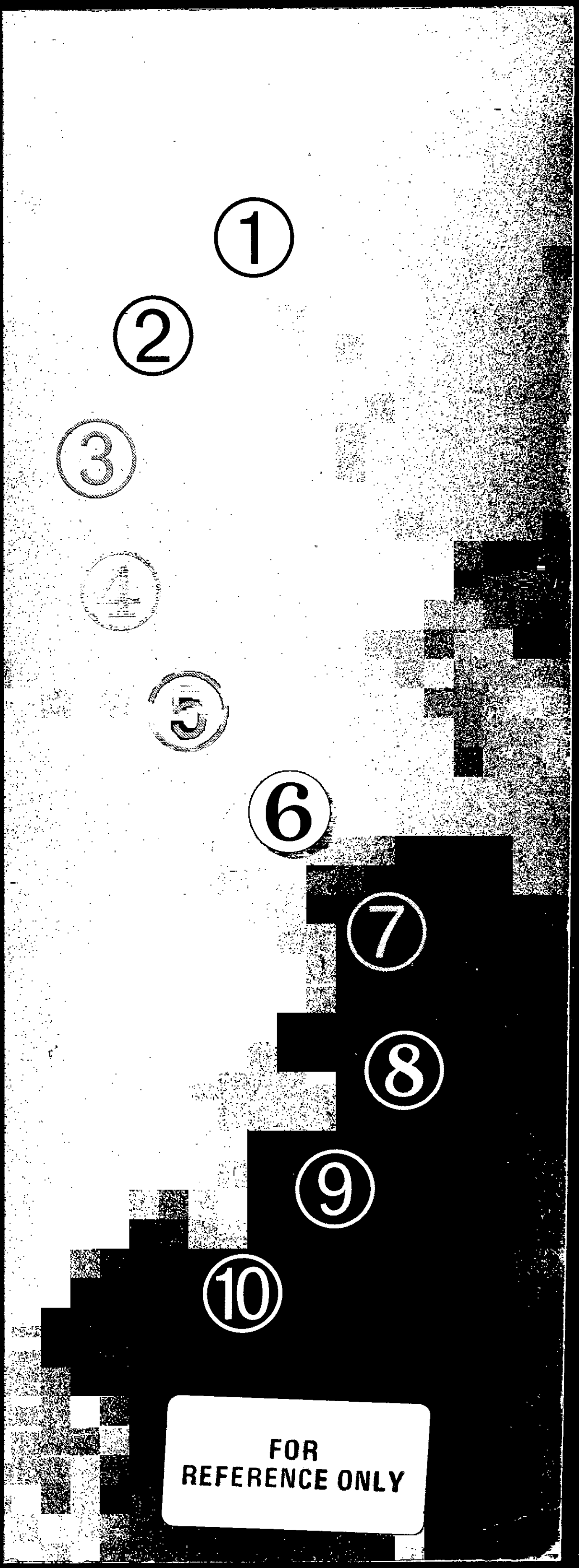
King's Fund

Face to Face

Patient, family and professional perspectives of head and neck cancer care

Dymphna Edwards

Promoting Patient Choice



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What cancer can't do

Cancer is so limited,
It cannot cripple love,
It cannot shatter hope,
It cannot corrode faith,
It cannot eat away peace,
It cannot destroy confidence,
It cannot kill friendship,
It cannot shut out memories,
It cannot silence courage,
It cannot invade the soul,
It cannot reduce eternal life,
It cannot quench the spirit,
It cannot lessen the power of the resurrection.

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Finally, I would like to thank Ian Nicholl for his excellent illustrations. Ian has cancer and is a member of 'Let's Face It'. He has undertaken a number of works of art around the theme of facial disability. He is currently working on a limited edition of sculptures on this theme.

Executive summary

There is an increasing emphasis on user/patient views in the NHS both individually in their clinical management and collectively in the development of services. The Expert Advisory Group report on cancer services [1] has outlined changes which are to take account of patient, family, carer and professional views. Head and neck cancer services, or more specifically upper aerodigestive tract (UAT) cancers, present a particular challenge because of the high impact,[2] the large number of professionals involved[3] and the lack of standard protocols.[4]

The aims of this study were to seek the views of patients, families and professionals of head and neck cancer services, to explore the impact of the condition on their lives and make recommendations for change where necessary. Participants from four hospitals (two teaching hospitals, one cancer centre and one district general hospital) were involved in the study as well as members of two local patient support groups. A qualitative focus group method was used.

There were many examples of both good and poor practice. The key issues to emerge reflect those of other studies.[5,6,7] There were wide differences in the services provided at all stages of treatment, between hospitals and between clinicians and ward staff within the same hospital. Recommendations focus on methods of good practice, ways of ensuring consistency and bringing the rest up to the standard of the best.

The main findings were:

- inpatient accommodation was often inappropriate. Patients need to be in a ward with adequate privacy where nurses are familiar with their condition and where other patients are having similar treatment. This needs to be ensured in future changes;
- internal communication and co-ordination of services were a major concern for both patients and professionals. Organisational problems were the biggest source of frustration for professionals. There is a need for better co-ordination of care both within and between different providers and sectors;
- patients reported that information on what to expect and on the side-effects of treatment was often lacking. Many people wanted to be involved in their treatment and to be better informed of treatment options than they actually were. Choice was a contentious area;
- patients expressed a need for someone to listen and advise. Existing counselling services were experienced as inaccessible and inappropriate. Psycho-social support needs to be made available and accessible to patients, relatives and professionals. Some professionals' attitudes also needed to be improved;
- professionals valued teamwork, acknowledging the contribution of each person on the team. Teamwork helped with clinical decision making, improved patient care and

provided support for clinicians. UAT cancer should be managed by a multidisciplinary team;

- head and neck cancer has a major impact on patients and families both in the short and long term. Many participants wanted others to appreciate what they go through;
- the proposed Calman changes[1] were welcomed by people with cancer, their families and professionals, although professionals had reservations as to the implementation and effect on work patterns. Purchasers and providers will need to ensure that this creates greater co-ordination rather than fragmentation of services.

Chapter 1

Introduction

This report presents the findings of a research study with professionals, relatives and people with cancer of the upper aerodigestive tract (UAT) – mouth, throat and face – often referred to as 'head and neck' cancer. It is intended for clinicians who are involved in the management of these conditions, trust managers, purchasers, researchers and not least, individuals with these cancers and their families.

Patient or user views have assumed increasing importance in the NHS over the past few years. This has taken several forms. *The Patient's Charter*[8] and hospital league tables have put forward a consumerist agenda in a market-orientated system. However, health care is not a true market from the point of view of the patient, and consumer choice is restricted by geography, knowledge, service availability and preferences of clinicians. Many people may not want to be active consumers and 'shop around' for their health care.[9]

There has also been a move to incorporate patients' views in auditing services in order to improve the quality of care. This has mainly been attempted by methods such as patient satisfaction questionnaires. These have been criticised both in terms of validity and of aims, which can be more about improving the image of the provider than really seeking patients' views to make the service more patient-focused.[10]

Quality of life has become an important indicator of treatment outcomes. These complement clinical measures and are as relevant from a patient's perspective. They are particularly useful in informing choice of treatment for chronic disease conditions where the outcomes are often more about living with different symptoms or disabilities than cure. For conditions such as cancer there may be a trade-off between length of survival and quality of life.[11,12] There are a variety of general measures and a number of specific cancer indices, including head and neck modules, which have been developed and reviewed.[13]

Another area of interest is the involvement of patients and the public in health service development and priorities as outlined in the paper *Local Voices*.[14] Local people can be involved in priority setting, commissioning and standard setting and evaluation.[15] Methods of involving people in decisions continue to evolve and include citizens' juries and health panels.[10]

Cancer services are in a period of change. The Expert Advisory Group report on cancer services[1] (EAGC or Calman-Hine report) has outlined a framework for cancer services. This Group was set up because of concern about the variation in quality of cancer services in England and Wales. There was some evidence that clinicians who treated more cases produced better results. There was also concern that the treatment should be patient-centred and that patients' wishes should be taken into consideration.

The report is founded on a number of key principles:

- care should be patient-centred;
- the impact and psycho-social aspects of cancer on patients, families and carers should be recognised;
- information should be clear and accessible;
- good communication should occur between sectors;
- patient, family and carer and professional views should be taken into account in the development of services.

The report produced a framework for cancer services with the focus on primary care where most care should take place. Cancer units (at DGH level) would treat more common cancers. Rare and complex cancers would only be treated at cancer centres by a smaller number of professionals than at present. Communication and co-ordination of care between cancer centres and units and primary care would be strengthened by the framework. But the proposed changes are set in the context of changes in junior doctors' hours, changes in higher surgical training and a shortage of oncologists and specialist nurses. The Calman-Hine report has been broadly welcomed by clinicians and patient groups but its implementation is far from simple.

Head and neck (UAT) cancers present particular challenges, including the following.

- The incidence and mortality of UAT cancer is comparable to cervical carcinoma and malignant melanoma combined, and is increasing.[16,17] It has a large impact but has largely been ignored by public opinion.
- The condition and treatment can result in multiple disability and have a greater impact on the individuals and families affected than most cancers.[2,18,19] How this affects the lives of people with UAT cancer has not been well researched.
- The views of patients, relatives and professionals need to be taken into account in any changes. This should not be confined to the 'wallpaper and coffee' issues but to the key elements of care.[15] The proposed changes provide an opportunity to make care more patient-focused but, conversely, if patient views are not considered the changes could make the services more fragmented, confusing and inaccessible.
- The proposed changes have specialty implications. There are five medical and surgical specialties who each claim competence in managing these cancers.[3] A multidisciplinary approach has long been advocated[20] but is not widely adopted.[3] Unlike other cancer sites, the debate does not focus on whether generalists or specialists should treat the cancer, but on the roles of different specialties and whether and how they work as a team.
- The proposed changes have human resources implications. There are 850 consultants in the UK who treat UAT cancer and 6,500 cases. It is estimated that 7–8 new consultants are needed in this field where in fact there are 57 ENT, maxillofacial and plastic surgeons being accredited per year.[3]
- There is evidence of variation in treatment with few randomised controlled trials or standard protocols on which to base treatment decisions.[4, 21] There is little systematic information collected to allow effective audit of services.[3]

Aims and objectives

The aim of this study was:

- to develop an insight into the patient, carer and professional perspectives of UAT cancer treatment in order to better meet the needs of this client group.

The objectives were:

- to document patient experiences of UAT cancer and cancer care;
- to explore patient and carer views of UAT cancer services;
- to explore professional views of UAT cancer services;
- to suggest ways in which these services could be made more patient-focused.

This study used focus group interviews with patients and carers and separately with professionals. Four hospitals and members of two 'Let's Face It' patient support groups were involved in the study. Most patients were treated in maxillofacial departments and this is reflected in their experiences and the impact of the condition. Although many patients came from the four hospitals, patients had experience of sixteen hospitals in South East England, not including those in other countries. Professionals from a variety of disciplines were involved in the study, including ear, nose and throat surgeons, maxillofacial surgeons, medical and clinical oncologists, and palliative care specialists, ward, outpatient, and community nurses, speech and swallowing therapists, physiotherapists, social workers, pharmacists, prosthetic dentists and a GP. The methods used are detailed in Appendix 1. The views of 66 patients, relatives and professionals are represented. All hospitals are referred to as X and Y for anonymity.

Chapter 2 details the care process from the perspective of the person with cancer, relatives and the professionals. Chapter 3 explores the issues of information and choice and Chapter 4 issues relating to the impact of the condition, attitudes and support. Key recommendations are given in Chapter 5.

Chapter 2

The cancer journey

When things go wrong as they sometimes will,
When the road you're trudging seems all uphill,
When funds are low and debts are high,
And you want to smile but have to sigh,
When care is pressing down a bit,
Rest if you must, but don't you quit.

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Introduction

The cancer journey refers to the process which people go through from the time of detection, investigation, diagnosis and treatment and beyond. It is a journey both in terms of the services which people encounter, the treatments which they receive, and also in terms of their lives, coming to terms with the condition and coping with it. It documents the process and services which people with cancer and their relatives go through and profiles these services from both the user and the provider perspective. It tells their story.

There are approximately 6,500 new cases of upper aerodigestive tract (UAT) cancers in the UK per year and the numbers are increasing.[16,17] The cancer can occur in a variety of sites, from the larynx (voice box), pharynx (throat), mouth and nose. Over 80 per cent are a type of cancer called squamous cell carcinoma (cancer of the lining skin). UAT cancer is more common in middle age and elderly people, with 90 per cent of cases occurring over the age of 50. It is more common in men than women, although the ratio of men to women has changed in recent decades from 5:1 to 2:1.[17]

The main causes of UAT cancer are smoking and excess alcohol intake.[17] This accounts for 75–90 per cent of cases, although cancer can also occur in non-smokers and non-drinkers. UK men born in South Asia have a higher incidence of oral cancer and this is thought to be due to the habit of chewing tobacco.[17] High intakes of fruit and vegetables are thought to be protective against cancers in general. The role of viruses and fungi is uncertain.

UAT cancer can present in a variety of ways. Cancer in the mouth or throat can present as a painless ulcer, red or white patch or lump which lasts more than a few weeks in the same place. Cancer in the larynx can present as persistent hoarseness. In the early stages many people may not be aware that there is anything wrong. Most people seek advice from their GP who then refers on. Other people may consult their dentist who may also pick up mouth cancer at a routine check-up.

There has been much recent interest in the early detection of mouth cancer in the hope of improving outcomes. In general, smaller cancers have simpler treatment with less side-effects and have better survival rates than larger cancers. There have been a number of campaigns to increase public, GP and dentist awareness of mouth cancer in order to detect cancer early.[22] However, small cancers may be small either because they are slow-growing or because they are early, so it is not known if 'early diagnosis' will improve results.[17] A small cancer may do better because it is a slow-growing cancer and would not have caused the patient as many problems anyway rather than because it has been treated early.

The person with UAT cancer could be referred to any one of a number of specialists – ear, nose and throat (ENT), maxillofacial, plastic or general surgeon – depending on the site of their cancer and who referred them. They may also be treated by a variety of other professionals – oncologists, ward nurses, outpatient nurses, district nurses and specialist nurses, speech and swallowing therapists, physiotherapists, prosthodontists and prosthetic technicians. The patient is usually seen in an outpatient clinic for investigation. This usually includes examination, X-rays, CT or MRI scans, a biopsy (taking some of the tumour for analysis) and perhaps endoscopy (looking at the throat through a tube). The patient is brought back a week or so later to tell them the diagnosis and the treatment plan. He/she may also be seen in a joint clinic with a range of professionals.

The major treatments for UAT cancer are surgery and radiotherapy. Chemotherapy is used to a lesser extent. There are few randomised controlled trials to show which is the best treatment for each site and stage of the disease and the treatment tends to be based on results of case series. There is variation in the types of treatment given.[4,21] The choice of treatment will depend on the site of the cancer and the stage, previous treatment and the personal and social history of the patient.[4] Surgery produces better survival for laryngeal cancer, whereas radiotherapy produces better speech, producing a trade-off between quantity and quality of life.[23]

If skin or bone is removed during surgery, this can be replaced in two ways. A graft can be taken from another part of the body such as the arm or rib (the donor site) and attached to the mouth or face. Alternatively, a prosthesis (artificial structure) can be made and fitted to the mouth or face. The most common of these is an obturator which is a denture with an extension when the upper jaw has been removed. There have been considerable improvements in reconstructive techniques and prostheses in the past few decades[24–27] and surgical techniques are becoming more conservative.[4,28] This has also resulted in patients previously thought to be incurable, being treated.

Radiotherapy can be given in two ways. The source of radiation can either be given internally from a radioactive rod or externally from a machine. The internal implant requires an operation, and a mask needs to be made for the external type. Most radiotherapy is given on an outpatient basis. The course of radiotherapy varies from a few weeks to months. It can result in mouth dryness and soreness, difficulty in eating, burning and some hair loss depending on where the radiation is directed. Chemotherapy is usually used in conjunction with surgery or radiotherapy and is used in more advanced cancer.

When patients return home following inpatient treatment, their care is managed by their GP, although they may still return to the hospital for follow-up care. The EAGC report[1] stresses the importance of primary care and of communication between primary and secondary care. Discharge is meant to be a partnership in continuing care rather than a permanent or temporary transfer of responsibility for the patient.[1]

The overall survival rates for UAT cancers have not changed in the past few decades, although improvements may be masked by a change in the type of cancers being seen.[4] About half of patients will survive more than five years from diagnosis.[16] One in six people with UAT cancer will develop another cancer,[29] most of these in the UAT area. Cancers on certain sites such as the lip or larynx have a better cure rate as do smaller cancers.[16]

The EAGC report[1] recommends that rare cancers should be assessed and managed in cancer centres by multidisciplinary teams who can accumulate expertise in treatment. No one specialist will be able to meet all the needs of people with UAT cancer, and a team approach has long been recommended in its management.[20] There are over 850 consultants in the UK who treat UAT cancer, and the treatment is spread over a wide number of specialties and provider units. The degree to which these specialists work together as teams and which consultant treats which cancers varies.[3] Just over half of the consultants assess patients in joint clinics and one quarter do not liaise with other specialties.[3]

Findings

Diagnosis and referral

Most people were not aware of mouth or throat cancer before their diagnosis. Others found out in unusual ways. Two men became aware of the cancer through friends who had oral cancer previously. One of them recognised that he had the same signs and symptoms and contacted his GP. The other man who worked in the publishing business came across an article on oral cancer in a women's magazine and referred himself for treatment. One woman came across a quiz in a dental magazine left in her dentist's waiting room with photos of oral lesions which she recognised as similar to her own.

Some of the respondents' cancer was diagnosed opportunistically on a visit to their dentist. Two were under long-term review for potentially malignant lesions at a hospital. Some of these people suspected that they might have cancer when they were referred, particularly if the dentist said that it was beyond their scope.

> *'When I came home from my dentist I had a cup of tea and I put two and two together. When the dentist said, "I can't handle this" I knew there was something wrong.'*

Delays in referral

Some people had a lesion in their mouth or face which was bothering them and for which they were seeking care either with their dentist or more often their GP. Many of these patients felt that their symptoms were not taken seriously and had difficulty getting referred for investigation. Many were delayed for several months before referral.

> *'The dentist said, "Be patient, it takes three months for your gum to heal", but it was longer than that ...'*

> *'It was similar to a friend of mine who had cancer and he had a white spot, so I learned from him. So I go to the doctor and I said to my doctor, "I think I have cancer". He looked at me and told me I hadn't. My doctor put me a good nine, ten months back.'*

These people often found another route to referral, either through another GP in the practice, or through a family member mentioning it to a hospital consultant whom they were under for another condition, or in one case, through a family member who was a dentist. Once this second contact was made, referral followed rapidly.

> *'I first went to the doctor's. It took about six months before they first realised what it was and it was all systems go, really ... I made an emergency appointment with the doctor the next day and got sent to hospital in the afternoon.'*

Administrative difficulties also delayed referral with, for example, hospital appointments sent to the wrong address. For people whose GP or dentist said that they would refer but who did not suspect cancer themselves, the delay could be quite considerable since they had no reason to chase the appointment and find out what had happened. Having had difficulty being taken seriously, many people were relieved when they were finally referred and diagnosed.

Finding out

Many people suspected that they had cancer by the time that they were diagnosed. In other cases relatives suspected, although the patient did not. Some people picked up clues from the way they were treated but for most people the diagnosis was a shock and the news could be equally devastating for family members.

> *'And they left us right until last to see* Mr X *and Sister came out and she called me in and she said, "*Mr Y*, you can come in with your wife". And I turned to him [husband] and I said "It is what I think it is". Because, I thought, they are saying he can come in with me, that was it.'*

> *'That was a big shock. I honestly wasn't expecting that ... I didn't know whether I was coming or going.'*

Most people in the study were told that they had cancer by their consultant in an outpatient clinic with a family member present. This was felt to be helpful to many people, particularly if they had to have further investigations done or in getting home. Most people felt that breaking the bad news had been done honestly, openly and sensitively at the hospitals involved and that there was nothing that could have been done to improve the situation apart from having a different diagnosis. A few people had had a bad experience.

> *'I was told that he had three months to live in front of a room full of students. The doctor said, "I don't know what day it will be but it will be before Christmas. Thank you very much, next patient please".'*

Everybody thought it important that they were told their diagnosis. Some asked their consultant directly if they had cancer or asked to know what the condition was.

Speed of response

Most people felt that they started their investigations and treatment very quickly once they were referred and diagnosed and were grateful for the speed of response. Much of this seemed to happen in a whirlwind with the person often not taking everything in. This speed was felt to be important for people with cancer.

> *'I think that it is quite good to have as quick a time [as possible] and not have much time to dwell on all sorts of things.'*

The fact that someone was taking positive action was particularly valuable for people who had experienced delays in referral. Any delay at this stage increased anxiety. One woman's operation was delayed for a month because her consultant was on holiday and there was no one else available to operate. This was described as a nightmare. There was no support or information during this period and her GP had not been informed of the cancer. Administrative delays could be extensive when patients were transferred from one hospital to another.

> *'But then he [the consultant] said he would set this up in London and we would hear within a few weeks. A few weeks went by, two months went by, three months went by and I was getting anxious so I phoned and they said, "Oh, he has gone away on a lecture tour abroad". I kept on phoning and after six months they apologised because he had forgotten … that's when they found that it had actually turned malignant.'* Relative

Treatment

People in the study differentiated between three distinct elements of their treatment:

- the medical or surgical treatment;
- the organisation of services;
- the interpersonal care and support which they received.

Although the three were linked, there were many people who reported that they were very happy with some aspects of their treatment and not with others. Their views on interpersonal care and support will be discussed in Chapter 4.

Many people had been seen in a variety of hospitals and had had a number of different treatments. About half of them had one or more recurrences. This range of experience allowed them to identify differences between services. Most people spoke very highly of the hospitals where they were treated. Any negative experiences tended to be portrayed as isolated incidents and reinforced how good the care usually was. Sometimes they blamed the condition or themselves.

Medical and surgical treatment

Over half of the participants had undergone both surgery and radiotherapy and some had had chemotherapy as well. The others had radiotherapy alone (either external or internal) or surgery alone. Most people viewed their treatment as a necessary evil; something unpleasant, often painful, which had to be gone through. They were very grateful to their clinicians for the treatment which they received.

