporation of the views of patients and carers. There were no technical problems in carrying out this study on patients with communication difficulties or altered appearance nor with recently bereaved carers. Occasionally, participants said that the meetings were therapeutic.

Conclusions Professionally facilitated and analysed focus groups are effective in assessing views of patients with cancer and carers on professionally derived standards for care and can be applied in settings traditionally viewed as difficult. Views expressed by patients and carers are powerful motivators for change in the delivery of cancer care.

Introduction

The Calman-Hine report recommended that planning in cancer services should take account of the “views and preferences of patients.” This requires research to ascertain what patients want and development of measures to ensure that these views are then reflected in practice. Initial national guidelines for care of patients with head and neck cancer did not take account of views of patients or carers. We carried out a study of focus groups with patients with head and neck cancer and carers to consider specific standards for their care. We subsequently incorporated their views into new national guidelines.

Methods

The study took place across the South and West region. We obtained ethics approval from all appropriate local committees as well as the multicentre committee. We obtained patients’ names from the ten consultants who formed part of the regional tumour panel (see acknowledgments), all of whom gave at least some information on relevant patients (n=290). We contacted general practitioners as needed to check that the patients were still alive. We did not select participants by stage of disease or prognosis, nor did we ask for detailed clinical information, but in all cases it was at least a year since the patients had received treatment. For carers we considered only spouses (or partners living at the same address) and obtained their names from general practitioners. Bereaved carers were limited to those who had been bereaved for one to three years, so the experience would be fresh but not too raw to discuss.

We arranged nine focus groups that comprised discussions with patients and some carers on standards of care from the initial consultation through to terminal care. Meetings took place in mutually convenient, private, and comfortable locations, such as the postgraduate centre of a local hospital. The meetings usually lasted two hours. The sole exclusion criterion was distance from the venue of the meeting (on grounds of travel costs, which were paid from the study budget), although we also had to exclude one person who was in prison. Because each group was set up locally, there were effectively nine different samples, with initial list size varying from eight to 50 names. We wrote to eight to 29 people for each group (selected in an unstructured, arbitrary manner by the social researcher when the list was too long) to ask them to take part. We included an information sheet, a letter from the consultant, a reply slip, a consent form, and a prepaid envelope. We telephoned those who expressed an interest to answer questions and set a meeting date.
The proportion taking part varied across groups because of attrition at different stages—for example, of 11 carers approached in one area from an initial list of 14, seven agreed to attend but only six actually attended because one was unwell.

We have previously shown in a pilot study that such groups could discuss standards effectively when participants had initially recounted what had happened to them. We therefore divided discussions into two parts, in some cases by reconvening the group, so that participants initially described their experiences and subsequently discussed the standards. Before the meetings we sent all participants a short, edited version of the relevant standards, differing slightly depending on the type of treatment they had experienced (for example, surgery, radiotherapy). An experienced group moderator used a topic guide to facilitate all meetings. After initial discussion about their personal histories of cancer, participants discussed the standards. Many common issues were covered, such as “reasonable” waits at various stages, how the diagnosis should be given, and sources of information. All 58 participants were also given an evaluation form so we could obtain views on their experience of focus groups.

Meetings were taped and fully transcribed. We analysed the experiences and views, noting variations across groups when relevant. Because the sample was small we did not attempt analysis by other variables, such as sex or age. There was no requirement that a consensus view be reached, but much agreement was found in practice.

Results

Altogether, 13 meetings were held, of which three were reconvened. One supplementary interview was undertaken with a man who was unwilling to participate in a group discussion. The meetings covered 40 patients and 18 carers. Most patients were men (26/40), and most carers were women (11/18). The participants included some people in whom research is considered difficult, such as people with a laryngectomy or with altered appearance. Table 1 shows the composition and location of groups.

Overall, patients and carers thought that some of the original standards should be dropped, others modified, and some new ones created (table 2). Comments on the standards were detailed so we have given just two examples here.

All patients should be seen at a hospital within 10 working days of being referred

There was widespread agreement with this standard. The patients accepted that there was a need for some waiting time to enable the system to work: “By and large, the cancer's been in your body for a given period of time, and irrespective if you go in 24 hours or 10 days, it's not going to make that much difference to your life expectancy” (patient).

Most people thought they had been seen within this period. Two groups suggested that the standard should be set at 10 days in total and not 10 working days. The waiting time was seen as particularly worrying as the person knows there may be a problem (“all the time you're thinking cancer, cancer, cancer”).

