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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."¹ 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.² 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.³

Methods

The study took place across the South and West region. We obtained patients' names from the ten consultants who formed part of the regional tumour panel, 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. 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.

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, 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 asked them to take part.

Before the meetings we sent all participants a short, edited version of the relevant standards. An experienced group moderator used a topic guide to facilitate all meetings. After initial discussion about their personal histories of cancer,⁴ 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.

Results

Thirteen 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.⁵

Overall, patients and carers thought that some of the original standards should be dropped, others modified, and some new ones created (see table). 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 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

Examples of views of patients and carers on existing standards for care and eventual published national standard

Activity	Task	1998 standard ⁶	Views of patients and carers	2000 standard ⁷
Process management	Coordination	All centres to have named head and neck specialist responsible for local provision	“When you get to see these consultants, you always feel a little bit of fear. The Macmillan nurse is really the best liaison.” The Macmillan nurse (or equivalent) was uniformly regarded as key coordinator	Added: All centres should have a dedicated specialist head and neck liaison nurse (for example, Macmillan), whose contact details should be provided to all patients at the earliest opportunity
Information	Patient support information	90% of clinics and wards to have written information sheets providing information on support organisations, general ward topics, general treatment issues, specific head and neck problems	“There’s loads of information but it was so nicely written. It was factual, but it didn’t prepare you for all the horrible nitty gritty.” Too many leaflets sometimes confused people. No one could understand why this standard was limited to 90%. Support organisations should include reference to local organisations as well	Replaced by two leaflets to be available in all of head and neck clinics and wards: 1 General one on head and neck cancer. 2 List of support organisations (national and local) and details of where to get extra information. One document should be national standards (in lay terms)
Palliative care medicine	Crisis planning	No existing standard for patients and carers	“There was blood everywhere just pouring from him . . .” (carer). In retrospect, she recalled that he had showed her a new [bleeding] lump and she had sought to reassure him. Although everyone appreciated that no one wants to frighten carers, it was thought that they should be told of things to look out for	New standard: All patients at risk of crises and their carers to be made aware of the warning signs

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 process⁶ and tested the standards by audit.² The key standards were subsequently entered into an iterative consensus process involving head and neck consultants nationally.⁸ After the report was released, a second national consensus process was undertaken, and the results were included in a second draft of national standards.⁹ Five specialists then screened the report and made amendments with a two iteration email technique. The results were circulated to a multidisciplinary group of 80 clinicians and paramedical staff, who added further comments. For any disagreements between clinicians and others, the views of patients and carers prevailed, with one exception. Patients and carers thought that radiotherapy should start within a month of the planning clinic. Present NHS resources, however, make this standard completely unrealistic. Thus a longer time standard was adopted.

The table gives some examples of how the original 1998 national standards have been replaced or modified by the results of our study.

Discussion

Possible disadvantages

It was difficult to assess how representative our participants were. Patients in more rural areas may have different views¹⁰ but were excluded from our study because they lived too far away from where the groups met. Some attrition in selection typifies this type of research, in which inconvenience, 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.¹¹ 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 often supposed. They understood the diagnostic dilemma faced by general practitioners arising from the vague nature of early symptoms.

What is already known on this topic

Patients with head and neck cancer require complex multidisciplinary care

Professional standards exist for much of this

Incorporating the views of patients and carers is often recommended

What this study adds

Focus groups are an effective and efficient means of assessing views of patients and carers on professionally derived standards of care in oncology

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

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,¹² but as the messages from the focus groups were so clear and compelling little dispute arose despite the involvement of many diverse professionals.

Our study shows how views of patients and carers may be assessed and contribute to changes in professional standards in a manner which is acceptable to all parties. However, we do not suggest that this is the only form of social research that may be used, and for other settings and budgets interviews or questionnaires may apply. The next challenge is to keep our understanding of the views of patients and carers and thereby professional standards current. This is as important as ensuring the scientific basis for practice is up to date but requires a new, cyclic process.

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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 her 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 must have had an effect on treatment as patients were denied a voice. The inclusion of patient' 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 be shorter only 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 emphasise 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.

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