> *'For all the complaints I think that you have to pre-empt that with the fact that you are so grateful to the surgeons for saving you to start with and, in my case, avoiding me from being completely disfigured'.*

The treatment itself was often the least controversial of the care issues for people with cancer. Some people who had had surgery marvelled at how little scars showed. Others who had more major reconstructions with less cosmetically pleasing results put the result down to the severity of the condition. The main problems arose when there was insufficient information or choice given about the treatment and side-effects or when conflicting information was given. In a few cases there was considerable delay in locating the primary tumour, in one case because of an oversight or in other cases despite extensive investigation.

Several people had unexpected adverse effects or complications of treatment which were quite serious. These were blamed on the condition rather than on the clinician. Doctors were not blamed for failures in the treatment but were blamed if the failure was felt to be avoidable, i.e. if doctors failed to respond to the signs or symptoms or failed to provide information. This was true of both pre- and post-diagnosis. Several people had postoperative complications which were not detected early enough. In a rare complication following a leg graft, one woman lost her leg. This was compounded by the fact that there was no information on the risks involved.

> *'I specifically asked how it was going to affect her leg afterwards and he said, "Well, I will have her up," and made a joke of it. Nobody ever told us that you could lose a leg … Fortunately the graft of the face has now taken but it was a hard price to pay losing a leg, just for a reconstruction.'* Relative

Patients judged the success of treatment not only on whether the tumour was gone but also how they could live and their quality of life. One woman had two reconstructions. The first had little morbidity but the graft didn't take. The second operation following a recurrence had a better clinical outcome but left her unable to eat and facially disfigured.

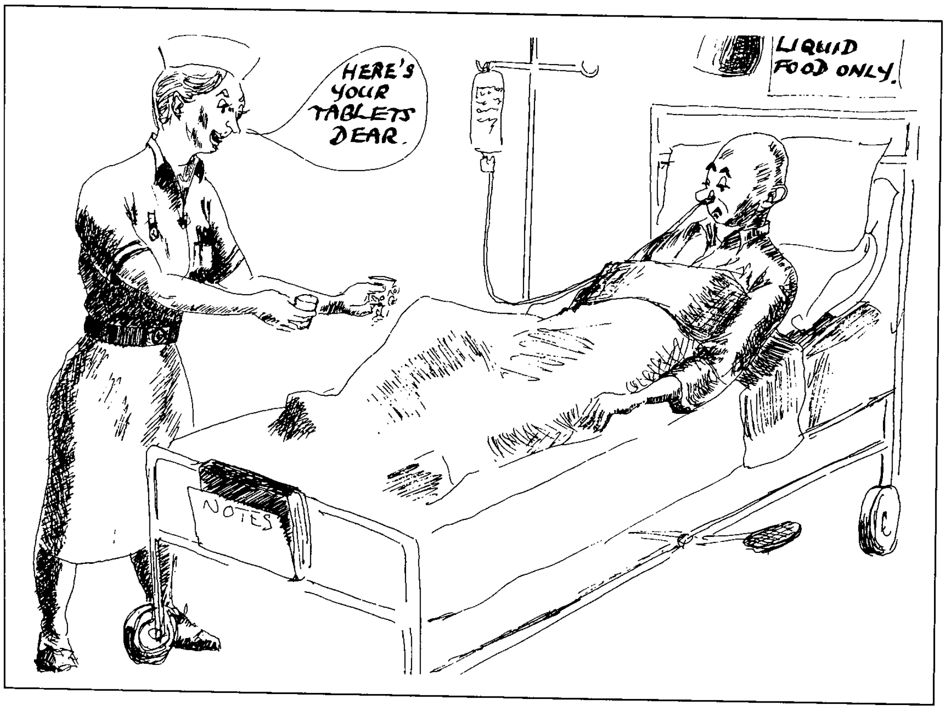
Hospital care

Accommodation

One of the key themes which emerged from the group interviews was accommodation in hospitals and particularly mixed wards, both in terms of condition and gender. The concerns were similar in men and women, young and older patients and relatives. A few patients had been in specialist cancer wards or head and neck wards but most patients had been on wards with people having very different procedures. Although they recognised the difficulties of finding beds, many people with cancer felt that this was inappropriate both in terms of the interaction with other patients and in terms of the nursing staff.

> *'If you are in a ward with people with similar things to yourself you can sympathise with one and other and you can talk about it openly. You can't talk about cancer to anybody else who hasn't got it. No matter how much they try they don't understand how you feel. Even the nurses don't understand unless they are dealing with other cancer patients and it is their speciality.'*

Being on a ward where staff were familiar with cancer patients was felt to affect their care also. Relatives, in particular, described situations where the ward staff did not seem to know anything about the patient or the condition and were not sure how they should be fed or nursed. One woman reported how a nurse tried to give her antibiotics by tablet, although she was being tube-fed because she could not swallow. People who were in a ward with mainly cancer patients were more confident in the care they received.



One woman was very upset by being put in a plastic surgery ward where many patients were having what she called 'cosmetically beautifying treatment', while she was being 'significantly disfigured'. Another woman in her twenties ended up in a geriatric ward with a very confused patient beside her, which she found distressing.

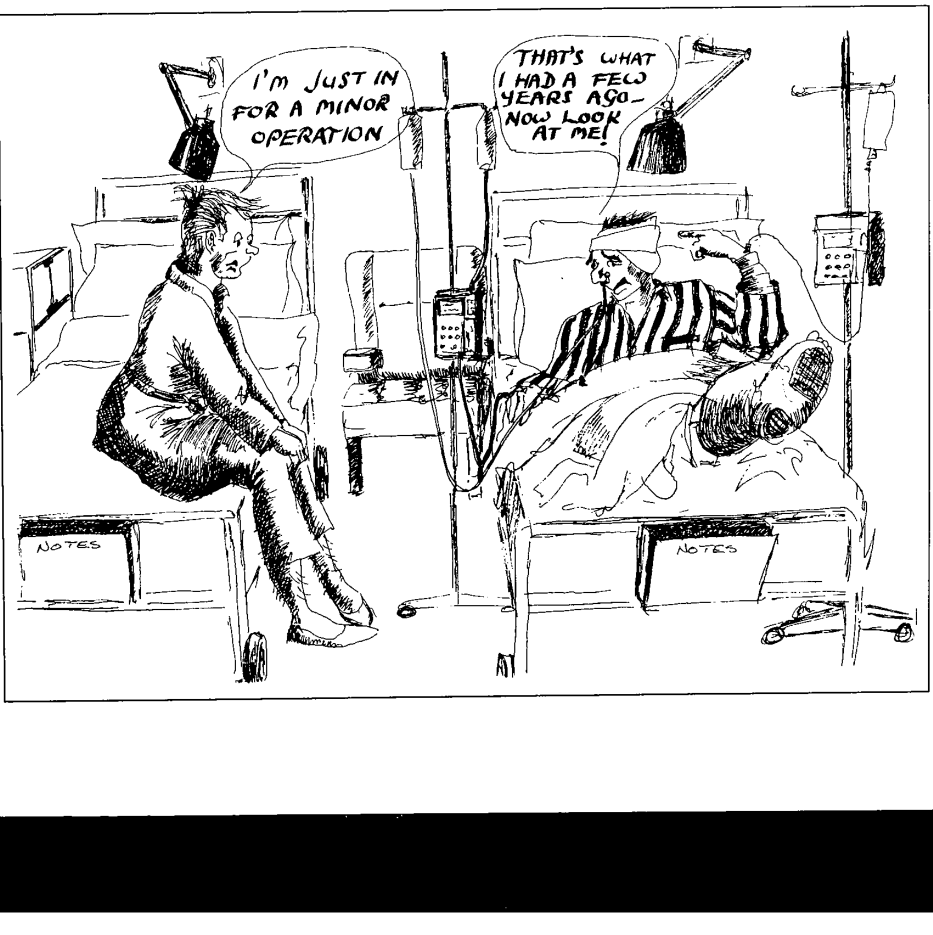
> *'It got a bit depressing sometimes being in this ward. I mean there was a woman next to me and it broke my heart. She didn't have a clue where she was, how she got there, you know, and she was constantly ripping her drip out of her arm trying to escape out of the hospital. And that was a bit off-putting when you are like that and there was only two of us there for oral treatment.'*

Some people were concerned with privacy in open wards. They said that they could hear everything that was being said in the next three cubicles. For others, mixed-gender wards were a concern, particularly if they were undergoing major surgery.

> *'I felt that I had lost all my self-esteem and confidence. With a young man just beside you it sort of rubs it in, doesn't it?'*

Being in open wards with people with other conditions was felt to be difficult all round, for those having major surgery and for other patients. Patients who had major surgery felt embarrassed by their appearance and by trying to speak or eat in front of others.

> *'If you are in a room where they can all talk properly … I thought, "I am not going to talk to them because they are not going to understand what I am talking about." So you just don't talk.'*



Interaction with other patients with similar conditions could occasionally have a negative effect. Some patients on arrival at the hospital were put in the same area of the ward as people who were recovering from major surgery. This could be upsetting and frightening for patients who had just been admitted for surgery.

> *'There was one poor lady there who looked black and blue … she looked as if she had been beaten up and a lot of the other patients were frightened.'* Relative

One man who had a small tumour was cheerfully informed by another patient on the ward who had just undergone major surgery that he too had a small tumour two years ago but it had recurred and was now much bigger. This was information the man could have done without at that time!

A few people who had radioactive implants described their stay in hospital as 'solitary confinement', as hospital visits were restricted and they were not allowed out of their room. They felt totally cut off from the world. This had a major impact on the people involved, one of whom developed claustrophobia.

The people who were most satisfied with their accommodation were those who were in a side room on a ward which had other patients with cancer. They had the nursing expertise which came from an understanding of their condition, they had privacy and could control their interaction with other patients.

Discharge from hospital

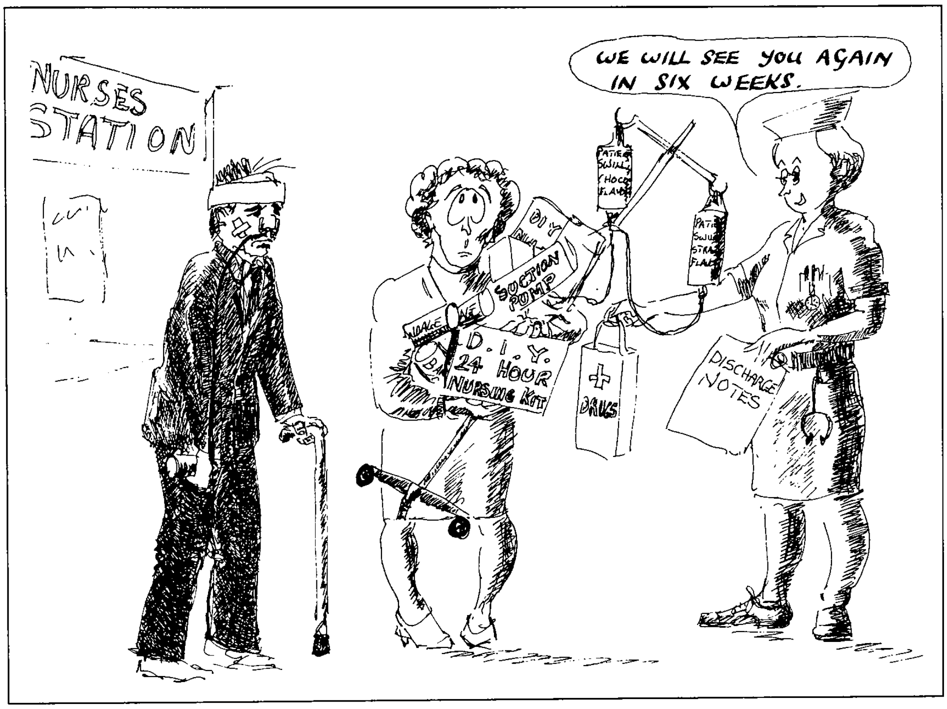
Patients had varying experiences of discharge from hospital. Some people were anxious to leave as soon as possible, but many others found that they were being asked to leave before they felt ready. Although people understood that beds were needed for other people, the process could feel like being on a conveyor belt.

> *'She couldn't even swallow her own spittle and I was sitting beside her all day long with one of these machines – it was ghastly … They were making noises for us to go home and take one of these feeding machines. She was being fed up her nose you see … I thought ,"How the hell can we go home and she was like this you know? What can I do?".'* Relative

Many people felt that medication on discharge was badly handled. Some people were on strong analgesics (pain killers) or sleeping tablets in hospital. These were withdrawn suddenly when they were discharged, leading to side-effects.

> *'I was on morphine for the pain. Then doctor X was ill so I couldn't get the prescription so I just stopped it. Immediately really. That made me quite ill for a few days.'*

Many people felt quite vulnerable when they were discharged. The security and routine of the hospital were being left behind, and they were not sure how they would cope. Having an appointment to return for review or speech therapy was often felt to be comforting. One woman, who was discharged for weekends initially before full



Discharge

discharge, felt that this was helpful in preparing her for life outside the hospital routine and support.

The professionals in the study recognised this vulnerability on discharge. They felt that it was important that the person with cancer and their families did not feel abandoned by the hospital services. Advising patients that there was always a nurse and doctor on call if there were problems, giving review appointments and communicating with community services were ways in which this was safeguarded against.

Outpatient treatment and review

Once discharged, most people had many review appointments with their surgeon, speech therapist, oncologist and other professionals. The reviews were welcomed initially as a means of keeping in contact. However, as time went on, the number of reviews could become a burden and almost a full-time occupation, particularly when several hospitals all had separate review appointments. If another member of the family was also undergoing long-term treatment or if the patient was under review for another condition, they felt that they spent most of their lives at hospitals. The time taken for reviews was also an issue.

> *'When you go you get an appointment for nine o'clock and you are still there at eleven o'clock waiting to be seen and it is – that in itself is depressing because there is nothing exciting about standing in a hospital waiting and it can be upsetting.'*

Many people found that when they went for review they saw a different doctor each time. The lack of continuity could be disappointing and distressing.

> *'Somebody who knows nothing about the case is wasting your time and you are wasting his as far as I am concerned.'* Relative

Speech therapy

Speech therapy was welcomed by all patients who had this service. Speech therapists were a major source of information at one hospital for support services and support groups. Many people were told prior to surgery that they might need speech therapy but were able to speak without difficulty, which gave them a sense of achievement.

> *'They didn't think I would be able to talk properly with the denture in even but, I can! So I said the only way if they want peace and quiet is to take my top denture away!'*

Most speech therapists got to know patients over a long period of time. They assessed patients prior to treatment for speech and swallowing and explained to the patient and their families what to expect and what treatment would be available afterwards. Most felt that this initial contact helped to develop a working relationship post-operatively.

In the initial post-operative stages the speech therapy role related to swallowing and this was the main concern of patients. Some therapists said at this stage that patients were often less concerned with speech. They ensured that the person with cancer had a means of communication whether written or verbal. Speech therapists felt that they had a supportive role for the person and family and were frequently asked questions about other aspects of the person's treatment long after the event. Most therapists thought that their patients and families became very involved in their speech therapy. The success of the treatment depended mainly on their involvement.

Primary and community services

GP services

Most people had little contact with their GPs following discharge. Many found that their GP had not been informed about their condition or treatment as referral had been made through the dentist.

People knew that UAT cancer was rare and did not expect their GP to be an expert on their condition. However, they did expect their GP to keep up to date with their case and support them in the community. They expected GPs to enquire as to how they were when they had an appointment and to take their symptoms seriously if they had further problems. Where GPs were open and honest about their knowledge, they were respected for that.

> *'Our GP didn't "beat about the bush" or panic, he was quite a good bloke really and he said, "I know nothing about it."'* Relative

In contrast where GPs either failed to take symptoms seriously or tried to divert blame for mistakes made, they were regarded with contempt. One woman was delayed in referral for six months by one doctor who kept giving her antibiotics. When he found out her diagnosis, he tried to cover himself by saying that the antibiotics he prescribed had not caused the cancer. She refused to see that GP again.

As GPs are key to accessing community services, for people their support is vital. Often that support was lacking and people slipped through the net. If their GP enquired about them, people felt supported even if nothing else was needed.

> *'He [our GP] is very good, yes. He come around to see us one day and said, "I feel very guilty because I feel that I am not doing enough for you." I felt that it was rather nice of him to say that, but there is nothing that he can do.'*

Many people felt that the attitude of their GPs could have been better and that many GPs lacked training in how to deal with cancer patients. Some were obviously frightened by the condition, and others did not know what to do. One woman reported what had happened when her husband's GP visited him in a hospice when he was a few days from death. A piece of bone had come out. The GP panicked and threw the bone out of the window onto the front lawn. He ran out of the room, told the patient's wife to have a stiff drink and disappeared. When she went into the room her husband was shaking with laughter at the doctor's reaction.

Professionals also thought that support from GPs varied. They thought that the workload and stresses of general practice could contribute to this. Community nurses felt that they had an educational role with some GPs and that they needed to keep them up to date with patients' progress. Relations between the patient and GP could be difficult where the GP had misdiagnosed the cancer.

Dental care

Many patients felt that their dentist knew more about their condition than their GP and that they received more understanding from them. However, people whose dentist had failed to diagnose their cancer did not have confidence in them and did not return to that practice. Many people had their dental care overseen by the hospital which treated their cancer. Most people had lost some teeth during surgery or prior to radiotherapy and several had lost all their teeth. Some people went to a dentist in practice and most found them helpful for advice.

Several people had dentures and obturators (dentures with extensions) as a result of their treatment. This necessitated further hospital appointments. Most people were very happy with the results of their obturators. However, many worried about emergency care if anything happened to their obturator.

Palliative care

Some patients in this study had received palliative care, but given that the patients in the study were well enough to travel, palliative care may be underrepresented.

Some people had support from a Macmillan nurse in the community but not in hospital. They provided support and information and organised services like feeding and suction machines. For people who had advanced cancer or who were at a critical stage of care, they were said to be invaluable. One of their main roles was in liaising between health professionals and co-ordinating care. They acted as a lynch pin. As people recovered, the service tapered off. Some people felt that the co-ordinator role was needed also for people with less severe conditions. Other people found that as the frequency of visits decreased, they needed other support services.

Many doctors found palliative care difficult. It was difficult to make the decision whether to treat curatively or palliatively. It was also difficult to acknowledge that curative treatment had failed or was inappropriate. This could feel like failure. Hospital clinicians sometimes felt that when there was no more that could be done to cure the patient, they had come to the end of the road. Communicating this to the person with cancer was difficult. Some doctors spoke of a balance between honesty and leaving the person with hope.

Doctors often felt most isolated and vulnerable when dealing with palliative care. There were more uncertainties in treatment and fewer guidelines. There were issues to be decided about how radical or otherwise to make the treatment. If it was not radical enough it would not control the symptoms, but if it was too radical the patient could have a poor quality of life. Some clinicians felt that the transition from curative to palliative care was not well managed.

> *'There isn't continuity between active treatment and palliative care. They may still need some treatment even if they can't be cured. They may still need to take away some of this bulk of the tumour to make themselves comfortable. And personally too, to make patients feel that they are not forgotten about.'*

This did not always happen. In one hospital the options were not openly discussed and the person with cancer was often ignored during the ward round as they were not having active treatment.

> *'When you know somebody is going to die and they're waiting for a hospice, on the ward rounds you go, "How's Mr Jones today?" and then you just walk by the patient.'*

Some people made a particular effort to maintain involvement with the person with cancer even though active treatment had stopped.

> *'You accept that the medical input is not going to make a difference and deal with that separately. I usually make an effort then, to go back and talk about the latest football result or how miserable it is outside … that sort of thing. Chit chat, really. So the emphasis changes.'*

Some people felt that something could always be done for the person with cancer even if they couldn't be cured. Clinicians who worked in hospices felt that there was always hope.

Hospice care

A few people had experienced hospice care. One woman's husband was nursed in a hospice during his last days. She found the staff very positive and encouraging and thought that he was nursed with the care and dignity which he deserved. This contrasted with the care which she had received from her GPs. Another woman was reluctant to attend a day centre at her local hospice as advised by her Macmillan nurse as she said that she was not ready to give up on life yet. She was persuaded and said that it had given her a new lease of life.

> *'They are the most caring people you would ever wish to meet. My husband and I have taken up art, for a lark! You get a lovely meal and you get so many people to talk to and you can get your hair done, massage, anything you want. And they are just absolutely wonderful.'*

Many professionals thought that hospice care was equated with terminal care in many patients' minds and it could be difficult to introduce people to hospice services. Once the barriers had been overcome, it could open new doors. Hospice doctors and nurses felt that they were there to support the person and facilitate them in living their lives.

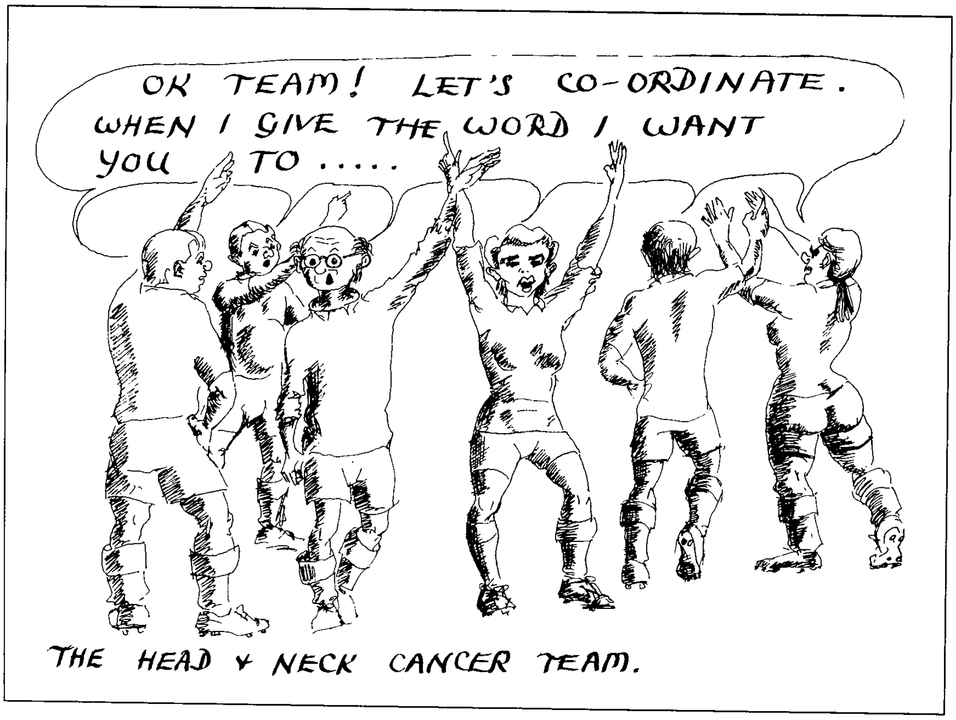
> *'We hope it gives them quality. We hope it gives them dignity and independence. We hope we haven't taken anything away so the patient remains that individual. So they are actually allowed to live, until they die, as they always have done.'*

Practical examples of this were reported. One man who had been in hospital for several months decided that he could cope at home having spent a short time at a hospice. Another man managed to get to the pub every day from the hospice despite having a tracheostomy and no speech.