Outpatient clinics and wards should provide written information on support organisations, general ward topics, general treatment issues, and specific problems in head and neck cancer

There was virtual consensus that information sheets should be made available on the issues indicated. Additional suggestions included information on local support organisations, complementary medicine, and some “good news” stories about patients. A special leaflet for carers was not needed. One group emphasised that someone, possibly a specialist nurse, should specifically give the information to people—not simply assume that they would find it on racks.

Participants widely agreed that better information about radiotherapy should be provided. This should include preparation for both the experience and its aftermath and should explain “the horrible nitty gritty”: “I thought that when it finished—OK it’s bad, it’s going to get worse for another month, but then it’s going to start getting better. But it didn’t, it got worse … six months later, all these things started to happen” (patient).

Evaluation of participants

Out of 58 possible replies, we received 54. Most responses were highly positive. Half of the respondents provided additional comments. The most common theme (cited by 10 people) was gratitude for the support obtained from talking to others in the same situation and a suggestion that the experience was therapeutic: “I found it very helpful to talk to other carers with similar experiences” (carer). Only one comment was somewhat negative, suggesting that the group discussions were “too positive.”

Incorporation into regional and national standards

The first set of comprehensive UK standards for care of patients with head and neck cancer was developed by the tumour panel for head and neck cancer of the south and west regional cancer organisation. The panel used a nominal group process (an established consensus technique) and tested the standards by audit. The key standards were subsequently entered into an iterative consensus process involving head and neck consultants nationally.

Table 1 Numbers of participants in each focus group by subject and location (numbers who returned for reconvened group session are shown in parentheses)

<table>
<thead>
<tr>
<th>Participants (n=58)</th>
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<tr>
<td><strong>Patients</strong></td>
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<tr>
<td>People with laryngectomy:</td>
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<tr>
<td>Bristol (reconvened)</td>
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<tr>
<td>Portsmouth (reconvened)</td>
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<tr>
<td>People who had radiotherapy:</td>
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<tr>
<td>Plymouth</td>
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<tr>
<td>Southampton</td>
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<tr>
<td>People with altered appearance:</td>
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<tr>
<td>Bristol</td>
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<td>Exeter (reconvened)</td>
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<tr>
<td>Bristol (interview)</td>
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<tr>
<td><strong>Carers</strong></td>
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<tr>
<td>Of people who had radiotherapy:</td>
</tr>
<tr>
<td>Bristol/Bath</td>
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<tr>
<td>Plymouth</td>
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<tr>
<td>Of people who died:</td>
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<tr>
<td>Bristol/Bath</td>
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possible disadvantages

It was difficult to assess how representative our participants were. Patients in more rural areas may have different views but were excluded from our study because they lived too far away from where the groups met. Some attrition in selection twifies this type of research, in which convenience, a desire to forget events, ill health, and unsuitable dates or venues all intervene. The degree of consistency in the response suggests that if non-participants had taken part this would not significantly have changed the results. The sample was large enough to cover the main viewpoints, especially given the relatively limited range of age, socioeconomic spread, and ethnic origin among patients with head and neck cancer in the area. However, this was not a study of how many people expressed specific views but of the considered response of patients and carers to existing standards.

Some consultants were reluctant to divulge names of their patients. More success was obtained through nurses and a support group, resources that should be used in future. The need for participants to talk initially about their own experiences is important, and allowing them to do so was crucial in obtaining their confidence. Such arrangements should be considered for future studies in clinical oncology, especially those in which complex questions are asked. Severe communication difficulties, such as lack of a larynx or oral structures, did not preclude meaningful participation. Patients were more sophisticated than is often supposed. They understood the diagnostic dilemma faced by general practitioners arising from the vague nature of early symptoms. They supported a maximum two week wait for an outpatient appointment long before the current government initiative.

Incorporating views into national standards

As the second draft of a national consensus document was about to be prepared we were able to incorporate participants’ views. Principles of consensus need to be adhered to for the results not to become distorted, but as the messages from the focus groups were so clear and compelling little dispute arose despite the involvement of many diverse professionals. Edwards reported group discussions with people with cancer of the “aerodigestive tract.” However, the research covered only maxillofacial patients and participants’
Patients with head and neck cancer require complex multidisciplinary care.

Incorporating the views of patients and carers is often recommended.

Focus groups can be used to assess the views of patients traditionally viewed as difficult—for instance, those with communication difficulties and altered appearance.