Teamwork

All professionals in the study said that they worked in a team and that they valued teamwork. There were different interpretations of what a team involved. Some people used the term 'team' in the widest sense, incorporating the patient and family and all people involved in their care. In other cases the team referred to a group of consultants from the same or different specialties who shared the management of a particular patient.

Many doctors reported that teamwork was important in treatment planning. It could be difficult to decide on the best form of treatment and they valued the input of others with different expertise and experience. This not only prevented them from making mistakes in management, but also made sure that they considered the full range of options for the management of the patient. Many clinicians said that joint decision making helped them to keep up to date with treatment options in which they were not involved. Surgeons, clinical oncologists and radiotherapists said that they could all learn from each other. This had benefits not only for patients but for clinicians too in that they felt less isolated, they had support in their treatment planning and someone to talk through their difficulties with.



> *'It [teamwork] keeps me up to date in what is happening on the surgical side of things as surgery is just as important as radiotherapy. If I don't know what the surgeons are doing, I can't design my treatments properly and I think that applies to the surgeons as well.'*

Joint working was also found to be valuable during the treatment. If several surgeons took part in an operation, it reduced the operation time and had a better chance of success. Teamwork was important to co-ordinate care between all the people involved. It could prevent conflicting information being given to the patient and ensured that everyone knew what the problems were, what was trying to be achieved and how. This was confirmed by the patients' views of their care. The degree of teamwork which they perceived was one of the factors that affected the confidence of patients in their care. Many people felt that conflicting information indicated a lack of teamwork within the hospital. Where they had confidence in their team, this was often the key factor which they wanted to safeguard.

One professional group made an analogy between airline pilots and surgeons.

> *'It used to be thought that the Captain knows it all and can fly the whole plane and all its contents and crew out of danger. And they have very sensibly abandoned that idea years ago and it's a team that flies the aircraft, taking due recognition of everybody's contribution.'*

This concept of teamwork had practical benefits in the management of patients as this example illustrates.

> *'We have had problems with patients with chest complications following this major surgery. It's no use me banging on my hand and saying, "physio, physio, physio". It takes somebody like a speech therapist to point out that the injury to the ... protective mechanisms for swallowing is such that the patient can't help but silently aspirate material into the chest. So, we can be banging up a blind alley until somebody provides the insight and the information that allows us to see what the problem is in a different light. [We can] perhaps change what we do so we don't run into that problem again and hopefully tackle the problem before it arises.'*

One hospital had a group which met together once a month outside the clinical area to discuss issues relating to the care of people with UAT cancer and individual patient care. This was felt to be very valuable in building a team and in co-ordinating the care services. This group consisted of two senior registrar surgeons, a speech therapist, a physiotherapist, a nurse, a pharmacist, a restorative dentist, an operations manager and a secretary. The group felt that they had come to understand and appreciate each other's roles, they had developed joint guidelines and protocols and were working more effectively together. The group also helped to change the working patterns and culture of the services provided by their departments, to make them more multidisciplinary and patient-focused. The operations manager reported that when presenting a management issue to other managers in the trust, the fact that it was recognised and owned by a multidisciplinary group added weight to his arguments.

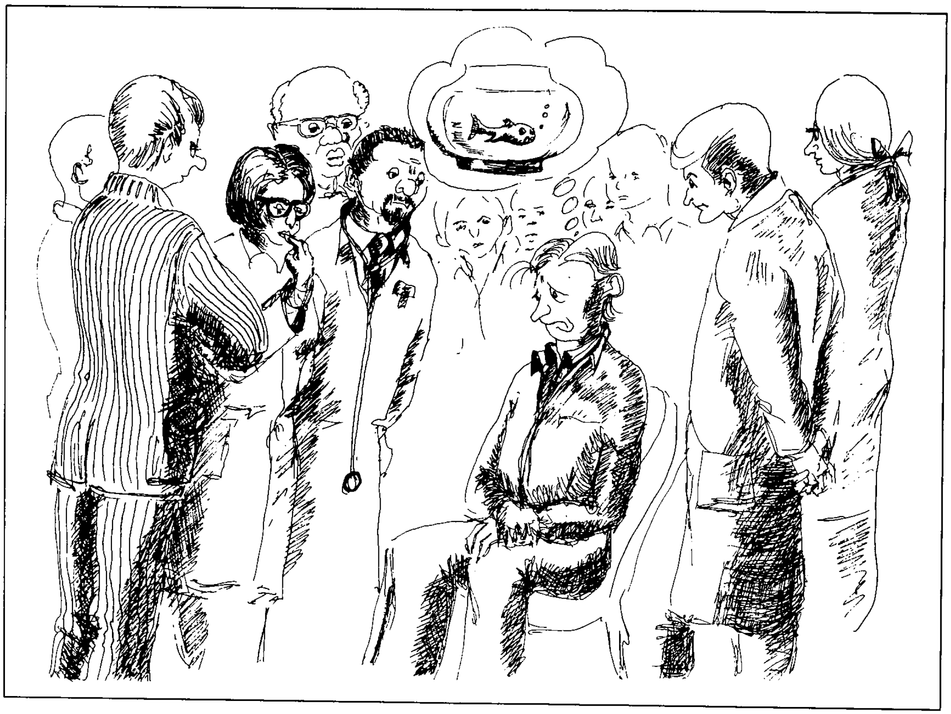
Many professionals felt that care should be patient-focused. Without the patient there would be no service, and the care should revolve around the person with cancer and not vice versa.

> *'I think it is because we have to respect that these are people we are operating on. It is very easy to get caught up in the process and forget about who's involved. Unless you tailor it to the patient's requirements and [they] know what we're going to do to them rather than just expecting them to comply, then you lose sight of what we are there for. We are not there to cut out a tumour – we are there to provide a route of survival for a person ... I've certainly met surgeons who lose sight of that and regard it almost as a manufacturing process – in one end and out the other.'*

Joint clinics

All hospitals had joint clinics but their organisation varied. In all cases they involved maxillofacial surgeons, a radiotherapist and a nurse. In other cases ENT and plastic surgeons, medical oncologists, palliative care specialists and speech therapists were involved. Many clinicians worked in more than one hospital and so were able to make comparisons between the hospitals.

In most cases the patients were assessed and diagnosed in the speciality clinics and then brought to the joint clinic for treatment planning. There were differing views on how



The joint clinic

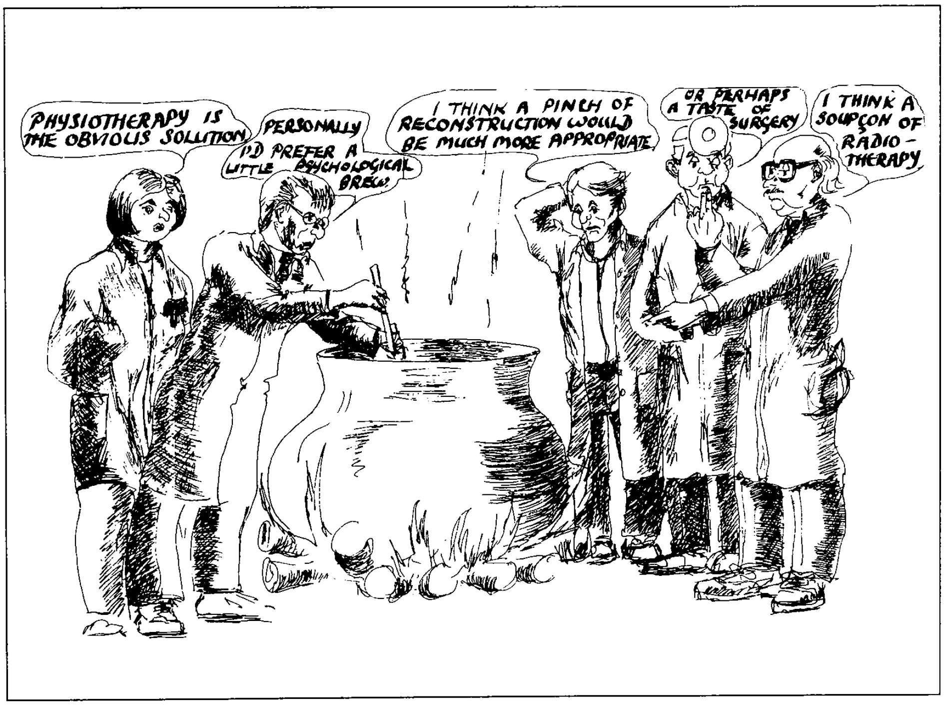
this should best be managed. One hospital had a small team and felt that they could provide continuity for patients in a close, friendly environment. Others had larger teams which they thought brought more skills. In two hospitals the joint clinics met once a month. However, they had arrangements for patients to be seen at other hospitals if a patient needed urgent treatment.

Some clinicians described a joint clinic at one hospital where the patient was faced with a large group of clinicians, many of whom were not involved in the patient's care. This was felt to be intimidating for the patients and discourteous when little interest was shown in the patient. One hospital had a system where the patient's notes were discussed, the patient invited in for a few minutes, asked questions and then brought to another room while their treatment was planned by the group. The patient was then advised of the group conclusion. Although the joint clinic was felt to be important for treatment planning and for the clinicians, some professionals felt that it might create inconvenience and anxiety for the patient.

There were mixed opinions on the benefits and drawbacks of involving junior staff. Some clinicians felt that by making joint clinics 'consultant only', there was con-tinuity for patients and a small dedicated number of people involved. Others felt that more junior staff needed to be involved both from a training point of view and a practical one but that if too many professionals were involved, it could be disruptive for patients.

Clinical decision making

Many of the doctors spoke about the process of clinical decision making. This applied at all stages of the cancer journey but principally to decisions about primary treatment following diagnosis. Some clinicians spoke of their role as being to assess the patient as well as they could and use their judgement to work out what they felt was best for the patient.



Treatment planning

Many clinicians spoke about the individuality of patients and the difficulty in working out what was the best treatment for that particular patient. There were many things which had to be taken into consideration. Clinical factors such as the type and site of the tumour, its stage and differentiation were considered. Other factors such as the age of the person with cancer, their physical condition, their attitude and social support were also important.

> *'Each case is unique in that it is a human being with their own thoughts, desires, medical history, type of cancer, extent of cancer, and it can be difficult to decide what is the appropriate form of treatment for that particular patient.'*

Many clinicians said that they assessed patients consciously or unconsciously for individual factors which were observed in their manner, body language, the type of questions which they asked and the response which they gave to the information provided. It was important to find out what the patient wanted in assessing what was the best treatment for them. These individual factors were felt by most people to be very important in determining an appropriate treatment plan for that person.

The role of evidence

There were a variety of opinions on the role of research evidence in decision making. Some doctors felt that there was good evidence for the treatments offered and felt confident basing their decisions on this evidence. Others felt that the uptake of clinical trials was too slow and by the time the results were published the treatment had become standard practice anyway. Some doctors thought that they kept up to date with recent developments, whereas others doubted that clinicians were as up to date with recent research as they claimed. Some doctors were suspicious of the drive for evidence-based decision making.

> *'Evidence-based medicine is usually, in my experience, an administrative weapon that is used by somebody who doesn't understand the actual pathology and in many cases even the basics of the disease and its treatment as a way of grinding down a financial tax on the NHS.'*

Many doctors felt that if there were good clinical trials and protocols, it would make their lives easier. However, others felt that protocols could be restrictive and not allow for individual patient differences.

Some people reflected on the difficulty of the decision making process in treatment planning.

> *'It can be very difficult sometimes to know what the correct thing to do is; to know what your chances of achieving success are in each particular case ... You first start getting to know them [the patient] and if you have problems with a case it changes your perception with the next case and so on and you build up experience over a period of time. When you first become a consultant you tend to treat very radically and everything is very clear cut and as you get older you tend to moderate. And which is the better treatment plan, the radical or the moderate one?'*

This uncertainty, plus the variety of factors which needed to be taken into consideration and the lack of hard-and-fast rules, put a lot of weight on the decision of the clinician formulating the treatment plan. Shared decision making in joint clinics provided support for clinicians in this process.

Organisation of services

Internal communication and co-ordination

Many patients were treated at several hospitals, perhaps having their cancer treated at one, being reviewed at another and having dental treatment at a third. Lack of communication and co-ordination could make the whole process difficult.

> *'They kept losing my files. When they were supposed to be at hospital X, they were at Y and vice versa. I'm not sure who I would contact if I had a problem.'*

Communication between primary and secondary care was even worse. Many people complained that even when they had been discharged from hospital following major surgery, their GPs had not been informed that they had cancer. Similar comments were made during further investigations and reviews.

> *'We found that with the Macmillan nurse, although she has been with my husband for nearly a year now ... the doctors have not sent her one synopsis of how he is progressing or what the problem is. The last time she was here she said, "Please ask the doctors to send me a report so that I can look through – I don't like working blind".'*

Some people felt that there should be one person who could co-ordinate care and liaise between different health providers. Some people found that the Macmillan nurses provided this role but most people had not had this service.

> *'If there was one person who could at least collate the notes from the different hospitals even. So somebody knew what was going on in your mouth and not four or five different people.'*

Some people were concerned with the equipment in the NHS. One man who had worked in the aerospace industry felt that the dissemination of new technology was very slow in the NHS and that the use of existing technology was poorly co-ordinated and inefficient. Another man who required laser surgery because of a bleeding problem was disappointed that this was not available at his local hospital which was a cancer centre. He was referred elsewhere, delayed six months by administrative errors and eventually when he had his operation the laser was out of order and not used. The result was delayed treatment, a longer stay in a hospital further away from his home and extra travel for his wife. This lack of co-ordination was a theme which emerged again and again at different stages of the cancer journey.

Professional views

Professionals also spoke of the importance of internal communication and organisation of services. It was important that the processes of care were clear, and this helped other people in the team to understand what had been done for the patient. Doctors were also concerned that the patients' perceive that the process runs smoothly. Many doctors felt that patients would lose confidence if their care appeared disorganised.

> *'They should perceive that everything is going smoothly, that we know what we are doing... and then there is a hold up and then there may be a problem with this or that ... but it just disrupts that feeling that everything is under control and going smoothly and for somebody who's already anxious about the prospect of a potentially massive operation, it must be very unsettling. To see these minor, everyday, niggling problems demolishing that sort of impression that everything is well organised and co-ordinated, that is very frustrating.'*

Many people felt that the practical realities often constrained how they would like to manage a person with cancer. There was a compromise between operating on a person as soon as possible and ensuring that all the services were informed about and assessed the patient preoperatively. Facilities and services which doctors were used to at one hospital were not available at another. Some hospitals had joint surgical/oncology clinics once per month. This meant that when urgent cases presented, they needed to find ways round the system.

Because major surgical cases were often urgent, time-consuming and unpredictable, this was felt to cause management and administrative difficulties. Many doctors asked for more understanding by the managers of what they were trying to do and for more flexibility in the system.

> *'It would be nice if the management sometimes realised that the reason why you have just cancelled your operating list next Tuesday is in order to fit a head and neck cancer patient in and the six, almost inevitable, letters of complaint that will come from the patients who have been cancelled need to be handled sensitively, but they do need to be handled firmly as well.'*

Many clinicians said that they did not have control of many of the organisational factors which contributed to patient care. The organisational factors had an impact not only on clinicians but on patient care as this example illustrates.

> *'The major problem is intensive care/high dependency care. If, for example, you've got a list on the Monday to be told on Friday that there might not be a bed for the Monday, but we can't tell you until the Sunday night and apart from the whole organisation disaster that a cancelled case is, it's an absolute nightmare for a patient who has psyched themselves up to have a major procedure to be told, "Sorry, chap, it's off until a bed is available wherever".'*

Organisation was felt to be particularly difficult and important in the transition between services.

> *'With all cancer care good communication [is important]; keeping people involved, district nurses, hospital specialists. As time goes by they may need more care from one group of carers than another. If they all have good communication and talk to one another, the patient is more likely to have a smooth series of transitions which could have caused extra trauma for some considerable time.'*

Professionals felt that it was particularly important that communication between sectors was good on discharge. One issue which two groups identified was the variety of community and social services in their wide catchment areas. The services could vary widely between each area, and one hospital social worker had difficulty making sure that people received the support which they were entitled to. People with cancer might also have a variety of needs. This could mean that it was difficult to access community health services.

> *'Community services tend to be boundary-based with services for this kind of person and services for that kind of person, and a person who has several needs can end up bouncing from one service to another.'*

Communication was one of the main things that clinicians at one hospital wanted to change. They felt that without adequate secretarial support, communication with colleagues in primary care was not happening quickly enough, which impacted on patient care.

Calman proposals

Many people with cancer felt that the principle of a 'specialist' team or hospital was very important. Most people knew that their cancer was rare and the treatment complex. The confidence they had in their team was important. The 'ideal service' was one where there was sufficient expertise both in medical and nursing staff about management of the condition but which was small enough to give personal care. A small specialist hospital or a cancer centre within a big hospital was thought to be ideal.

> *'It's quite nice having a small set-up. Although it is small it is very good. It is about expertise but also about personal care. You do not want to be a number or on a conveyor belt.'*

Some relatives were concerned that the hospital would be near enough to visit. Younger people with cancer and those with major facial surgery were less concerned with geographical access than expertise.

There was a mixed response from professionals to the Calman proposals. Many professionals felt that the proposals were a step forward.

> *'I think if we could have centralised areas that have treatment for head and neck cancer patients then you're going to have all the support groups, and all those sort of various specialties feeding in. Therefore I think you have the satisfaction of being a team and hopefully the patient has a better quality of life because they get all the services available.'*

Some doctors supported the principles of the strategy but had difficulty with the implementation. Some felt that there were not the human resources to implement it, particularly in oncology. Others felt that centralisation needed to be balanced with accessibility for the patient and relatives. Many consultants felt that they were already specialists in their area. Some felt that further specialisation would remove variety from work both for those undertaking more and for those undertaking less cancer cases. Others saw it as a form of management interference.

> *'As I said, I know exactly what I can do and what I can't do and I resent the possibility of being told what I can do and what I can't do by an administrative set-up. They don't know what I can do but the decisions are being made purely on economic grounds, not on grounds of expertise.'*

The meaning of success

Some professional groups explored the meaning of success for them and their team. Lack of cure was often described as failure but when explored further there could be success or failure in both curative and palliative care.

The first criterion for success was cure – that the person was alive and the cancer cured. When this was not possible, it was important for the person to have a good quality of life.

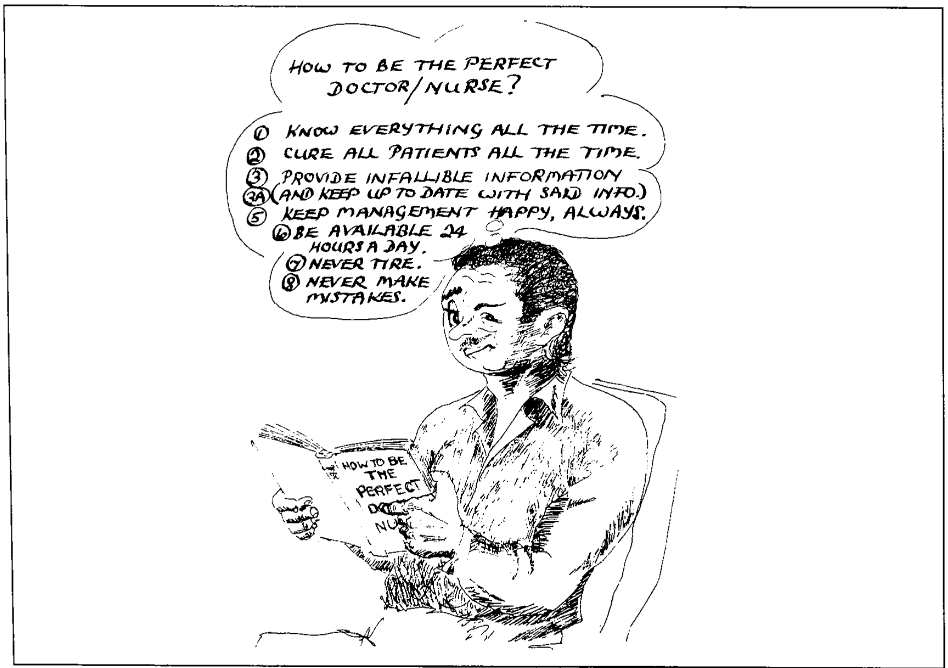
> *'We go almost by the football results, you know, Surgeons 1, Death 0, or the other way round and that's the concrete result. But I suppose yes, win or lose if the patient feels, or the relatives feel, or anyone who's objectively watching feels that either no better service could be provided at each stage then I think we'd be happy with that at every stage.'*

> *'[The patients would be] cured if they could be cured with the least possible morbidity and supporting the patients who aren't being cured and knowing the difference between the two!'*

Quality of life was the second criterion, although this could depend on individual factors.

> *'And that they've been given a quality of life. I do think, not that the cancer has gone or they've been given a year longer, or whatever, but within that time they've actually got something to live for.'*

> *'Quality of life varies from person to person. Two people with the same condition, one might be able to cope and another might have a poor quality of life. In terms of evaluation has the person had the best quality of care available?'*



How to be the perfect doctor/nurse

This concept of success being that the person had the best care available related not only to clinical care but to social and psychological support for the person with cancer and their families, and should be judged not only by the team but also the person with cancer and their families.

> *'Patient satisfaction I suppose is, you know, if they're satisfied by it ... When we've come to the end of the road, and there's no further treatment and he [the patient] still gives you the thumbs up.'*

Patient and carers had similar criteria for success. An ideal outcome for a person with UAT cancer would be to be able to eat, speak, and socialise, to have a facial appearance and quality of life acceptable to them and to be involved and treated with dignity and understanding at all stages of the process.

Providers of a gold standard service would:

- treat the person with cancer as an individual respecting their needs and wishes;
- give the best possible clinical care;
- involve patients in their care as much as they would like, making them part of the team;
- have an open and caring attitude and manner making the patient feel that they were worth caring for;
- work as a team, providing consistent care;
- have good communication skills – listening, understanding and providing answers to questions;
- provide information on what to expect and the side-effects of treatment.

What needs to be changed/safeguarded

Patients, relatives and health professionals were asked at the end of the discussion if they could identify one thing that they would like to change about the present UAT cancer service and one thing they would not like to change.

Some patients wanted to safeguard their clinical result both in terms of their cancer cure and the good cosmetic result. Many wanted to safeguard their current professional team in which they had confidence. Most professionals wanted to safeguard the team and the team approach which they had built up. They thought that they provided a good service for patients. One doctor wanted to safeguard the fact that he had consultants from different disciplines who worked together rather than competed for roles.

When asked what they would like to change, many patients and relatives mentioned the information available, particularly on what to expect and side-effects of treatment. For others it was the attitudes of some health professionals and the public awareness and understanding of what it is like to have facial cancer and facial disability. For a few it was the internal communication and co-ordination of services.

Many professionals mentioned organisational factors. Some people wanted greater flexibility in the system to facilitate major surgery, and another greater secretarial support to improve communications with primary and community services. One team wanted to change the layout of the clinic, which was difficult for staff to work in and not patient-friendly. Two hospital teams said that they wanted to introduce a counselling service.

Some professionals wanted to make services more patient-centred and hoped to influence their colleagues to enable this to happen. And finally, one clinician echoed the feelings of many in relation to the cure rates:

> *'It would be very rewarding if you could make progress in results, [so that] we weren't always headed for a draw, half being cured, half die. That would really make everybody's day if there was some way of tipping the balance slightly, just that little bit, so we could think we were going to make progress.'*

Discussion

Most patients and their families were very grateful for the treatment and care which they received from the health professionals, whether they had had good or bad experiences. They recognised areas for improvement and identified these.

A number of people were delayed in referral and diagnosis, and others had post-operative complications which were initially dismissed and not picked up. Some studies have suggested that most delays in diagnosis are due to patients rather than professionals and that delays in diagnosis do not affect survival.[30,31] Because UAT cancer is not very common, most GPs and dentists will only see 3–4 cases in their working life. Recent campaigns to increase awareness in primary care may help. From the patient's point of view they wanted to make sure that their symptoms were not dismissed and were taken seriously at all times.

Inpatient accommodation was an obvious area of concern. Given the trauma of major surgery, clinicians and managers need to ensure that appropriate accommodation is available. Ward allocation by specialty and low numbers of cases per specialty may make this difficult. If, for example, the ENT, maxillofacial and plastic surgeons all have their cancer patients on different wards, then this would not help to build up nursing expertise or provide patient interaction and support. Privacy and placement of newly admitted patients need to be sensitively managed. If the current cancer changes result in centralisation of inpatient operating facilities, this could lead to head and neck cancer wards where these issues could be more appropriately managed.

Multidisciplinary teamwork has been long recommended for UAT cancer care.[20] Current standards state that UAT cancer should be managed by a team.[33] Despite this, almost half of consultants in the UK who treat UAT cancer do not take part in joint clinics.[3] Teamwork was valued by professionals in this study. It was advocated as improving patient care, providing more co-ordinated and comprehensive care, as a learning process and as a way of keeping up to date. It also provided valuable support in clinical decision-making and in feedback from patients.

There are different understanding and a changing philosophy in teamwork. The consultant-dominated, top-down approach was illustrated by the airline pilot analogy of the captain knowing everything and taking all the responsibility. Some patients experienced this approach. Rapidis *et al.*[20] in 1980 suggested two teams: the doctor led the major or curative team and the minor or care team. Professionals in this study had moved on from this concept to one team which included the patient and family. They recognised everyone's role in the team, and in one hospital the team was led from the bottom up. There were some differences of opinion as to the number of medical specialties which should be involved in a team. This may not represent the views of all professionals, as those in this study may be more forward thinking than some of their colleagues.

Smooth administration of services was a major cause of frustration for clinicians. Administrative difficulties were the major reason why good intentions were not carried out in practice and delays occurred during treatment. Delays between surgery and radiotherapy can affect survival.[34] Good communication and understanding between managers and clinicians would help this process. This communication seemed to vary between hospitals. The Calman-Hine[1] proposals were widely welcomed by patients and families, particularly the concept of the 'centre of excellence'. Many clinicians welcomed the principle but some queried the feasibility of implementation.

Primary care treatment and support following hospital discharge was an area of concern both by people with cancer and professionals. Good liaison at this stage has been shown to improve follow-up of head and neck cancer patient.[35] For patients it could feel like being stranded with no information or support. The EACG report[1] recommended close liaison between primary and secondary care. Often this didn't happen. The transition between services, the workload of GPs and the variability of primary and community services were all felt to contribute to the difficulties. The fact that many GPs were not informed that their patients were in hospital until they were discharged, exacerbated the situation. Ways to improve co-ordination and collaboration between primary and secondary care need to be found. Patients also need to know what to expect on discharge from hospital.

Many clinicians found clinical decision making and palliative care very difficult. The uncertainties in decision making echo the findings of Maher.[35] Palliative care is an area of care with fewer guidelines, more uncertainty and some professionals felt more vulnerable. It could also be emotionally draining in dealing with people who were not recovering. Close liaison with palliative care services, guidelines and training in communication skills may support clinicians in providing palliative care.

Recommendations

These recommendations stem from the differences in care experienced between services and between clinicians and wards within one service. They are about recognising the quality of the services that is already there, ensuring consistency in those services and bringing others up to the standard of the best.

- All professionals should listen to patient symptoms, investigate and refer early, if appropriate, at all stages of the cancer journey.
- Persons with UAT cancer who are admitted to hospital should be accommodated, where possible, in a ward where staff are familiar with the condition, where there are patients with similar conditions and there is adequate privacy.
- Administrative procedures and internal communications systems should be examined to minimise administrative difficulties for both providers and patients.
- Co-ordination of services between primary and secondary care and between hospitals needs to be improved.
- Guidelines for information and primary care support should be developed with and made available to people with cancer and their families so that they know what to expect on discharge.
- Ongoing audit of services should include patients of those services and their relatives.

Chapter 3

Do you know where you're going to? Information and choice

> *Do you know where you're going to?*
> *Do you like the things that life is showing you?*
> *Where are you going to?*
> *Do you know?*
>
> M. Masser & G. Goffin

Introduction

Information and choice were two of the strongest themes to emerge from the patient, carer and professional focus groups. This chapter will review the literature on information and choice, present the findings in this area and discuss them in the light of current research.

A person faced with a cancer diagnosis is disempowered.[36] He or she faces an uncertain future, treatment which is unknown, and with unknown outcomes and side-effects. A person with UAT cancer may fear facial disfigurement and loss of speech and ability to eat. Hospital admission and waiting in hospital bring a loss of personal control over daily life. Life is in the hands of a doctor or team who know more about the condition and treatment than the person concerned. Cancer is surrounded by medical language, and people with cancer have been regarded as 'victims'.[36] In order to regain control of their lives and health many people with cancer need to be empowered. Meeting their needs for information and participation in care is a strategy for empowerment both of the person with cancer and the team who are supporting them. Patients facing major head and neck surgery need appropriate information on what to expect and to be involved in their care if they are to make a full recovery.

Information

There has been increasing interest in the provision of patient information in recent years. Government initiatives have included information on patients' rights in the form of the *Patient's Charter*[8] and the publication of waiting list and hospital league tables.[37] Health care providers and support groups have produced patient information in a variety of media, from leaflets and helplines to interactive videos.

There has been a shift in attitudes to medical information from the paternalistic 'tell the patient only what is good for him' to a more open style of communication which recognises that the patient has a right to information about their condition.[38-41] Research has been conducted into what information patients want, what information they receive and what happens when more information is provided. Although patients receive information from a variety of sources, much of this work has been done in the context of doctor–patient communication and patient participation in treatment decision-making. In the field of cancer, breast cancer has been the focus of much of this work. There are no studies on the information needs of patients with UAT cancer.

Many studies have shown that patients want as much information as possible, both good and bad, about their condition at the appropriate time.[42-44] Although doctors feel that they are providing patients with information, studies have shown that they consistently underestimate patients' desires for information.[45,46] People's information needs have been related to age, education and stage of disease, with younger, better educated people wanting more information shortly after diagnosis.[47] The type of information needed also varies with age and type of treatment.[48]

Good information benefits patients. Kaplan[49] showed, in a randomised trial of patients with a range of conditions, that patients who were given more information had better health outcomes physiologically, functionally and subjectively. Interestingly, consultation times were no different from those not given additional information. Information can improve knowledge, self-care, compliance and satisfaction[50,51] and has been shown to reduce anxiety.[52,53]

Most information from doctors to patients is given verbally. How well is that information retained? The first and most recent information given is more likely to be retained,[51] but following emotional news, such as a cancer diagnosis, little may be retained. The way the information is given, the language used, whether medical or lay, and the non-verbal cues play a large role in how information is received.[51] Although many patients prefer verbal information, written information as a supplement can help communication with relatives.[51] New multimedia technologies can provide interactive information that is tailored to the patient's condition.[54,55]

Communication should be a two-way process of information exchange with information being given and sought. The doctor's information needs are in relation to diagnosis and treatment planning. The patient's needs are twofold: to know and understand and to be known and understood.[51] Information is assessed objectively by doctors in terms of the stage of disease etc., but subjectively by patients in terms of personal relevance. It is possible for the doctor to feel that he or she has given a great deal of information but the patient to feel that they have not learned anything new. It is possible for a great deal of information to be given without engaging the patient in participating in their care.

Ong[51] describes the ideal medical consultation as one which integrates the medical and patient-centred approaches, with doctors taking a lead on their area of expertise (disease and treatment) and patients leading on theirs (symptoms, preferences).

Choice

Patient involvement or participation in their care has become the subject of current debate.[56,57] There has been a move from an active-passive model of care to a collaborative process between professionals and patients. This change began with the management of chronic conditions where the choice of different treatment options is a trade-off between different outcomes with which the patient has to live. Different treatment options for UAT cancer have different outcomes in terms of survival and quality of life.[23] Patient preferences are one of the key factors in determining choice of treatment.

Participation in treatment has been linked to provision of information. Information is needed for choice, and those patients who participate in their treatment tend to have better information. However, many studies have shown that people's information needs are relatively independent to their wish to participate in treatment decisions.[48,49,58,59] Most people want to participate in their treatment decisions and would like to participate more than they currently do.[51,60–62]

Younger, female and better educated patients with less severe illness at an earlier stage in their treatment are more likely to want to be involved in their treatment decisions.[45,63] A number of advantages to a participative approach have been identified, including decreased anxiety[60,63] and better satisfaction with and acceptance of treatment.[62] Patients who wish to participate have a more hopeful outlook than those not wanting to choose, independent of disease factors.[64]

The level of participation which patients want varies. Three levels have been described: passive, where the doctor makes all the decisions; collaborative, where decisions are made jointly; and active, where the patient has the final say in decisions. Studies have shown that in relation to cancer, approximately 20 per cent of patients said that they wanted an active role, 28–40 per cent wanted a collaborative role, and 25–50 per cent wanted a passive role.[43,48,61,65] In studies where choices have been given to people in their care, a minority found the choices very difficult and asked their doctors to choose for them.[60,64] This has led researchers to conclude that information and autonomy may be more important to many people than choice in their treatment.[59,66,67] It is important that patients have a right to be involved in their care and treatment decisions as much or as little as they wish.

There are many barriers to patient choice. The doctor may decide not to offer choice. There may be no real choices available in the circumstances because of the available treatments, geography or other factors. The patient may not have enough knowledge or experience on which to base an informed decision. Patients are influenced by how the information is presented and by what they believe the doctor wants them to do.[68]

Choice is associated with responsibility. Most patients do not want doctors to abdicate their responsibility or to disregard medical advice but to ensure that their considerations are taken into account in treatment decisions. If used inappropriately, patients could be blamed for the choices which they made if treatment was not successful. This might deter some patients from choosing. In order to overcome some of these difficulties, a model of enhanced autonomy has been suggested as a balance between the paternalistic and the independent choice models. This is a collaborative approach where options, values and recommendations are fully shared and the final decision rests with the patient.[69]

Findings

Information

Few people had any information on UAT cancer prior to diagnosis. Most had not heard of mouth or throat cancer and were not aware of potential signs or symptoms. The people who were aware obtained their information from friends who had cancer or from magazines. Those who had friends with UAT cancer felt that they were more prepared for the impact of the condition and treatment because of it. People who were seeking care and were having difficulty being referred, found the lack of information at that stage difficult. Many people said that they wished there was more information and awareness of mouth and throat cancer both in the general public and among health professionals. This was both to avoid delay in presentation, diagnosis and referral, and to inform attitudes towards people with oral cancer.

Once diagnosed, the main source of information on their condition was the hospital team, particularly the consultant in charge of their care. Some people felt that they had good information and that their hospital team had been open with information. Most people had mixed experiences with some good information and some poor information. Relatives, in particular, were concerned with the quality of information.

> *'They involved us every part of the way –* Mr X *was always telling us what was going to happen and what may happen and as my mother said, he was very open about it. It was very refreshing compared to what had happened before with* Mr Y.*'* Relative

Many people felt that the shock of the diagnosis meant that they found it difficult to take in any information given. Some felt that they were given too much information too soon, without time to assimilate it. Information exchange was very much a one-way process.

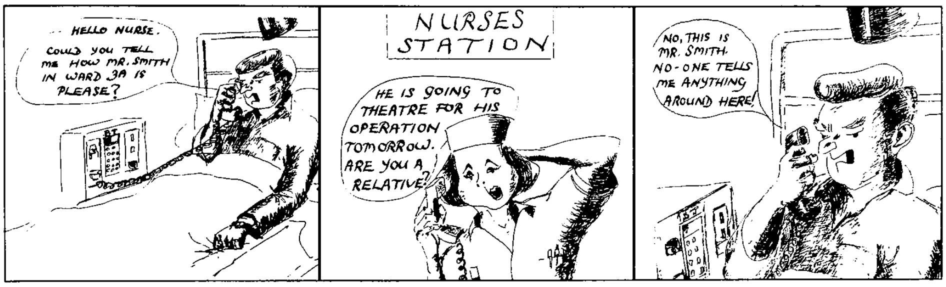
> *'Once they tell you you have got cancer, I think you must be numb anyway and what they say after that it really is not sinking in anyway'*. Relative

The information which most people received from their consultant included details of their surgical procedures. This was welcomed by a few people but most did not want to know all the technical details.

> *'When I was told what they were going to do to me I was shell-shocked and I really thought it sounded like a horror film, and I used to be a nurse.'*

Once people were admitted to hospital, information was often sought from ward staff. Some people found responses to their requests to be poor. Many people had information from other patients, either on the ward, through a support group or through personal contacts.

Lack of information was the major factor which needed to be changed in their care for many patients in the study. Some information was given but this was often not the



information which people wanted about their treatment. They felt in the dark about what would happen next, why certain procedures were being done and what they were meant to do. This lack of information increased the uncertainty and decreased their control on the situation. This could be just as difficult for relatives as for patients.

> *'Lack of information coming forward. All the time they are like politicians. They never answer a straight question.'* Relative

Many people received conflicting information on their treatment. One man was told by one consultant that he would have radiotherapy and had a mask made. Then suddenly the preparations stopped for no apparent reason. The result of this was often a lack of confidence in the team or the treatment. In other cases it increased anxiety.

> *'There were half a dozen doctors and each one was giving you a different story. One was saying one thing and another would come in the next day and say another thing ... Who do we believe? ... The thing is she was as scared as anything and with all this going on it added to it.'* Relative

Information needs

Most people in the study wanted:

- access to information, open discussion and answers to their questions;
- information on the impact and side-effects of treatment;
- information on support services;
- access to ongoing information on what to expect.

People wanted access to information and advice. They wanted to have their questions answered at all stages of investigation, diagnosis, treatment and follow-up. They also wanted the information at times and in amounts with which they could cope.

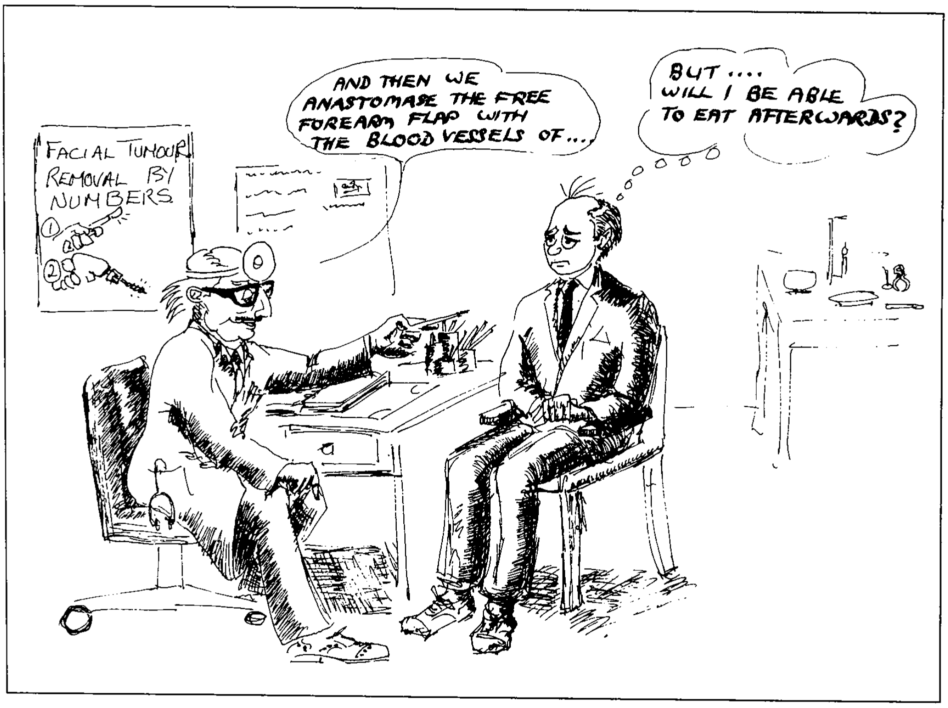
Different people had different information needs and in general the younger people and those with more advanced cancer wanted more information. It was the access to information rather than the quantity of information given that was important for many people.

Many people felt that it would have helped if they had been given access to information a few days after their diagnosis in order to have their questions answered. At that stage the diagnosis had sunk in and many people wanted more information.

> *'I said, "I would like to know just what it is please." And he was very good and he told me and explained to me everything, he explained what they wanted to do; and then he said, '"Is there any questions you want to ask me?" It throws you a bit and you can't think quick enough.'*

People with cancer were more concerned to know the impact of the treatment on their lives than the technical details of the operation. Some people were provided with this information but most were not.

> *'I think the most important thing that is lacking is information that doctors and nurses give you about what to expect.'*



Many other people had no idea of the impact of the treatment which they were going to have. This applied to radiotherapy as well as surgery. People said that they did not realise how much scarring they would have where a graft had been removed, or the side-effects of treatment. Information on risks was not always forthcoming.

> *'I read a leaflet somewhere that I had found in some cupboard that it [the chemotherapy] was probably leading to the menopause and I asked him about it and they were very dismissive and didn't want to know, yet it seems like an irritation for someone to explain to me and they said, "Yes it will make you sterile." And that was literally just as I was about to have it … ten minutes beforehand.'* Six months later this woman was pregnant and was advised to have a termination.

The people who did receive information on what to expect found that it helped them in coping with their condition during and following treatment.

> *'Before I actually started radiotherapy he took me in so that I could see what I would be facing and it wasn't going to be a shock seeing this machine … They did tell us everything that was going to happen to the letter. They were very good.'*

Most information which people received occurred at the time of and related to their treatment. Many people did not know that support services and support groups were available. They felt that they had to actively ask to find out about services. At one hospital speech therapists were the main source of information on support services. Once treatment was completed, there were often unanswered questions relating to their care, to recovery or to accessing services.

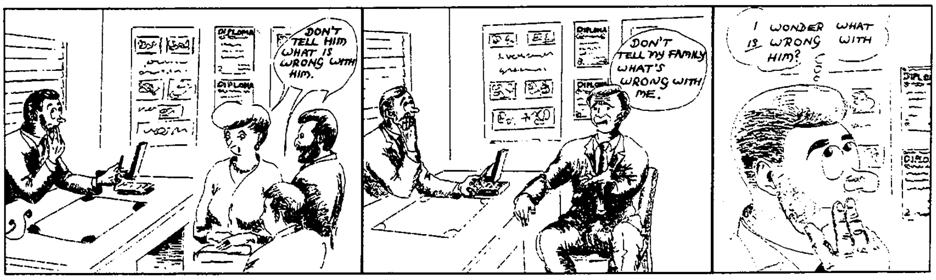
> *'Nobody told us how to rinse J's mouth out! I didn't know. Nobody told us how to clear his airways – it was a nightmare.'* Relative

Some people found that they had been given information about their treatment but worried because they didn't know what to watch out for if they had a recurrence. Many people found accessing information or advice difficult. When they did need advice or information, people had different experiences even within the same hospital. They felt that their consultant was too busy to be bothered with queries which might appear trivial.

> *'You can worry yourself silly for weeks and one little phone call like that can put you at ease. But, you don't like to worry them do you? … I wish I had somebody I could speak to and say, "What shall I do?".'*
>
> *'When I eventually got there the consultant said, "It is not a lot of good coming now." And I said, "I can't get past your receptionist. She won't book me an appointment".'*

Professional views

All the professionals said that it was important for the patient to understand their condition and the proposed treatment. They recognised that much of the information given on the first visit, once the diagnosis had been made, was not retained and would need to be repeated on the following visit. This was something which some consultants felt that junior staff did not recognise but was well managed by nursing staff. Some people felt that it was important to clarify what the person understood by cancer and that assumptions were not being made.