Satisfaction with the method among participants is high, even in groups of recently bereaved carers.

We thank Penny Nettelfield, who undertook the day to day administration of the study, Jill Keegan, focus group facilitator, and the medical and paramedical members of the South and West regional cancer organisation (SWRCO) tumour panel for head and neck cancer. Local contacts in each hospital freely provided help, without which the groups could not have been convened. We also thank SWRCO for administrative support, especially Veronique Poirier and Eva Hicks in the University Department of Otalarynogy and Claire Clayton for transcription skills. At the time of this study, the SWRCO Tumour Panel for Head and Neck Cancer was Martin Birchall, Liz Lee, Chris Baughan, Nick Baker, Graham Zaki, Mike Bridger, Hugh Newman, Perric Crellin, Tim Flood, Peter Saxby, Phil Guest, John Eveson, Julian Kabala, Karen Forbes, John Boyles, Jennifer Smith, and Kay Howe.

Contributors: MB conceived the study, chaired the tumour panel, wrote the grant application, helped to direct the project, directed the incorporation of results into national standards, and coedited the report and paper. LL helped to direct the project and was responsible for recruitment for the pilot study, editing the existing standards for use in the focus groups, and developing the evaluation questionnaires. AR directed the study design and recruitment of researchers, helped to direct the project, undertook all data analysis, and coedited the report and the paper. The SWRCO Tumour Panel for Head and Neck Cancer was responsible for the initial development of professional standards and for providing lists of patients and venues for the study; MBS is guarantor.

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Commentary: Patients’ involvement in their treatment matters

P Morton

Patricia Morton had a mastectomy in 1975 for breast cancer and was diagnosed as having metastatic cancer in bones in 1985. She received palliative radiotherapy in 1985, 1989, 1994, and 2001. Here she gives her views on focus groups for people with cancer.

In the past the lack of focus groups as described in the paper by Birchall et al all must have had an effect on treatment as patients were denied a voice. The inclusion of patients’ views into national guidelines must be a step forward.

Focus groups should be led by a sympathetic person, not just a professionally aware one, and not too much should be demanded of patients. The professional participants should not downgrade the process to a pointless exercise. Patients are not going to be fobbed off with amateur approaches. Even without the additional problems of communication for patients with head and neck cancer, some find it difficult to express themselves or to take part fully in a group activity, especially if time is limited.

Waiting times

After the diagnosis and suggested course of treatment waiting times should be as short as possible—certainly not more than 10 working days. Waiting times could probably only be shorter if all tests could be processed more quickly.

Information

Patients are so often left to find their own sources of information on the social, financial, and physical implications of treatment, and whenever possible written information should be available in all outpatient clinics and wards. Specialist nurses do indeed fulfil an important function, but the clarity of verbal information may sometimes be poor. Local support organisations are very helpful as their times of contact are not hospital led.

Many patients who have just been told they have cancer are fearful—frightened of the future, their treatment, and their families’ reactions. They may be confused by the treatments being suggested, and many are still not completely prepared for what is happening or what might occur after treatment. There is a gap in communication between medical staff and patients and carers, and it may be helpful for videos to be available for patients to watch at their convenience. Such a video could show a patient going through the major activities that arise from day one—from smiling consultant saying “you have cancer” (which might also help newly qualified medical staff to learn how to communicate bad news) through magnetic resonance imaging (a truly frightening experience for some) to the actual treatments and surgery (not too much detail here), and on to face masks, pipes, tubes, etc, that may be needed. Some people seek additional information from the internet. This may not always be wise as it may raise hopes of a “magic bullet.” Guidance here is imperative.

Radiotherapy should be better explained—all that facial fitting and then having to be still for long periods and the difficulties with eating and swallowing. Sometimes professionals are a little vague, almost deliberately, having a patronising “wait and see” attitude. Part of the training for all medical staff should emphasis the importance of listening. Patients’ satisfaction should be sought. They need to have “hard facts” presented so that they are able to accept them.

Carers need to be involved at all stages and should be prepared for what to do in the event of any difficulties. It is essential that carers have a telephone number for a named nurse who they can contact in the event of an emergency.

The future

Standards must be consistent throughout the country. This paper, helpful though it is, does indicate there is room for future development. Clients—the patients—must have a say and, while accepting advice and guidance from the experts, must be allowed to arrive at their own assessment of the implications of their diagnosis of cancer and its treatment.