Many people spoke of attitudes which were prevalent in previous years of not telling the patient their diagnosis or prognosis. They felt strongly that nothing should be hidden from the patient.

> *'My particular hobby-horse is not hiding things because I have worked in different disciplines where malignancy is being dealt with where the whole thing is being glossed over, "Oh, it's just a little problem that we need to do something about fairly soon". That is not the way to deal with the surgical management of malignancy. The patient has to know what they are dealing with because that is the biggest fear. The biggest thing that scares them is not knowing.'*

Likewise, many professionals felt that the information was the property of the patient. It was for the patient to decide how much to tell their relatives and, in occasional circumstances, their families were not told the full extent of the information which the patient had. However, clinicians often had requests from families to hide information from the person with cancer. They felt strongly that this should not happen and avoided doing this.

Clinicians felt that it was important not to lie to patients. They felt that it was equally important not to destroy people's hopes and so information needed to be given sensitively. Many people spoke of the varying information needs of people with cancer which they felt they needed to respond to.

> *'Some people say, "Stop, Doctor, I don't want to know any more. Get on with your job and do it" and that's enough. Other people want to know an awful lot of detail.'*

Some professionals highlighted the need to listen to people with cancer. They said that in order to give information they needed to spend more time listening to the person with cancer and picking up non-verbal cues as to what the person wanted to know and what they didn't. This was very much a two-way communication process rather than an information-giving exercise.

> *'I have learnt, I've been working [as a cancer nurse] twelve years, never to take for granted what the patient is actually saying. I check everything out because they give little warning shots and they will quite often divert the conversation away from what they've just been talking about.'*

They felt that this listening process not only helped the team to find out how the patient was getting on but helped them to offer support and provide the right information to them.

> *'It's giving the right information. And if you're not listening acutely, observing as well as listening, then you're going to be giving completely wrong information.'*

These communication skills were felt to be generic and a basic part of good clinical care. Some professionals felt that this was an individual aspect of care for which there could not be any set rules.

Many professionals acknowledged that most of this communication occurred with nurses or speech therapists who often spent more time with patients than consultants did. Patients would talk to them and ask questions as they were having a dressing changed. The type of information sought also varied. Consultants were more likely to be asked questions about long-term prognosis, whereas nurses would be asked questions about the impact of the treatment, eating and speaking. Speech therapists said that they were often asked about details of the person's operation many months after it had happened.

Choice of treatment

Most patients felt that they wanted to be involved in their treatment and many wanted to be involved in the treatment decisions. This was an area in which there was a lot of interest and debate. A few people felt that patients should not have to make treatment decisions, which was the role of the doctor.

> *'But surely the patients should not have to make them [choices]. They are surgeons, they should know the best way of doing it.'* Relative

Others felt that any patient choice was irrelevant, as the doctors would change their minds at the last minute and do what they wanted.

> *'Do you really think it makes a difference? Because in our case they told us one operation ... and at the end of the day they changed their minds.'* Relative

Some felt that in many situations there was no real choice.

> *'He said, "Either you have it done or you die".'*

Most people distinguished between choices which would affect the success in medical terms of the treatment and choices which involved preferences of and impact on the patient.

> *'Sometimes you don't have a choice. Obviously, it depends on if there is a life or death situation and the surgeon says, "[There is] only one choice" and you have to go ahead with that, you know. I am a prime example. They would have taken my right breast instead of my muscle in the back [for a graft]. And I think I would prefer the back. But it was all the same to them [the surgeons], there was no distinction. To them one part is much the same as the other... Now that is really fundamental, you know, for a woman. And I think that that should really be hammered into them.'*

This woman had found out from another patient who had a breast removed for reconstruction that an alternative graft was possible and insisted on having the alternative. Her friend was not given the choice and felt that she should have been.

Some people said that, in retrospect, if they had known the impact of treatment and the potential side-effects, they would have asked about alternatives and wanted to have a choice. Many people were unaware of the options available.

> *'I think it is a state of a* fait accompli *because I went to X to see a surgeon ... who said, "This is what we are going to do". When I got back to my other surgeon a week later he said, "Well, shall we do it?" And I thought, "Gosh, we have a choice!" and it was only then things were explained to us ... There are choices, most definitely, but you are not told about them.'*

Some people who were undergoing operations for reconstruction or recurrence became more assertive than they had been at first, because they had more information and more time to think.

> *'When I had my second operation I was a little bit more choosy by then because when they work the second time you have time to think about it.'*

In most cases, where choice was presented, the process involved consultation with the patient about the treatment options rather than presenting treatment options with their advantages and disadvantages. The decisions were often made in the end by the clinicians.

> *'So there it was, we were given both options and I think* Mr X, *he knew what he wanted to do.'*

Choice of care applied not only to the primary treatment decisions but to many aspects of care. Some people who felt that they were pressurised into discharge before they were ready said that they would have preferred to stay but felt that they had no choice.

Enough information to make choice

Some people were given an element of choice in their treatment. People with cancer at one hospital reported more choice than others. There was some choice as to which hospital to be treated and followed up at, depending on access. However, many people felt that they were not given enough information in order to make a treatment choice. They said that they would like to know the advantages and disadvantages and impact of the treatment options before being able to make the choice. Choice on primary treatment was being made on the convenience of the hospital without much knowledge of the different impacts of the condition.

> *'He wanted me to go to hospital X [for radiotherapy] but it was too far for us to travel as it would have been every day for six weeks so I had the operation at hospital Y instead.'*

> *'We had spoken about it previously. So when I went to this meeting their mind was made up sort of thing. I thought it was going to be an open discussion but it wasn't. I wanted to know the good and bad but we never spoke like that.'*

Professional views

There were mixed professional opinions about the amount of choice that should be offered to patients and their families in the decision-making process. Everybody agreed that the patient should be involved in their care and have a veto over proposed treatment. Everyone agreed that individual patient factors such as their age, attitude, social factors and wishes should be taken into consideration in treatment planning. The debate hinged on whether the patient should be presented with alternatives and offered choice or whether the clinical team should weigh up what was best and then present that to the patient.

Some clinicians felt that patients should have choice in the location of their treatment and support services but not in the primary treatment decisions. They would be presented with the best option rather than a number of options. There were several reasons for this. Some clinicians felt that giving the patient choice would confuse them and that the patient would lose confidence in the team. Other clinicians felt that equal treatment options were rare in terms of outcome and that the patient should be discouraged from choosing an option which would not be in their long-term interest.

> *'I think it's wrong to give a patient the choice in the sense that if there are two alternatives, if they are not equal alternatives, it is wrong to give the patient a choice under those circumstances. I think the role of the physician is to say, "This is what the best option is. If you don't like that, this is the second best option and if you don't like that as well, that's the third best option".'*

Some consultants felt that they had the expertise in terms of treatment planning and that patients and society expected them to advise. In contrast people with cancer were expert in the areas of how they were feeling and the psychological aspects of their care.

> *'When you're in the palliative domain the patients' rights of choice must be respected at all times.'*

On the other hand there were doctors who felt that people with cancer should be given a choice in their treatment, if at all possible. They were confident that people with cancer were able to make the treatment choices. Some professionals said that it would be easier in some ways if patients had a strong view on their treatment decision as it would share the responsibility. Whether a patient wanted to be involved or not, doctors recognised the need to ensure that the patient understood and had enough information about the treatment which they were undergoing.

Some people felt that there were difficulties involving people in the decisions given the timescale involved.

> *'We try and involve the patient in the discussion as much as possible. It is often difficult because you have so much to impart to them. And to try to get them to understand the decision which needs to be made in a relatively brief time is extremely difficult.'*

In many instances a compromise situation occurred where patients' views were sought, all the factors weighed up by a team and a treatment plan worked out. This would then be presented to the patient for approval.

> *'Very often what we do is to make a decision and test with the patient whether that decision is completely unacceptable, which is probably paternalistic. It may be the wrong way round but I suspect that's what we do.'*

There were rare occasions when patients' views were overridden in the treatment decision. An elderly ill person could be discouraged from exploring options which carried a significant risk or the danger of a worse quality of life, but which could theoretically have produced more chance of a cure if the person survived treatment. Similarly, a young person could be encouraged to have treatment which had a better long-term prognosis even though it might be more difficult in the short term.

Some people felt that the degree to which they were involved could affect patients' attitudes to rehabilitation.

> *'From the point of view of rehab. afterwards, unless they have been actively involved, they are going to perhaps be very angry and they're not going to get involved in their rehab. afterwards, so that it may well be that they don't make the progress that they could have done because they are fighting you away... From my point of view that can make such a difference.'*

There were more opportunities for involvement at different stages of the cancer journey. Speech therapists reported that most of their treatment depended on patient involvement and motivation. People involved in palliative care and hospice services said that choice was an integral part of their management. The person with cancer chose to come to the hospice and their role was to support the person to live their lives as they wished. They helped the patient to manage their own care.

Specialist nurses said that they often acted as an advocate for the person with cancer. However, the amount of choice which people wanted varied. In some cases the person was helped to make the choice themselves, in other cases they wanted to be advised as to which choice was best.

Discussion

Information

Information was thought to be a key factor by people with cancer, their families and professionals, but they had different views on how well information was managed.

Professional attitudes to information have changed, with many professionals wanting more openness and honesty in communication with patients than previous generations. The professionals in this study appear to be more open with information than others.[38-41] The idea that the information is owned by patients and not relatives is shared with patients.[70] Most professionals spent time and effort to ensure that the patient understood the details of the proposed treatment. Most felt that they did a good job. Many people with cancer had unanswered questions and some thought that information was poorly handled. The information given was sometimes not the kind which people with cancer wanted or needed and they had difficulty in accessing information. Doctors concentrated on details of the procedure, whereas many people wanted details of the impact of the condition.

Side-effects of treatment were highlighted as an important area where information is lacking. This confirms the results of a Scottish survey [42] but contrasts with another study where breast cancer patients ranked it as a low priority.[48] Lack of information exacerbated the side-effects of treatment, as found in other studies.[71–73] As many side-effects of UAT cancer are predictable, better information could be given to patients. Younger, better educated patients tended to want more information, as has been found in other studies.[48] Conflicting information undermined confidence. People who asked for more information were sometimes met with indifference.

This lack of information or conflicting information was often not reported back to the professionals involved, although some uncertainties emerged months later in conversation with speech therapists or community nurses. This may be due to the fact that many people may feel reluctant to ask questions, appear to challenge the authority of the doctor or appear to be a nuisance. This echoes the situation outlined by Ong[51] where the doctor thinks that he is giving a great deal of information but the patient is not getting the information which he/she needs.

Information was often described by people with cancer and their relatives as a one-way process in which the professional gave and they received. The two-way process of listening to people to understand their concerns in order to better meet their information needs, as described by some professionals, was what many people with cancer wanted but did not seem to receive. The willingness for more open communication and information was evident both with professionals and people with cancer, but the means to achieve this need to be developed.

There are some simple measures which could improve communication. Baker[74] outlines a communication system which has been used with people with Parkinson's disease. The consultant begins by asking the patient what they think is wrong with them. He/she gives the diagnosis and asks the patient what they understand by the diagnosis. The patient is then seen by a counsellor who asks them what they have heard, clarifies the information and deals with any conflicting information. The patient is seen by various members of a multidisciplinary team over a period of one to two weeks. They report to the consultant who has all the relevant information before the second appointment. At this appointment the consultant tells the patient that they have all the time that they need and can ask any questions which they want. Consultation times have not increased and the information provided has improved. Adopting or adapting this model for UAT cancer with the use of a specialist nurse would be useful.

Initiatives such as written information and audio taped consultations may be helpful. Given the different sites and stages of presentation and treatment of UAT cancer, standardised information may not always be applicable but could help in providing general information. Individualised programmes of information are being piloted for persons undergoing radiotherapy and may provide a useful addition to existing verbal and written information.[55]

Choice

The patient–relative views on choice confirm previous studies. The professional views add a new dimension to the debate. People with cancer and their families wanted to be involved in their care as much as possible and professionals agreed that they should be. Patient choice in decisions about primary management of the cancer was contentious with both patients and professionals. There was tension between the patient's wish to be involved in their treatment decisions and professionals' belief that it was their role to present the best treatment option. Professional reluctance to share in the decision-making process may reflect the difficulties of the process and the uncertainties about treatment options. Many people with cancer recognised the difficulties and limitations of their choices but still wanted to be part of that process, particularly when the options would have similar medical outcomes but different personal ones. Some patients wanted an active role, most a collaborative role and some a passive role as found in other studies.[43,48,61,65] They did not want to disempower doctors' decisions but to participate in the process. Developing a patient–professional partnership may help doctors in their decision-making process and may help patients to understand and participate more in their treatment and rehabilitation.

Many more people wanted to be involved in their treatment decisions than actually were, confirming other studies.[51,59,60,62] Many people said that they were consulted but that an open discussion of treatment options with their relative merits didn't occur. Even when choice was presented many people felt that there was not enough information to help them make an informed choice.

Both patients and professionals described a situation where patients needed to register a strong objection to the proposed treatment in order to be involved in the treatment decision. Few patients are likely to have the assertiveness to strongly object to treatment. They are often not being helped to participate in choices about primary treatment.

Conclusion

Information and choice were key areas identified by both patients, relatives and professionals. Both recognised the difficulties in communication but professionals felt that information was handled better than patients and relatives did. Access to information and a two-way communication process are likely to meet patient and professional information needs. Choice is a contentious area with differing attitudes and opinions among patients and professionals. In general, many patients wanted more involvement in treatment decisions than they had. While many professionals acknowledged this, in practice they often presented what they thought as the best treatment option.

Recommendations

Information

Two-way communication with patients and families should ensure that the information needs of patients, families and professionals are met. This could be improved by:

- asking patients and families what information they would like and in what form;
- involving people with cancer and their families in development of information sources and systems;
- checking the understanding of information given to prevent misunderstanding or conflicting information and clarify any further information needs;
- ensuring consistency of information from all members of the team;
- providing access for patients to further information about their condition and treatment and ensuring that this information is seen to be accessible by patients;
- making information on support groups available;
- making information available both in verbal and written form.

Choice

The patient and family should be invited to participate as full members of the head and neck cancer team. This would involve:

- finding out their preferences for information and choice, and respecting these;
- involving and informing them in each stage of the cancer journey;
- providing full information on the benefits and side-effects of different treatment options;
- encouraging patients to participate in decisions about their treatment, including primary surgical and radiotherapy management to the level at which they feel comfortable.

Chapter 4

Living with cancer

Attitude to me is more important than the past,
than education, than money, than circumstances,
than failures, than successes,
than what other people think, say or do.
We cannot change our past, we cannot change the inevitable.
The only thing we can do is play on the one string we have,
and that is our attitude.
I am convinced that life is 10 per cent of what is happening to me
and 90 per cent how I react to it.
And so it is with you...

Charles Swindoll. Reproduced with permission from *Let's Face It* newsletter

Introduction

The experience of cancer can have a major impact on people's lives. Many respondents wanted others to understand the impact of this form of cancer on their lives and to appreciate the support which they needed. Support of the person with cancer and maintaining quality of life were two of the main themes to emerge from the professional discussions.

Traditionally, clinical measures such as disease, disability and death have been used to assess the impact of a condition. The emphasis has been more on disease and disease processes than life and living processes. There have been two changes to this. Firstly, there has been an increasing awareness of the quality of life of the person with cancer both during and after treatment. This has led to the development of a number of quality of life measures which have been used in head and neck cancer.[72,75–80] Secondly, there has been a growing interest in the experience of the cancer journey and how that has affected persons with cancer, their families and communities. Despite advances in treatment, the survival rate for UAT cancer has not changed, leading to an emphasis on maintaining health and improving the quality of life of the person with cancer.

Physical impact

Pain may occur prior to or during treatment. In a cross-sectional study one third of head and neck cancer patients experienced frequent or persistent pain in the previous two weeks.[81] The pain interfered with sleep, mood and enjoyment of life in nearly half of patients, and with work, social relations and general activity in one quarter to one third of patients. Effective management of pain is a team responsibility[82] and involves understanding the patient's beliefs and value systems.[83] Although difficult, UAT cancer pain can be successfully managed.[84]

One quarter of patients with major surgery of the mouth and throat will have difficulty swallowing.[85] Surgery can result in loss of structures needed for swallowing, such as the tongue and soft palate. Radiotherapy results in soreness of the mouth, aversion to food and mouth dryness, which make eating difficult.[4,11] This is exacerbated by chemotherapy.[86] In one small study 80 per cent of patients who had radiotherapy had a dry mouth and three-quarters needed to change their diet because of the radiotherapy.[11]

Swallowing problems can lead to eating difficulties and weight loss. In a Scottish study only half of the patients with oral cancer were able to eat solid food, one third semi-solid food and one sixth liquid food only.[11] The 60 per cent of patients who had some teeth (natural or artificial) were more likely to eat solid food than those without teeth. The patients who had either surgery or radiotherapy were more likely to be able to eat than those who had a combination of both. People who have swallowing problems are least likely to regain weight which they had lost.[11] Improvements in diet have been associated with improvements in speech and eating.[87] Patients have rated the ability to eat as the most important factor which affected their quality of life.[86,88–89]

The stage of disease and ability to eat influences a person's nutritional status. The disease itself can cause malnutrition and some people are malnourished at the beginning of treatment. Eating and nutrition are important for quality of life. However, there are conflicting reports on role that malnutrition plays in survival of patients with UAT cancer.[90–92]

A person uses the larynx (voice box), throat, nose, lips, tongue and teeth when speaking so it is not surprising that speech is affected in many people with UAT cancer. Surgery of the larynx produces loss of speech and radiotherapy can produce change in voice.[19] Lack of speech can lead to difficulties in communication, frustration and depression. A patient's perception of their speech and swallowing is often different from an objective assessment.[93] Individual rehabilitation is needed to take account of this difference in perception.

Surgery can cause limitations of movement of the head and shoulder. If a graft has been used to reconstruct the face there can be problems in healing at the site where the graft has been taken.[94] There may be loss of smell, taste, feeling and movement. There may be facial disfigurement following surgery[95] and individual accounts of the impact of this have been reported.[96]

Psycho-social effects

There has been increasing interest in the psycho-social effects of cancer. Most research in this area has been undertaken with breast cancer patients in the USA. It is estimated that 25–30 per cent of people with a cancer diagnosis experience anxiety or depression at some stage which is severe enough to need medical treatment.[98] The person with cancer and their families are particularly vulnerable at certain stages, such as at the initial diagnosis, on discharge, and at recurrence.[99]

Persons with UAT cancer have been shown to have a higher incidence of anxiety and depression and to have it more severely than people with cancer at other sites.[18,100–103] People diagnosed with UAT cancer have been found to have a sevenfold higher incidence of suicide than other people with cancer.[104] This has been linked to difficulties with eating and communicating, and changes in facial appearance. Facial disability has been shown to cause emotional upheaval and withdrawal.[105,106] It can affect self-image, relationship with a partner, sexuality and cause social isolation.[107] This seems to get easier the longer the patient survives without recurrence[103] and may be less of a barrier to social interaction in the longer term.[4,109]

Speech difficulties can lead to isolation and tensions within the family.[103] Difficulties in eating and swallowing can also cause social isolation. Many people adapt to difficulties in eating and swallowing over time but find the continued lack of smell and taste irritating.[4] People with cancer are less likely to be promoted, and are more likely to lose their job or their traditional roles.[70,109] This is particularly true for younger people and those in less well paid jobs.

Living with cancer

The experience of living with cancer has been described both for individuals and groups of people.[96,99,109] The focus has moved away from the individual alone to the impact and response of the partner, family or significant others in the community. Adjustment is easier for those with more income, higher level jobs, more education and access to other resources.[109] Many people with cancer see themselves more as 'survivors' than 'victims' and as healthy despite illness.[110] This concept of health has been described as an ability to maintain a sense of integrity.[110]

There are many different coping styles and stages.[111–113] Individual, family, social and cultural factors influence the way people and families with cancer cope with their situation. Kagawa-Singer [110] illustrates the different ways in which Anglo-American and Japanese-American families dealt with their cancer, which reflected their cultural backgrounds. For example, the Japanese-Americans were expected to look for causes and solutions to their problems from within themselves and endured their condition, showing strength by hiding their pain. In contrast, the Anglo-Americans looked for external causes and solutions and adopted a fighting attitude, showing strength through their pain. People of South Asian origin have high rates of mouth cancer. There may be ethnic differences in the way different people cope with mouth cancer in the UK. There are also gender differences in coping in the UK. It is socially more acceptable for women to express a need for support, as witnessed by the focus on breast cancer, whereas men are expected to maintain a 'stiff upper lip'.

A person's psychological state and ways of coping before diagnosis of cancer are two of the most important predictors of the psycho-social impact of the condition on them.[98] Optimistic and assertive people have the best outcomes.[114] Interpersonal factors may be as important as individual factors in coping. The best predictors of breast cancer patients' psychological distress in one study were their husbands' ability to cope and his rating of their relationship.[114]

Many other factors influence the impact of the condition. Differences in clinical treatment can affect the physical and psychological outcomes [73,75,115,116] Patients given complementary medicine as well as traditional medical care had a better perceived quality of life than controls in one study, although there was no difference in survival.[117] The timing of the quality of life measure is important as some treatments can be very upsetting to patients but produce no long-term anxiety or depression.[118]

Support

There is increasing evidence of the role of social and psychological support in the recovery of a person with cancer. Psychological therapy has been shown to be effective.[111,119] In one study of women with metastatic breast cancer, those who had group therapy lived twice as long as the control group.[120]

Social support is one resource for coping.[98,121] It has been shown to increase resistance to infection and disease, to improve psychological adjustment, to aid recovery and decrease conflict.[122] Perceived social support is associated with better psycho-social adjustment and rehabilitation in people with head and neck cancer.[4] It is a major factor in whether people who have had a laryngectomy develop speech, and in rehabilitation.[19] Patients' emotional state plays a large role in how they receive information and education from the health care team.[111] The benefits of social support are well recognised. How it occurs, at what stages, and how it can be supplemented by health services is less well understood.[121]

Families and social support

The source of support is important. People with cancer have said that they want emotional support from their families and information from professionals.[123] They request empathetic support from both family and professionals.[123] Families and particularly partners are the primary and most important sources of support for people with cancer.[124] Family support has been shown to be particularly important for speech therapy.[19]

Family support has, in the past, been referred to in terms of a bank to which the person with cancer goes to receive topping up when needed. We now realise that social support is more complicated than that, and family support is being described in terms of an interdependent relationship of mutual support.[124–126] Giving and receiving support involves risks and costs to both partners, including appearing vulnerable, dependency, being obligated and responsibility.[122] This is a dynamic process and can have a positive or negative effect.[124]

Living with a partner where there is a good relationship seems to protect women with breast cancer from developing psycho-social problems post-operatively.[98] Conflict in relationships could have a negative effect. Lack of social support from a partner was not compensated for by other sources in another study.[97]

Even when patients perceive that they have good support, they may not discuss their cancer openly with their partner and family for fear of overwhelming them.[124,127] This is improved if information is given jointly to the patient and partner,[128] whereas lack of information to families makes coping and support of the individual with cancer more difficult. It can increase family stress and conflict and may lead to inappropriate support.[124] The informational and emotional needs of families are often neglected.[129,130] Isolation of the person with cancer within the family can be paralleled by isolation of the family in society, particularly for long-term care-givers.[109,124] Family members may also be discriminated against in work.[131]

Support groups

Cancer support groups, both local and national, have developed over the past 20 years both in the USA and the UK. Three functions of support groups have been identified: exchanging information, sharing the illness experience and providing strength.[132] Support groups give people with cancer the opportunity to compare their progress with others and to be reassured about what is normal.[133] Support groups have been shown to improve quality of life,[134] decrease pain,[135] help with coping[136] and improve survival.[137]

Support groups have become well accepted and are thought to be the most important source of social support outside the family for people with cancer in the USA.[109] However, only a minority of patients participate in support groups.[138] Those most likely to join support groups are young, well educated, unmarried and tended to join groups and voluntary organisations.[133] They are also more likely to seek help and to have had a negative experience with the medical team.[139]

Professional support

There is an increasing focus on assessing and meeting the support needs of the person and family with cancer; the care as well as the cure. Patient-focused care is one of the key principles of the Expert Advisory Group Report on cancer.[1] Good interpersonal communication has been shown to reduce psychological morbidity.[67] Specialist nurses have been shown to reduce anxiety and depression in women with breast cancer.[140] Specialist nurses, Macmillan nurses, counsellors, psychologists and social workers provide social support along with the support provided as part of good clinical care by other members of the cancer team. There is a wide variation in the availability of these services in the UK for cancer patients.[141]

Psycho-social needs are difficult for clinicians to predict, with four out of five oncologists underestimating patient's needs.[97] Patients' and professionals' understanding of what is meant by support, and what support is given, also varies.[142,143] Patients value doctors for information and open communication[123,144] and nurses for promoting self-esteem and emotional support.[121,145,146] Professionals who support patients through their cancer journey have been described as 'tourists' and 'guides'.[99] 'Tourists' point the way to patients but do not get involved, whereas 'guides' join the patient in their cancer journey and are there for them at various stages. More 'guides' rather than 'tourists' have been called for.[99]

Head and neck cancer patients have reported receiving less information and support to meet their psychosocial needs than their treatment needs.[147] Baker [4] described barriers to providing support for head and neck cancer patients. Early discharge reduces the time for consultation and encouragement. Although half of the patients survive more than five years, professionals may perceive that head and neck cancer has a poor prognosis and support services 'may not be worth it'. Patients who are more ill are most in need of social support services and least likely to receive them. There may also be a perceived poor compliance with treatment where the disease is linked with tobacco and alcohol consumption.[4]

Caring for the carers

Involvement in the cancer journey as a 'guide' involves risks for the health care team. Ramirez *et al.*[148] report a level of psychiatric morbidity in cancer clinicians similar to that found in patients. Doctors may not be willing to explore patients' needs for fear of opening a 'Pandora's Box' which would overwhelm them and which they would not be able to meet.

Burn-out has been described as an imbalance between stress and positive reinforcement and support. In a US study of head and neck surgeons treating cancer, the average working week was 66 hours.[149] Almost all liked their work but one third said that they felt 'burnt out'. Frustration with government interference and overwork were reasons given rather than the stresses of the disease.[149] As burn-out decreases patient care, the stresses on clinicians or the support available may need to be addressed.

Hospice nurses have been found to cope better with the death of a patient than hospital nurses.[150] This is because hospice nurses acknowledged their feelings, shared them and supported each other, whereas hospital nurses were expected to hide emotions, have a 'professional attitude' and were more isolated in their grief.[150]

In summary, cancer can have a major impact on the lives of people with cancer, their families and the professionals who treat them. Physical impacts have traditionally been measured but are now being complemented by quality of life studies. The psycho-social impacts can be particularly severe in people with head and neck cancer and the extent of impact is often underestimated by clinicians. The process of coping and living with cancer has been studied. Individual and interpersonal factors play a large role in the impact of conditions and how people cope with them. Social support is a coping resource. Support from the partner and family is the most important and most frequently used although families' needs are often not addressed. Support groups and professional support can also help. Professionals often have unmet needs which impact on the support which they give to patients and their families.

Findings

The cancer and its treatments had major impacts on the physical, psychological and social well-being of people with cancer and their families. These occurred at each stage of the patient journey. The extent to which the condition and treatment impacted on day-to-day lives depended on the severity, the stage of the cancer journey and the individual person and family situation.

Physical impact

Pain

Pain was a common feature of cancer treatment. Some people were in pain prior to treatment. Most people experienced pain during treatment, following surgery or during radiotherapy. This could be very severe at the time and lead to other problems.

> *'It was like having my mouth full of razor blades.'*
>
> *'When the treatment started my tongue started to swell. I just couldn't eat or drink. It was terribly painful. I lost a stone in just over a week. They took me straight in [to hospital] and put me on a drip.'*

People who had surgery were more likely to have pain relief while they were in hospital. Some people were on a morphine pump in hospital where they could control the level of analgesia. They felt that this was helpful.

> *'If I was in terrible pain I could press this little button to keep the pain away and so I thought that was wonderful.'*

In contrast, one woman having radiotherapy felt that her pain was not taken seriously and had difficulty in getting pain relief.

> *'The doctor said I shouldn't be having pain while I was having radiotherapy. The doctor thought I was making a bit of a fuss.'*

Long-term pain seemed to be less of an issue for many people in the study than the acute pain which they experienced during treatment.

Eating

Impairment in eating, drinking and swallowing was the most common physical impact of treatment. Almost all patients had difficulty eating at some stage in their treatment, although the causes varied. People who had undergone surgery had physical difficulties eating and swallowing and about one third of people interviewed were still unable to eat a full range of foods. Some could eat only soft foods, others liquidised; one man still had a naso-gastric tube. Most people who had had radiotherapy had difficulty eating during treatment because of pain in their mouth. Dryness in the mouth and changes in taste and smell also made eating more difficult.

> *'With the radiotherapy I couldn't touch food. I couldn't stand the smell of it. I had to force myself to eat it.'*

The end result of the difficulties for some people was that they lost the enjoyment of food. Eating became a duty in order to keep their weight and strength up rather than an enjoyable part of their lives.

> *'I haven't got any encouragement to eat because I get so tired of it swimming in gravy. I liquidise it in the food processor and when you can't taste it, it is really awful.'*

People overcame their difficulties in many ways. Some people ate lying down, others ate only soft foods with their dentures out while others never ate in public.

Weight loss

The inability to eat had a large impact on people's lives. The most dramatic impact during and following treatment was weight loss.

> *'I lost a lot of weight, didn't I? I came down from thirteen stones, from a size 22 to a size 12 over a period of six months. I had got too thin at one point when I was eight stones it was a bit painful to sit down!'*

It required quite a bit of will power for people to ensure that they ate enough. This was true for most people for a number of weeks while they were having radiotherapy or following surgery. However, for those people who still had eating difficulties, eating enough to maintain weight was a conscious effort.

> *'I just ... make myself pretend I am looking after someone else and make myself eat. So – now I have got myself in hand and I do not ignore meals. I say, "Put yourself first, you're the invalid now".'*

Other physical effects

Many people had difficulty speaking following surgery, but this had improved with time and with speech therapy. There were other physical side-effects of the condition and treatment. During treatment people felt drained of energy and reserves.

> *'It [the radiotherapy] takes all your energy. The first three weeks wasn't too bad but the last three weeks was really tough.'*

Some people had problems hearing or had tinnitus. Many people had difficulties doing simple movements, such as licking their lips or licking stamps, kissing, opening their mouths. Other people, where a graft had been taken, had difficulties moving limbs, with scarring or in one case losing a limb. Although not as common as eating problems, these conditions could have a significant impact on individuals.

> *'I've had twelve operations and four flaps put in my mouth, which has left me, well, I would think quite disfigured, and certainly finding it very difficult to cope with life in many basic ways. It affects your hearing, your taste, your touch. I can't kiss anybody, I can't taste very well – my hearing's affected too, I can't move my arm very well; there are lots of things.'*

> *'Even now, I go to hospital with this deafness in my ears and my head and it feels as if it is going to explode. They said it was tension in my neck and I have got this bell ringing in my ears ... and it is just driving me mad.'*

Psychological effects

The psychological impact varied between people, with the severity of their condition and treatment, with personal factors and social support. One man described his cancer and treatment as a 'blip in his life' which had not had any long-term effects. For other people, the psychological impact of having cancer and its treatment could be very significant. This could be caused by the fact of having a cancer, by changes in appearance or eating, or by specific aspects of services which they received. The main psychological impacts on people were embarrassment, shock and anxiety.

Embarrassment

Some people felt embarrassed about having cancer. Cancer was a word which many people avoided. Some people did not tell others that they had cancer.

> *'Not many people know that he has got it, and when we go anywhere and he realises the person does know he has had cancer of the mouth he always says, "Do you mind me using your cups?". And I say to him, "Why do you have to say that? Because it is not anything contagious".'* Relative

Many more people felt embarrassed because of their appearance or difficulty eating. They were embarrassed in case they dribbled or if they were not able to eat the food which was prepared. Occasionally people were embarrassed by difficulty in speaking and in being understood, particularly if they felt that they were being made fun of.

> *'If I am drinking a cup of coffee or something, it dribbles right down because I haven't got any teeth.'*

Shock

The shock of having their diagnosis has already been described in the chapter on the patient journey. Finding out the extent of their surgery could also have a major impact on people, who described a sense of loss.

> *'When I first realised the hole that I had in my mouth I was really scared and I thought, "How am I going to cope with the rest of my life?". That week I found very, very hard.'*

> *'The fear simply washes up from your feet to your head and you cannot think and it takes a couple of days before you can get yourself sorted out.'*

Anxiety and depression

Some people had a very philosophical attitude to life and said that nothing worried them. However, many people said that there were times when they worried. Some people described times when they were anxious for the future or were overcome by fear. This occurred even when they could rationalise the situation.

> *'Sometimes when I am sitting by myself I sometimes think, "If it should come back again I am not going to live to see my grandchildren grow up", which I would love to do.*

> *This is when I am by myself and I get a "black hour" I usually call it. And then another time I think, "What a daft thing to think about".'*

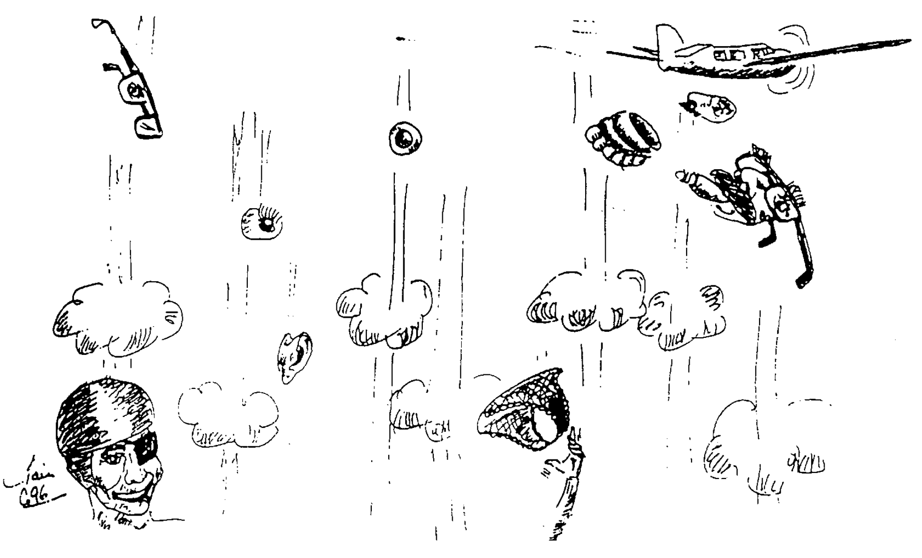
> *'It is like losing a relative so really you need time to grieve – I mean she was very depressed quite soon afterwards obviously, and I think she is only just getting over it now after fourteen months.'* Relative

Sometimes the anxiety could be triggered by an event and this could be exacerbated by lack of information. Worry could also be brought on as a result of treatment. One woman was told after her operation that she had had a transfusion and that there was a chance that she had contracted AIDS, but would have to wait six months for a blood test. This risk has worried her more than the cancer.

Social impact

The embarrassment that many people felt when eating meant that they avoided eating out. Some people devised ways around difficulties eating out by sitting facing a corner or signalling their partner to take over conversation when they were tired. Most people who had difficulty eating solid food didn't eat socially.

> *'I get embarrassed because I can't eat properly … I will not go into new company because I am ashamed of the way I look and it's just finished our social life altogether.'*



Sky diving is not generally recommended with prostheses

Many people found that they did not have the same energy as they had previously and had to plan any days out very carefully to make sure that they were able to eat suitable food in privacy and had enough rest. For many people having the cancer and subsequent treatment affected their lives in many small ways. One woman wanted to go on holiday but wasn't sure if she would be accepted for insurance as she had cancer.

> *'There are so many things that you feel that you haven't done in your life. When your family are young you couldn't afford it and now they have grown up and got married and have gone off on their own and we should be enjoying our retirement but we can't.'*

Impact of radiotherapy vs surgery

Many people with cancer had either surgery or radiotherapy and about half had both. Patients who had surgery knew that they were having a long operation and/or the extent of the surgery even if they did not appreciate the impact in terms of quality of life. Radiotherapy had more of an impact on people than they expected.

No treatment for head and neck cancer was pleasant and people with cancer appreciated this. Most of the short-term problems with surgery were most severe when the person was in hospital. Although the problems continued on discharge, the management had been started in hospital. In contrast most radiotherapy problems increased in severity with time and were managed on an outpatient basis with the person having to cope at home. Both treatments could have long-term side-effects. Radiotherapy could cause xerostomia (dryness of the mouth), and deafness. Surgery could lead to disability, disfigurement, loss of feeling and paralysis.

People who underwent surgery had to come to terms with an altered facial appearance, even if that was transitional and they ended up with a good cosmetic appearance, whereas this was less of an issue for people who had radiotherapy alone. Because of this, patients marvelled at the technical skill of the surgeon when a good cosmetic appearance was achieved. Although they were equally grateful for success with radiotherapy, they were less likely to mention the skills of the radiotherapist.

Other effects

Side-effects of treatment could have a major impact on people. One woman lost a leg as a result of a reconstructive operation and another a breast. One woman had an unplanned pregnancy and termination because of lack of information about chemotherapy, and one woman was told that she may have contracted AIDS as a result of a blood transfusion. Other people experienced pulmonary embolisms and intracranial haemorrhages. Many other people in the study had less significant impacts; for example, scar tissue which made it difficult to wear swimwear, or paralysis which made it difficult to smile. Although these are individual incidences that affect about one third of the people with cancer, in the study they illustrate that UAT cancer can have an impact on people far beyond the initial tumour.

Some people had more than one medical condition to contend with. One man had a rare bleeding disorder which made surgery difficult. He ended up in intensive care with a prolonged stay in hospital following any surgery. Another woman had a myocardial infarction (heart attack) following surgery.

Three people in the study had partners who also had cancer. They filled both the roles of carers and patients. This had a major impact on their recovery. They not only had to cope with two sets of hospital appointments but they had to support their partner while not always having the support which they themselves needed. One woman said that she didn't start her recovery until her husband died six months after her surgery and radiotherapy. Another woman found it difficult to cope with her husband's chemotherapy.

> *'As he has more and more chemotherapy plus the medication he has to take, he does become more and more irritable and can be absolutely hell to live with him. He doesn't realise he is doing it.'* Relative

One woman, having survived breast cancer, said that she was better able to support her husband through his illness and fight for him. The cancer could have as much of an impact on the families of the person with cancer as on the person themselves. Sometimes the partner took on the role of the worrier.

> *'I think I worry more than he worries and I think that that's often the case. It's the one that hasn't got the trouble that does the worrying.'* Relative

Attitudes

Personal attitudes

People's personal attitudes to their condition and care varied with their personality and experiences. People responded differently to their diagnosis, some people receiving a great shock, others expecting the diagnosis and others being more philosophical. The people who were philosophical described how they accepted their diagnosis and treatment as inevitable and something that they had no control over. Having accepted that, they then went about making the most of their situation whatever came their way.

Other people described their journey as a more active process. Although they accepted their diagnosis, they were not prepared to accept any outcome. They described making a conscious decision not to give up on life and to tackle each hurdle as it came along. Some people described this as a fight against the cancer.

> *'You have got to have an awful lot of determination and will-power to get through this. I am not going to let it get to me.'*

People felt that this attitude helped them to eat when it was difficult or painful and to recover, as they had a goal to strive for. They felt involved in their care. This also applied to partners and family members, as the process was often shared and sometimes the partner was the one leading the battle. It could be a difficult process.

> *'Well, somebody has to fight for him. But it is tiring, very, very tiring.'* Relative

There were times for some people when the battle seemed too much and some described anxiety, depression and weariness. This was particularly so when they felt unsupported in their cancer journey. There were other people who had been through this process, were able to support others in the group and who had largely put their experience behind them and carried on their lives much as before. It was important to many people that the cancer and its treatment did not take over their lives. Some people made a conscious decision not to dwell on the cancer or on mistakes made by professionals in their care.

> *'It [the mistake] has happened and that is that. But, it does seem to me pointless to have that anger and keep it, so we have kind of forgotten it really because it gets you nowhere and it doesn't do you any good. It is non-productive. I think the important thing is to have that positive attitude ... You have to have it to get through it and that is one of the things that really does help.'* Relative

Humour kept appearing in the focus groups. People with cancer and their family members retained the ability to laugh, joke and to laugh at themselves as well as support each other. As one person said, laughter was a better medicine than tears.

Most people felt that the condition and treatment had changed their outlook on life. This was true for both people with cancer and their families. Only a few people said that it had not changed their outlook, and these were people who had a philosophical view of life and tended not to worry anyway.

Most people felt that the process had made them more aware of life. Because of this, most people said that they tended to worry less about the day-to-day problems and to appreciate life more.

> *'I don't worry half as much as I did beforehand. Before I had the cancer I'd be thinking about this job and that job, now I don't care as much.'*

> *'I think really I enjoy life more, I enjoy each day, I enjoy whatever we do each day and I think I appreciate it more. I accepted everything before and took it, but now I appreciate it.'*

In contrast some people felt that the process had made them less tolerant as a person, particularly with trivial problems.

> *'I can't get worked up about little things. I can't stand people who fuss about nothing.'*

Attitudes of health professionals

This was one of the major themes of the focus groups. The attitudes that people with cancer encountered had a major impact on them and how they perceived their care. The lack of understanding of what it is like to have cancer and the attitudes of professionals were for some people the main things that needed to be changed in head and neck cancer services.

Personal care

Many people said that the care they received was excellent and couldn't have been better. They were very grateful for the care and attention of the hospital staff, from the receptionists to the consultant. People felt that when the consultant's attitude was positive, it rubbed off on all the staff. Patients in one hospital were touched that even the cleaners regularly asked patients and relatives if there was anything that they could do for them. This also applied to reception staff in an outpatient setting. The personal touch was felt to be very important. People who had experienced this personal care said that they had more confidence in their team and that it helped them to recover.

> *'I walk in there now and they all know me and so you feel confidence and that helps you to cope with it a lot better.'*

People described wide differences in the care and attitudes of staff in different hospitals or different wards in the same hospital. This was often put down to whether the people involved were used to dealing with people with cancer. One woman who had two major operations in two separate hospitals said that in one hospital she was encouraged to recover, as staff were positive and caring and made her feel that she was worth looking after. In contrast, she felt that in another hospital the nurses were uncaring, spent the minimum amount of time with her and were giggling about her facial appearance. This was very distressing for her and had a significant impact.

> *'At hospital X they [the nurses] made me feel as though it was worthwhile fighting to get back to normal. But at hospital Y every time they came to the bed they were laughing at me. It was distressing me very much ... I was down so low that when I came out it was months and months before I came out the door. I was so depressed.'*

This lack of sensitivity was echoed by many people in the focus groups and could apply to any health care professional. In many cases people felt that staff were not interested, in others that they were afraid of the cancer or the patient and did not know how to cope with it. This made people feel that they were a burden and made them less confident in their care and their ability to recover. People said that it was difficult enough to cope with a major operation, and perhaps radiotherapy, and develop the will to recover if those who were involved in the treatment did not encourage them and gave the impression that they were not interested in what happened to them. People with cancer had enough hurdles to cross without having to contend with negative attitudes from their carers.

Many people acknowledged that some professionals had good communication skills and a good bedside manner and that others did not. They also were very aware of how busy nurses and doctors were. However, there were many examples where people were treated in an offhand manner and without care or courtesy. When one woman who was having a graft from her leg asked about risks, she was told by her consultant that the last patient he operated on had his toe fall off when he took his sock off. He then told the patient not to take her socks off. This was the woman who subsequently lost her leg.

Kindness

In contrast many people spoke of the kindness of health professionals. Those patients and relatives who were the greatest critics of care were also those who were the most grateful when care was shown. People were particularly touched when doctors or nurses went out of their way to help or showed more concern than the person would have expected. This was true for both patients and their families. One woman described coming round after her operation with her surgeon holding her hand and saying that the operation was a success. Many relatives were touched that the surgeon rang them at home in the evening when the operation was finished. One woman recalled an incident which touched her deeply.

> *'The consultant asked the nurse to shave him. Well, three days later he still wasn't shaved and the consultant came down and he shaved him himself. The man cared, he cared so much ... Then we stopped going to hospital X. He [the consultant] got to know that my husband had died and I got a charming letter from him ... Now that boosted my morale no end.'*

In many cases it was just a kind word or enquiry which made a difference between feeling that people were on your side and working with you to overcome the difficulties rather than your cancer being a bother. People with cancer and their partners described a sense of vulnerability which made them more sensitive to kindness or unkindness.

Understanding by health professionals

Many people felt that there was a lack of understanding by health professionals of what it was like to have their condition and treatment. They thought that much of the lack of sensitivity stemmed from a lack of understanding rather than deliberate lack of care. Many people mentioned that there was a lack of understanding of the impact of the condition on people's lives.

> *'Eating is a major part of everybody's social life … That's what the doctors and nurses don't ever think of, what on earth goes on when we go out to eat.'*

This was particularly true when people were discharged from hospital. The impact on the person's life and that of their families could be great in terms of work, daily routine, social and family life. Even something like a prosthesis assumed an importance to the person far beyond a conventional denture.

> *'I don't think the medical profession really realise what it really entails for a person trying to use an obturator. They don't realise that you can't talk without it, you can't eat without it, you can't drink without it. They do not realise the great immense fear. You live with the fear that it is going to break or fall out, you're going to drop it and I keep it by my bed at night so it's the biggest pot of gold I could find.'*

Many people reported a lack of understanding of the impact of facial disability among health professionals. The face was felt to be important by everybody, particularly to women, and affected not only how the world viewed them but how they could interact with the world. Over half of the people in the study had to come to terms with an altered facial appearance and another third with alterations to their mouth. Most of these people felt that health professionals did not really understand what they were going through in this process.

A minority of people felt that their needs were not been taken seriously. Others found that platitudes were being given, and others were very hurt by comments made by staff. Humour could work both ways. One woman laughed when she was told by staff in intensive care that her face looked like Mr Blobby. As she could not see it herself, she was not bothered, and the humour helped to break the seriousness of the situation. Other people said that they were very hurt by insensitive jokes made by nursing staff. Although they could laugh at themselves, it might be inappropriate for others to do so.

Psychological support

Needs

What most people said that they needed at different stages of the cancer journey was someone to talk to. They might not need to turn to that person very often or at each stage but it was important to have that contact. The emphasis in the early stages was on being able to talk about what they were going through rather than on getting advice. When people were being followed up, there was also a need for advice from someone who had some medical knowledge when they had a problem.

This support was usually given by family members, and for many people this was the only support they said they needed. However, many people valued the opportunity to talk through their situation with other people. This could be a few days after diagnosis, during the recovery period or following discharge, when people had time to think about it. There were times of crisis when people felt that they needed external help.

> *'For that period of time you just sink inside of yourself and you can't reach out to people for help. It is impossible. You are like in the bottom of the basin and you can't get out of the slippery basin. You can't reach out, at that stage people have to reach in. After a period of time you then get yourself sorted out and then you reach out. And then you hopefully reach in for other people. But there is a stage when you really can't help yourself.'*

When a crisis came, it was important to have support quickly. One man who thought from a hospital consultation that he had a recurrence found that he needed to talk it through with someone. He had recently moved house and his family were out. He went to three churches but didn't find anyone there to talk to.

> *'I was walking and walking, I thought go on the booze?– no, don't do that. I just needed someone to talk to ... You need to have it immediately. There's no point in making an appointment for three weeks.'*

Counselling

People's experiences of support services varied. Everyone felt that counselling services should have been available. Some people were aware of the emphasis in recent years on counselling services for patients with breast cancer and felt that similar services should be available for people with cancer of the head or neck.

Most people said that they were not offered counselling services. Many people felt that they had to actively seek counselling if they wanted it rather than it being offered. This could be quite difficult to do. People felt that they wanted to talk about their situation without having to say that they were not coping or without having to make a great fuss.

> *'If you did want to speak to somebody you had to actually ask. It was not something they would suggest to you. I think that is quite difficult to do because you feel that you should be coping by yourself.'*

People with cancer had poor experiences of the counselling services which they had received from a variety of sources, including voluntary organisations. Often they had been approached without warning on the ward by a variety of people, ranging from nurses to nuns. The people with cancer felt that the counsellor had come with a prepared piece, had not listened or tried to understand them and had not helped.

> *'She said that I had to get used to a new body image. But it was a body image that I didn't want. I felt awful but she left me feeling much worse.'*

> *'It was totally inappropriate and it made me angry.'*

What the patient often wanted was not a set answer to their problems but a listening ear. One woman's counsellor told her that she looked fine, but this did not help her to come to terms with her altered facial appearance and how she felt about it. In contrast many people said that they had an unexpected source of support from a student nurse or young doctor rather than the counsellor or person managing their care. The important feature of these people who helped is that they were prepared to spend time, they listened and they didn't give advice.

> *'There was a young lady doctor who helped me a lot after one operation. She was very sympathetic and just listened.'*

Patients acknowledged the difficulty of understanding what it was like from their point of view when the counsellor had not been through the same experience. They also said that the support which they received depended more on the personality of the counsellor than on the training which they received and that the relationship was an individual one. One woman summed up the feelings of many by saying:

> *'I'd love to have a counsellor if she had a face like mine!'*

Some people had support from another person who had undergone a similar procedure. This was often arranged by the hospital and was felt to be valuable. The other person provided understanding, encouragement and gave the person undergoing treatment hope and something to aim for. In some cases people maintained contacts for many years.

Support groups

Some participants were members of the patient support group 'Let's Face It' and others had been in contact with BACUP and Changing Faces. These people spoke very highly of the support which they received and were happy to support others. They described the relief when they met someone who understood what they had been going through. There was access to someone at the other end of the telephone if they needed to talk.

> *'So I phoned X and a lovely voice said, "Hello, how can I help you, I am cooking sausages but carry on talking". And I talked and talked and talked. And she was just magic, somebody listened!'*

Many of the people who had not been in contact with support groups said that they had not known of their existence. Some did not feel that they needed a support group and thought that it would be more beneficial for people who were single. Others felt that they would have liked to have been told by the hospital that they existed so that they could decide whether to be involved or not.

Some people distinguished between the need for psychological support and advice. There were times when they needed someone to talk to and there were other times when they needed to know if their symptoms were normal or if they should contact their hospital team. People felt that this person would need to have the authority to advise and would need to be in some way connected with their care and the hospital involved. Support groups members acknowledged that formal support networks, such as a cancer support nurse, were needed alongside support groups.

Family and social reactions

People were asked how their families and friends reacted to their having cancer. Families went through the same shock and fear which people with cancer described on receiving the diagnosis. Some people coped with this by not telling many people. One woman did not tell anyone except her son until after her operation that she had cancer. Having a family member at the consultation was helpful but it could still be difficult to tell other family members.

> *'I had to tell them all by phone. My mum's one of these people who panics and I nearly hung up the phone on her.'*

Most people said that their partners had been very supportive through the process and had helped them through it. Partners spent 12 hours per day at the hospital when necessary and took time off work to go to hospital appointments and to nurse people at home. This impacted on their jobs and leisure. In many cases people said that the process had drawn them together. Difficulties arose when both partners had serious medical conditions and both needed support.

Children's reactions to their parents' cancer varied. Most people's children were young adults when they were diagnosed. Some were described as a tower of strength and supported their parents. Others found it difficult to talk about the cancer.

> *'She [my daughter] wanted it to go away so she didn't talk about it.'*

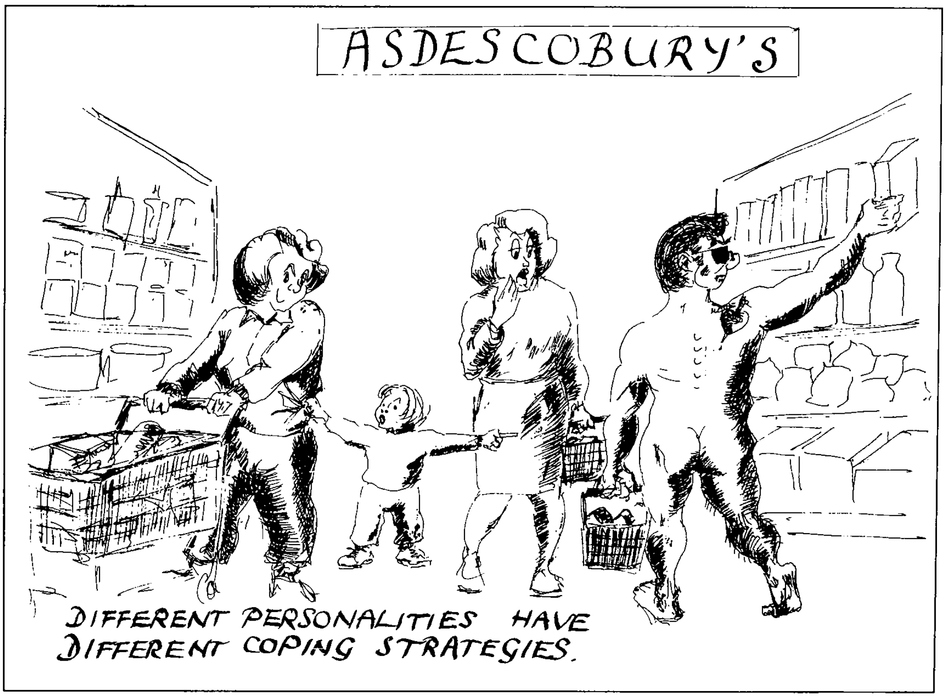
> *'Children find it difficult to cope with a parent who has always been fit and is suddenly not and is down and depressed and they don't know how to cope.'*

One woman found that her 12-year-old son was initially embarrassed by her appearance but that it passed as he grew older.

Many people found that their wider family and friends rallied round to help them recover from the condition. People visited on a regular basis, brought liquidised meals and provided nursing care and support to allow the partner to go to work.

> *'My husband's family were great, his sister especially, after the operation, bringing me spaghetti bolognese that she had made and put in the liquidiser for her two little kids. I think having family support is really important. The family all rallied around so that he could carry on doing his shifts.'*

Some people involved their families very much in their condition and treatment. One woman showed her prosthesis to her immediate family as they were interested in seeing what it looked like. Another woman felt that it was something personal which she did not want to disclose. One woman who had a suspected recurrence asked her consultant to show her husband her maxillectomy cavity and what to look for if there were problems.



There was a mixed reaction from friends, acquaintances and the wider public. Many people felt that others were embarrassed and did not know what to say. Many people found that their friends didn't want to talk about the condition even though they needed to. Some people said that they found out who their friends were through the process.

> '*My husband's friends, our married friends were conspicuous by their absence – cancer! "Oh we don't want to come and see you. Oh no! We won't come and disturb you, darling." They were scared witless!*' Relative

> '*Afterwards [after the operation], it is a little bit like when someone died and no-one wants to mention it and talk to you. Cancer is one thing people don't want to know about.*' Relative

Reaction from employers varied. Some were said to be very supportive, others made the process of care and recovery more difficult. One man nearly lost his job when he took time off work when his wife was discharged from hospital. One woman with cancer had to work through her radiotherapy treatment, taking half an hour off per day. She then found that her performance-related pay suffered because of her condition and she had to take a day's holiday to attend the focus group interview.

Many people felt that 'cancer' was still a taboo word and that many people were afraid of it. This could be reflected in nurses and GPs also. This, combined with facial disability, made it even more difficult to socialise. Many people found that they were accepted by their families and close friends. However, when they went outside those circles, people felt less confident in disclosing their illness. If they had a facial disability also, they often felt that people were staring at them. The consequence of this was that many people tended to stay within their defined circles.

> '*I lean heavily on my children and my family and my friends. When I get out of that environment then it becomes difficult. I need my home quite a lot.*'

Without that support some people had a poor quality of life.

> '*This friend of mine, she is virtually a prisoner in her own home – she is constantly depressed. Her family are in Devon and she doesn't know anyone. She would be a lot better if only she would talk to somebody.*'

Professional views

Support for people with cancer

All the professionals were conscious of the need for psychological support of people with cancer and their carers. The physical, social and psychological needs were also linked.

> '*It is quite difficult to separate one from the other. If they have problems communicating or eating, you can't actually separate that. For example, if they don't have good communication they then feel more isolated. They find it more difficult to communicate with their clinician how they feel and with their families. So I think that a large part of our role with patients is being the patient's friend and supporting them.*'

Many people spoke of the need to be there for people with cancer, to be there to listen, to answer questions and just provide a friendly face. This was thought to be important for all members of the team, from the secretary to the consultant, but nurses identified most closely with this role.

> *'We get to know the patients very well and obviously become quite close to them. We get to know their backgrounds and encourage them ... opportunity to ask questions and try to express their fears about their situations, possibilities for the future.'*

Support services

Some clinicians did not distinguish between acute and support services, as they felt that they were all part of the same team. Counselling was felt to be important for people with UAT cancer. It was reported to be available at two hospitals, and at the other two the staff felt a need for there to be a counselling service. Some professionals reported that patients did not want counselling initially but did at a later stage.

The degree of professional support needed could be considerable and related not only to the patients' condition but to their personality and social support. Support services were felt to be particularly important at times of transition such as discharge and changing from active to palliative care. This was important both for the person with cancer and the clinical team.

> *'I think that those transitions are very difficult. Patients with head and neck cancer are treated very radically, very aggressively, very much supported by their own specialists and it is very hard for specialists to say to a patient, "Right, the situation has changed, I am no longer able to treat you" without abandoning the patients.'*

Many people spoke about the processes of bereavement, anger, anxiety and depression which they had come across in patients and their relatives. Most professionals felt that patients come through the process well. One group discussed the difficulties in dealing with anger and depression. It could leave them feeling powerless to help and frustrated.

> *'No amount of physiotherapy, occupational therapy, tender loving care, in fact if people have switched off and lost whatever you call it, mobile motivation or whatever, then just nobody's beating that with any medicine or therapy or anything.'*

Patient interaction

Many clinicians mentioned getting patients together for mutual support. One hospital had a network of support groups in different areas, another had a group that met in the hospital. One hospital had tried to start a group and the fourth said that nobody had requested a group.

Some doctors brought together past and new patients. One group referred to this as 'tea-partying' where a person who was about to undergo a treatment was introduced to one or a group of people who had undergone a similar procedure.

> *'We'll pick the first person up in the clinic who comes in and say, "Look, come and have a word with Mr So and So" and they always do and that's the easiest way of, I wouldn't say overcoming this problem, but assisting the patient to appreciate that there is life after a laryngectomy and there is hair after chemotherapy and all the rest of it.'*

The doctors felt that this was therapeutic to both patients, as it gives the person doing the talking the opportunity to reflect on their treatment and sort our how they felt about it and in feeling that they are supporting another patient and the team. This interaction happened to varying extents in the hospitals either because it was not felt to be necessary or because treatment was urgent and there was not enough time to organise it before treatment.

In other cases patients were not actually introduced. One speech therapist booked all her cancer patients on the same session where possible so they would have the chance to interact, but they just passed each other in the corridor. One physiotherapist felt that in her work, interaction between patients in hospital would be counterproductive, particularly at the early stages when treatment was difficult and uncomfortable.

Families

Many professionals felt that family support was very important for people with cancer. This was particularly stressed by nurses, speech therapists, social workers and hospice carers. Some people with advanced cancer had symptoms which were difficult for their families to deal with. Community clinicians thought that there was an implicit assumption that families would be able to care for the person with cancer but that it was not always possible. Many felt that the support which could be offered and which was offered by social services was very much poorer than that which a supportive family could offer.

> *'I think that sometimes it is difficult with professionals who cope with people who appear distressing all the time to appreciate the reaction of relatives who aren't familiar with it. And even something as simple as cleaning someone's mouth can be quite difficult for someone who has never done it before ... You can't follow the person round in the community all the time. The majority of people and their carers learn to deal with their care. But for some people their symptoms can be very, very difficult.'*

Some clinicians found some difficulties in dealing with relatives. The clinicians had to deal not only with the person with cancer coming to terms with their condition and treatment, but their relatives who might have different needs.

> *'I have had experience of relatives post-operatively, who have really been almost more of a management problem than the patient themselves just coming to terms with it. And I think this goes to the bereavement stages as well, the relatives are possibly at one stage behind their patient in the bereavement stage or whatever you could call it and so that's sometimes quite a problem.'*

Caring for the carers

The professionals in the focus groups were asked what the services were like from their point of view. Many people said that the work could be very challenging and rewarding, as this hospice nurse illustrates:

> *'I think we're very lucky because we see things that other people just don't see. We do see tremendous courage and we get, I think, strength from that. It's tremendous knowing someone feels better and is doing all right and there's nothing that makes anyone ... happier. Even if at the end of that time they die a good death, that's fine too.'*

Doctors, nurses and others spoke of the satisfaction when they felt that someone was improving or when they had done their best for a patient.

> *'One of the most positive things is when you actually finish and you feel that they are going home and they are feeling happier, they're looking better and I think you get a lot of satisfaction from that.'*

Several of the ward nurses said that they liked to get feedback from patients following discharge. It could be very heartening to have a letter or visit from a previous patient or to hear from community services how they were getting on. They needed to have that feedback. In one hospital some of the staff visited the patient support group to see how people were and kept the contact in case any of patients needed help; but they felt that the people with cancer needed that time on their own without the health professionals.

Many clinicians said that they did get involved in the lives of their patients. They got to know the people and their families over a long period of time and felt that they needed to follow the process through by maintaining contact throughout the care even if indirectly. One doctor had been upset when a patient who he had treated over a long period had died in hospital and he had not been informed, although he had asked to be. He felt that when a person with cancer died the team was forgotten and the process of dealing with bereavement with both the family and the team was not very well handled. Other people felt that although it was sad when someone died that they were able to detach themselves from it.

> *'Everybody feels the failure in treatment but you have to separate it off from yourself somehow, not to get too personally involved.'*

Professionals spoke about their causes of concern and difficulties. These could be the frustrations with organisational issues, the uncertainties in decision making and the difficulties in communication. Most professionals were keenly aware of the mortality statistics and treatment could seem like an uphill struggle trying to cure people. Others found it more hopeful.

> *'It's surprisingly non-depressing actually because there is always something you can do for somebody. Even if it's just, I say just, even if it's pain relief for instance and if somebody has a lot of pain they feel pretty depressed and pretty rotten and sorting out somebody's pain can make a huge difference to the way they perceive their overall illness.'*

For others the difficulties, the nature of the condition and getting communication right could be draining.

> *'I find in talking to patients I try to always be honest as I can. I find it difficult at times to be so honest, to tell them, "Sorry, your time's up, there's no further treatment, we can't offer you any more". It tires me out.'*

When occasionally people failed to respond or to become involved in their care, it could be very demanding.

> *'You try to sit with them and talk the various problems through and there have been times you do that and then, "No, I don't want to do this, I don't want to do that" and they do deteriorate and that is quite difficult to see. It is very frustrating ... Because you know they could be doing better than they are. And because it is actually very demanding, quite challenging for all of us but psychologically as well, to do that work so then to see it's not completed can be, is actually, quite draining.'*

Most people said that they received support from their peers. Head and neck clinics were a good source of support for surgeons and oncologists as well as aiding the decision-making process. Therapists received support from their colleagues and the multidisciplinary group who met in one hospital supported each other. As cancer care was about people, most professionals felt that support was needed all round.

> *'A successful anti-cancer operation becomes quite a closed society. There's a lot of mutual support needed and given ... Obviously there is a lot of mutual support between our surgeons and our radiation therapists, or chemotherapists. There is a lot of mutual support between the nursing staff and the medical staff and I don't really distinguish between those. There is also a lot of mutual support given from patient to patient. Patients want to be part of the team. We try to encourage them to be that and to do that. I think this is a very important aspect of producing a cohesive approach to cancer management in general.'*

Discussion

Impact

The study did not attempt to measure the impact of UAT cancer on patients' quality of life. Instead, the respondents assessed and described the impact of the condition on their lives providing an insight into what it is like to live with UAT cancer. These have been described in terms of physical, psychological and social effects, although these are linked. The professionals focused mainly on the psychological effects.

The impacts of the condition and treatment could be short-term or long-term. There is no doubt that the disease and treatment had horrific short-term effects, physically and psychologically. Most of the respondents in the study had overcome these short-term effects and had come through the process. The long-term effects had to be lived with.

Some limitations, such as difficulty in eating, could be accommodated by liquidising food or eating lying down so that the person could eat and maintain nutrition and weight. The limitations could have a long-term grinding-down effect. Difficulty eating could lead to eating a limited range of foods and avoiding eating socially. The combination of effects often had a greater impact than the sum of each effect individually. For example, the physical difficulties of eating following surgery were compounded by the pain and aversion to food caused by radiotherapy. This could be severe and cause weight loss. Similarly, a seemingly small limitation such as lack of taste or smell could have a major impact, as Baker[4] found. Lack of taste compounded the difficulty of eating for some people, so they could neither eat 'real food' nor taste the liquidised food. The result meant that eating was a chore rather than a pleasure. The professionals observed that the symptoms in advanced UAT cancer could be particularly difficult to manage, for professionals, family and for the person involved. Due to the nature of the sample, patients with these severe problems are perhaps under-represented and could form the basis of a separate study.

In a condition with such major primary effects, the side-effects of treatment may tend to be forgotten. The side-effects of treatment had a large impact on the people in the study. This may be because they were unexpected, there was little information on what to expect and they were felt to have been unnecessary, as found in other studies.[71,73] Side-effects also contributed to their satisfaction with care. The ability to cope with an obturator is a predictor of adjustment.[151] Prostheses such as obturators assumed a central role in some patients' lives in this study.

Many of the psychological effects described are similar to those described by people with other forms of cancer. Coming to terms with a diagnosis of cancer was often accompanied by having to come to terms with a new body image while undergoing major treatment.

Facial disability has been reported to be a source of short-term distress, but not of long-term isolation.[4,108] The respondents in this study reported that it was a sensitive issue and one which the person had to come to terms with in their own time and in their own way, as is generally recommended with cancer.[152] Although by virtue of attending the discussion groups the participants were not isolated from society, many people reported that they tended to stay within a small circle of family and friends and that facial disability had limited their social contact.

Attitudes

Personal attitudes played a large role in recovery. The respondents in this study were very positive and most could put the experience behind them; they had moved from 'suffering' to 'surviving' to 'thriving'. Personal attitudes of the person with cancer and their family were recognised as being particularly important by professionals. Most found patients very positive and willing to be involved in their care. A negative attitude of depression or anger could be very difficult for professionals to deal with. They felt frustrated and powerless to help.

Professional attitudes were identified by all patients and relatives as crucial to their care, as has been found in other studies.[5–7] The differences in care between individual clinicians within a hospital and between staff in different hospitals were striking. Professionals' own attitudes and vulnerability to cancer may affect patient care.[153] Even where one member of the team was supportive, another member could completely undermine the confidence of the person with cancer or their families by an inappropriate remark. Patients were not demanding, and their expectations were not unrealistically high: merely to be treated as a person. The loudest critics were also those who most expressed their gratitude to those who did show that they cared. The implication from the findings echoes other studies;[5–7] if some professionals can manage to achieve good interpersonal care then others should also.

Support

The two main support needs identified were the need for someone to listen, particularly a few days post-diagnosis; and the need for advice, during and following active treatment. As with Carlsson and Hamrin's [98] study, the partner and family were the main sources of support for persons with cancer and in most cases met their psychological and social support needs. Where, for some reason, partner support was not present due to concurrent illness or absence of a partner, the effects on coping were dramatic. Other support mechanisms did not seem to be as effective. Many families and friends were very supportive but, as Ell[124] found, many people with cancer could not talk openly about their cancer to other family members, particularly children.

There is room for improvement in counselling services. Patients, relatives and professionals agreed on the need for counselling. It could be difficult to access. Many people who felt that they would like to talk to someone about their experiences found that the services were not offered, even in hospitals where the professionals said these services were available. Asking for counselling felt like an admission of not coping, being difficult and having problems. Even in hospitals where counselling was available there were several patients who said that they needed psychological support. On the other hand, those people who had counselling felt that it had not helped and had often angered them when set solutions rather than a listening ear were offered. Informal counsellors such as members of the team, other patients and family or friends were often more effective. Given the difficulty of clinicians assessing psychological needs, there is a need to improve the psychological support services offered. The use of specialist nurses as part of the team could help to meet patients' listening and advice needs. Simple measures such as changing how counselling is presented from 'do you need counselling?' to 'there is always someone here if you would like to talk at any time' and the offer being repeated at different times may make services more accessible. These services should also be available to families and staff. Counselling and support services need to be audited to ensure that they are meeting the needs of clients.

The process whereby a patient who had undergone a particular treatment talked about their experiences to another patient, or 'tea-partying', was found to be beneficial by both sets of patients and by professionals. This provided both information and support for the community, many others did not and would have liked to have had the opportunity.

This should be introduced wherever possible to patients at an appropriate stage of their treatment.

Support groups were found to be valuable by their members. Some non-members regarded support groups as only for people who did not have family support. Interestingly, the non-members found the focus group discussion valuable but said that they needed a reason to get together. This is perhaps one of the reasons why the process of 'tea-partying' was beneficial; it gave an opportunity of reflection and talking through experiences while helping another person and the clinical team. Most people who were not involved in support groups did not know that they existed and would have liked to have known. Although not everyone will wish to join one, details of support groups should be made available to all people with cancer.

It was clear that the professionals who took part in this study enjoyed their work and found it both challenging and rewarding. Although none of them expressed that they felt burnt out, the pressures and frustrations were discussed. In common with the US study [149] administrative difficulties were the major cause of frustration. As the formation of cancer centres and units has the possibility of causing administrative difficulties between trusts, this will need to be guarded against in the formation of head and neck cancer services in line with the Calman proposals.[1]

The difficulties of clinical decision making, the survival statistics and communication were other causes of frustration. The 'Pandora's Box' analogy of clinicians not willing to explore the patient's psycho-social needs because they could not cope with them did not seem to apply to the professionals in this study, but informally many clinicians said that they suspected that this, along with time pressures, was a major reason why some clinicians did not support patients.

Many professionals appreciated their need for support. In some cases it came from other members of the team, particularly with consultants. In others it came from other members of the professional group not involved in cancer care. Many hospital staff felt it important to follow up people who had been in their care and were supported by news of former patients. Different support issues emerged in different hospitals, such as support for decision making and bereavement, and these were being worked through.

Conclusion

The impact of the condition and treatment on people's lives were described. Many persons with cancer felt that their personal attitudes and support from their partners and families were important in coping. The need for someone to listen and the need for advice were the main support needs identified and were often not met by health professionals. The need for counselling services was recognised by all respondents but many persons with cancer found that these services were not as accessible as health professionals thought. Counselling needed to be done well, if at all, as many persons had negative experiences. Being introduced to another patient was found to be helpful by both patients and professionals, and some people found support groups helped. Attitudes of health professionals were felt to be particularly important in people's care and gave them self-esteem and confidence in the professional team. Professionals also needed support and many received it from their peers.

Recommendations

- Clinical care should aim to minimise both the short-term and long-term impacts of UAT cancer.
- Cancer teams should ensure that a supportive attitude underpins the care provided by all members of the team. Supportive mechanisms should also be provided for members of the team.
- Good information on the likely impact of treatment should be given to lessen its impact.
- Psycho-social needs of patients and families should be assessed and addressed.
- Psycho-social support should be available and perceived to be accessible at different stages of the cancer journey for both the person with cancer and their families. This support should be able to address listening and advice needs. This role could be provided by a specialist cancer nurse and should be individually tailored.
- Where possible patients about to have treatment should be introduced to another patient who has had similar treatment for information and support. A network of available patients could be built up by each team.
- The impact of the condition and satisfaction with the care provided should be included in audits of head and neck cancer services.

Chapter 5

Recommendations

The recommendations are presented to purchasers, NHS trusts and head and neck cancer teams. They are aimed both at promoting and at ensuring consistency of the best care as well as bringing the standard of the rest up to the best. The recommendations can be incorporated into the changes in services for people with upper aerodigestive tract (UAT) cancer at this time and into the future.

Purchasers

1. Purchasers should ensure that the views of patients and their families are sought and taken into account in any service changes.
2. Purchasers should consider purchasing UAT cancer horizontally, i.e. as a whole integrated service across primary, secondary and tertiary care providers, to ensure co-ordination and consistency of the service across different sectors.
3. Standards should be agreed with providers and users and monitored for both process and outcome measures. These measures should include quality of life measures.
4. The care of persons with UAT cancer should be under a multidisciplinary team with the appropriate skills and qualifications.

NHS trusts

1. Providers should ensure that persons with UAT cancer are managed by a multidisciplinary team from the outset of treatment who have the appropriate skills and qualifications and work as a team. Non-clinical time may be needed to co-ordinate and build the team.

2. Inpatient accommodation should, where possible, be in a ward where staff are familiar with the condition, where there are patients with similar conditions and there is adequate privacy.

3. Providers should ensure that the service is co-ordinated with primary care and voluntary sectors as well as between and within provider trusts. This may be achieved through:

   - development of guidelines for the transfer of patients from one sector to another which are available to patients and families.
   - examination of administrative procedures and internal communications systems to see how effective these are and, if necessary, how they could be improved both within trusts and between sectors.

4. Patients with UAT cancer and their families should have access to a specialist cancer nurse. This nurse would be an integral member of the team and would provide support and advice through all stages of the cancer journey.

5. Psychological support should be accessible for patients and relatives and professional members of the cancer team.
6. Ongoing audit of services should be undertaken and include patients and relatives who use those services. Audits of information, support and choice should be undertaken as well as the processes of care across primary, secondary and tertiary care sectors.

Head and neck cancer teams

These recommendations centre around teamwork and communication, to maintain the high standards of some aspects of care and improve the standards of others. Each head and neck cancer team are advised to examine their practice in the light of these recommendations and, where appropriate, change practice. The recommendations stem from a common aim:

To build a partnership between the person with cancer and their family and all the professionals involved in their care; to work together in a supportive environment; to provide the best cure and care for that individual person; and to do it consistently.

1. Teamwork: UAT cancer should be managed by a multidisciplinary team which includes the person with cancer and their family. This could be facilitated by:
   - considering the composition and leadership of a team, the skills needed and how they are used across primary, secondary and tertiary care sectors;
   - examining how the team works, its internal communication and how it could be improved if necessary;
   - setting pathways for information, processes of care and support to ensure consistency, while recognising that each person with UAT is an individual;
   - ensuring that persons with cancer and their families are encouraged to participate as full members of the team.

2. Information: Two-way communication with patients and families should ensure that the information needs of patients/families and professionals are met. This could be achieved by:
   - asking patients and families what information they would like and in what form;
   - involving persons with cancer and their families in the development of information sources and systems;
   - checking the understanding of information given to prevent misunderstanding or conflicting information and clarifying any further information needs;
   - ensuring that information from all members of the team is consistent;
   - improving patient access to further information about their condition;
   - providing information on support groups;
   - providing information both in verbal and written form;
   - introducing patients to other patients who have undergone similar procedures for information and support.

3. Participation: The person with cancer and their family should be invited to participate as full members of the head and neck cancer team. This means:
   - finding out patient and relative preferences for information and choice and respecting these;
   - involving and informing patients and relatives at each stage of the cancer journey;
   - providing full information on the benefits and side-effects of different treatment options in order to facilitate an informed decision;
   - encouraging persons with cancer to participate in decisions about their treatment, including primary surgical and radiotherapy management to the level to which they feel comfortable;

4. Psycho-social support
   - Clinical care should aim to minimise both the short-term and long-term impacts of UAT cancer.
   - A supportive attitude should underpin the care provided by all members of the team.
   - Good information on the likely effects of treatment should be given to lessen its impact.
   - Professionals need to listen and respond to patient symptoms both to ensure good clinical care and relieve patient anxiety at all stages of the cancer journey.
   - Psycho-social needs should be assessed and addressed by someone with appropriate skills.
   - Psycho-social support should be available and perceived to be accessible at different stages of the cancer journey for both the person with cancer and their families. This support should be able to address listening and advice needs. This role could be provided by a specialist cancer nurse and the service tailored to the individual person with cancer or relative.
   - Supportive mechanisms should be available for members of the team.

5. Audit
   - Ongoing audit should be a feature of the UAT team.
   - Patients in their families should be involved in the process of audit and research; setting the agenda, viewing the results and implementing change.
   - Audits of whole services should include both clinical and quality of life measures.
   - Suggested audits include:

     Information
     Consistency of information and communication
     Impact of the condition on people's lives
     Communication between primary, secondary tertiary and voluntary sectors
     Organisational processes
     Participation in care
     Support services – whether persons involved felt that it met needs
     Satisfaction with care at different stages of the cancer journey

Patients and families

Many participants in this study made suggestions which other people with cancer and their families may find useful.

1. Contact an organisation such as BACUP or 'Let's Face It', and decide how much information you want and at what stages.
2. Before your hospital appointment, if you have any questions, write them down and give them to the consultant. Otherwise you might forget.
3. Take a friend or relative with you to a hospital appointment. They can often remember more clearly what was said afterwards than you can.
4. Some people find it useful to tape-record the appointment to remember what was said. Check if your consultant is happy with this.
5. Remember that it is normal to sometimes feel worried, depressed, angry and worn-out. There are lots of people who have the same problems eating and speaking.
6. Make sure that you have someone that you can talk openly to, a relative or friend, or someone at the hospital.
7. Share your experiences with other patients and consider offering to talk to other patients who are about to have a similar treatment to you. It could help them and your doctors and nurses.
8. Find out about support groups and see if you want to go along.
9. If you are worried, or have a problem, ask the doctors, nurses or therapists. They are there to help.
10. If you find that you cannot do what you have been doing, work or hobbies, then take up some new hobbies which are fun, will challenge you and give you a sense of achievement.
11. Keep your sense of humour, it is the best medicine.

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Appendix 1

Methods

Qualitative research

A qualitative research method was chosen as being the most appropriate to meet the aims of the study. Qualitative methods can elicit people's understanding and the meaning which they attach to things. They can also allow people to describe their experiences and the impact of a condition or treatment on their lives in the subtlety and depth that a quantitative survey method may not capture. They are more interested in the 'what' and 'why' questions rather than the 'how much'.[154] They allow the respondents to set the agenda and explore issues which are relevant to them rather than responding to a predetermined research theory. Qualitative methods can produce insight into an issue rather than measuring it, and are more concerned with validity rather than reliability.[155,156]

Focus groups have become an accepted part of health services research, having derived originally from anthropological and marketing traditions.[157] They usually consist of a series of groups of 6–10 people who usually don't know each other, who meet for approximately 90 minutes to discuss a number of issues in response to a series of open-ended questions posed by the facilitator of the group. The topic guide of questions is modified and developed as focus groups are conducted. The groups are taped or notes made, these are analysed and key themes identified.

The aim of a focus group is 'not to infer but to understand, not to generalise but to determine the range, not to make statements about the population but to provide insights into how people perceive a situation'.[158]

The group interaction is a specific feature of focus groups; it allows people to develop their ideas and opinions and is particularly valuable in areas where the respondents may not have developed their opinions fully beforehand. It is also useful for eliciting feelings that are common to that group but different from others.[159] Focus groups have been thought to be particularly appropriate to assessing the views of patients/users of services.[159]

Process of study

Development

The ideas and protocol for the study were developed in consultation with health professionals and with patient support groups. The topic guides were informed by issues raised in informal discussion with people with cancer on the issues relevant to them. The professional focus groups were undertaken after the patient/relative focus groups. The topic guide for professional focus groups was informed both by informal discussions with health professionals and by the issues raised by people with cancer and their families. The topic guides are included at the end of this section.

Sampling

Four hospitals were chosen to participate in the study: two teaching hospitals, one cancer centre and one district general hospital. All the hospital departments who were approached agreed to participate in the study. The main link in each hospital was the maxillofacial department. Ethics approval was sought and given by the committees in each hospital. The hospitals were chosen to present a variety of provision in the UK but were not intended to be statistically representative of all provision in the UK.

A systematic approach to selection of patients was undertaken. Two-thirds of patients in the study were recruited from the maxillofacial departments at the four hospitals. The other third were recruited from two 'Lets Face It' support groups who met at two of the hospitals.

Each hospital were asked to identify patients using the following criteria:

- patients should have been seen in the department within the past year;
- patients should have been diagnosed more than one year but less than three years previously.

The hospitals were asked to compile a list of patients who met these criteria (number n). They selected every n/15th patient on the list. For example, if they had 30 patients who fulfilled the criteria they selected every 30/15 or every second patient. This would then produce fifteen potential participants for the study from each hospital.

The patient was contacted by the hospital and asked to participate. When consent was given, their names were passed to the researcher. An invitation letter and consent form were sent to the participants at this stage. During preliminary enquiries some patients requested that a close family member accompany them to the focus group. At this stage all patients were invited to bring a family member if they wished.

Focus groups

Six patient and carer focus groups took place with between three and eight participants in each. In total 22 people with cancer and 11 relatives took part in the study. There were 17 women in the study, 11 with cancer and six relatives, and 16 men, six with cancer and 10 relatives. People with cancer from each group attended a variety of hospitals. In all, 33 patients and relatives and 33 professionals took part in the study.

Composition of the groups

Two groups took place in the grounds of two hospitals and had patients from those hospitals only. This was because of geographical access. There was one group of 'Let's Face It' members only. The other three groups had mixed members – from different hospitals and support groups. Even participants recruited from the same hospital often had had treatment at a variety of hospitals. The different composition did not affect the group dynamics, openness of the discussion or content of the results. All patient/relative focus groups took place at a neutral venue (the King's Fund) apart from the two at the hospital sites.

Group dynamics

The focus group method allowed interaction between participants. It provided participants with opportunities to discuss and to explore issues in their own minds and to come to conclusions which may not have been arrived at in individual interviews. Hearing other people's experiences of care allowed participants to be more complete in reporting their own care. People who had initially said that everything was wonderful and the care couldn't have been better were later on in the discussion recounting incidents where the care had not been as good.

A great deal of empathy and support developed between participants in the patient/relative groups, and many said that they found it beneficial to talk about their experiences and listen to others. The researcher was aware of the sensitive nature of the subject, and contacts for support groups were available if required.

The professional focus groups

A request was made to each hospital department to assemble a multidisciplinary team to include as wide a variety of people as possible who were involved in the care of people with head and neck cancer. In some cases, it involved the team who attended joint clinics, in other cases, primary and palliative care professionals were involved. Four focus groups took place with between four and eleven participants. They included maxillofacial and ENT surgeons, medical and clinical oncologists, and ward, outpatient, district, hospice and Macmillan nurses. There were several speech therapists and social workers as well as a physiotherapist, pharmacist, operations manager and prosthodontist. The focus groups took place at the hospital where the group usually met. The hierarchy in the team affected the interaction in some groups, as the consultants tended to be most vocal and nurses least vocal. The possibility of getting groups of like professionals together at a particular venue was investigated but was not feasible. This might have overcome the hierarchy issue but may have produced problems of point-scoring and may not have brought out the issues of teamwork which emerged.

Data

All focus groups were audio-recorded and transcribed in full. The content of the data was then analysed for themes and key issues and for consistency. A map of each focus group was built up and analysed for interrelationships between the different aspects of the findings. The findings of the patient/relative and professional groups were related. The findings were grouped into three main sections and key issues identified. Literature on the key issues was reviewed, and the findings presented in the light of these.

Representativeness of sample

Although many patients were treated in other departments, patients in this study are more representative of head and neck cancer as treated in a maxillofacial department than in other disciplines. Issues such as speech may have been more prominent in patients from an ENT department but many of the issues will be common.

Over three quarters of the patients who agreed to participate in the study did so. The others did not attend due to ongoing treatment or illness. The people with cancer in this study were, by definition, survivors, with the exception of one widow, and were well enough to travel and participate. The participants represented a range of patients with UAT cancer treated in these departments. They are less representative of advanced or terminal cancer. There were two people who were not of British origin in the study, but the study could not explore ethnic minority views. A separate study would be needed to find out if the experiences of the people in this study differed from other ethnic groups. There were more women represented in the study than would be expected, given the incidence of the condition. Perhaps men with cancer were more reluctant to participate, although the male relatives of the women with cancer were happy to participate.

The professionals in this group all participated in joint clinics, which is true of only half of the consultants treating UAT cancer in the UK. They may be more advanced in terms of teamwork and patient-focused care than some of their peers. The findings in the study cannot represent the experiences of all persons with cancer, their families and professionals in the UK, but explore a range of issues which are likely to be common elsewhere in the UK and beyond.

Professional focus group topic guide

1 **Introduction, thanks, aims of study, confidentiality ...**

2 If you could introduce yourself and say a little about your role with patients with head and neck cancer ...

3 **Tell me a bit about the group/joint clinic**
Why do you meet, who meets, how often, how does it help?

4 **What do you think is done well in head and neck cancer care?**
What do you feel confident in? Why? Do others share the same views?

5 **What things do you feel are done less well?**
Why? How does it make you feel? Do others share the same views?
How can it be changed?

6 **What do you think about the Calman changes?**
Why?

7 **Patients have mentioned about information and choice.**
How do you find giving information? What do you think about patient choice?
Explore with different professionals

8 **What would you change/safeguard?**

9 **Any other comments**
Anything left out that people want to say

10 **Thank you**

Patient/relative focus group topic guide

1 **Introduction, thanks, purpose, confidentiality ...**

2 **Introductions,** name and a little about yourself

3 **First told**
Remembering back to when you first found out that you had cancer:
Who told you? What helped/didn't help?
Did you have partner there?
How do you feel the staff treated you?
How did you feel about it?
Was that experience common to other people? Broaden it out to others

4 **Information**
Were you given enough information?
The right information?
Communication between professionals ...

5 **Treatment decisions**
Do you feel that you have much control over your treatment and care?
Are you consulted or involved? Would you like to be more involved? Why/why not?

6 **Support services, going home**
What about support services – did you have any support services/did they help, how?
Support from GP, dentist
Support from district nurses, Macmillan nurse, etc.

7 **What impact has the oral cancer and treatment had on your life?**
How has it changed you – physically, social life, eating, dry mouth, etc.?
Treatment – travelling to hospital etc.

8 **Calman changes**
Fewer centres treating their cancer but doing more of them. What do people think?

9 **What would you change/safeguard?**
If there was one thing you could change (apart from having cancer), what would it be?
If there was one thing you would not want to change, what would it be?

10 **Any other comments**
Anything left out that people want to say

11 **Thank you**

Appendix 2

Useful contacts

BACUP
3 Bath Place
Rivington St
London EC2A 3JR

Cancer information service — Freeline 0800 181199
Cancer counselling service — London 0171 696 9000
Glasgow 0141 553 1553

Let's Face It
Christine Piff
10 Wood End
Crowthorne
Berkshire RG45 6DQ
01344 774405

National Association of Laryngectomy Clubs
Ground Floor
6 Richett street
Fulham
London SW6 1RU
0171 381 9993

Changing Faces
1/2 Junction Mews
Paddington
London W2 1PN
0171 706 4232

CancerLink
17 Britannia Street
London WC1X 9JN
0171 833 2451

Head and neck cancers present unique challenges to patients, their families and the professionals who manage these conditions. These cancers and their treatment can result in multiple disability and have a greater impact on patients and families than other cancers.

This new report from the King's Fund explores the views of patients, their families and health professionals about NHS services and their experiences of them. It highlights many examples of good and bad practice and makes recommendations for change.

Cancer services are going through a period of change. There is increasing emphasis on patient views, choices of treatment and ensuring consistency of services. In an area of care where little research has been carried out, this report will be particularly valuable to patients, families, clinicians, trust managers, purchasers and researchers.

Promoting Patient Choice

The publications in the Promoting Patient Choice series are part of a continuing programme of work within the Clinical Change Programme at the King's Fund Development Centre.
For the past five years, the programme has been promoting concepts and materials which help patients and the wider public to become involved in their own treatment and health care decisions. Government initiatives such as *The Patient's Charter* and *Local Voices* have created major changes in patients' rights and responsibilities and have sought to involve the public in decision-making on a wider scale. The Promoting Patient Choice programme has supported a number of projects, including the use of interactive videos for shared clinical decision-making and a survey of consumer health information services.
Each book in the Promoting Patient Choice series tackles a specific set of issues and is intended to help change and develop professional and public attitudes towards patients' involvement in health care.

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