



THE HEALING FOUNDATION

Rebuilding the bodies, minds and lives of people with disfigurements

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making patients' views count

○ Information for People Living with Conditions that Affect their Appearance

REPORT I

THE VIEWS AND EXPERIENCES OF PATIENTS AND
THE HEALTH PROFESSIONALS INVOLVED IN
THEIR CARE – A QUALITATIVE STUDY

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Picker Institute Europe

The Picker Institute works with patients, professionals and policy makers to promote understanding of the patient's perspective at all levels of healthcare policy and practice. We undertake a unique combination of research, development and policy activities which together work to make patients' views count. There are three key strands to our work:

- Measurement - researching and evaluating patients' experience
- Improvement - leading initiatives that make improvements happen
- Policy - building evidence to inform health policy.

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1 Executive Summary

Introduction

- In September 2003, the Picker Institute began a three year research programme to investigate the information needs of patients with conditions that affect appearance, that is, they cause disfigurement and/or visible loss of function.
- This report describes the findings of a qualitative study and review of previous research.
- The study involved interviews with patients, health professionals and representatives of the voluntary sector. Thirteen focus groups and ten one-to-one interviews were conducted.
- The research has provided an insight into the information needs of this group of patients and the complexities of the information exchange between patients and clinicians.

General and specific information needs

- The literature provides evidence of the wide range of information needs common to all types of patients. These include information about diagnosis, condition, treatment options, side effects, self-care and coping skills.
- In addition, patients in our focus groups wanted information related to their specific condition, for example, genetic information for the parents of children affected by congenital disorders, the latest developments in prosthetics for amputees and scar care for patients with burn injuries.
- The long-term nature of most of the conditions discussed meant that several patients talked about information needs changing over time.

Information needs related to appearance

- Many focus group participants expressed a need for realistic indications of how they were going to look following surgery or as scars healed.
- There was a general recognition that the media attention given to cosmetic surgery can lead to expectations that could never be satisfied.
- Burns patients particularly mentioned the importance of before and after photographs to help them visualise how their scars might heal in the future.

Information to support psychological readjustment

- Patients and carers in all focus groups spoke about the psychological and emotional impact of their own or their child's disfigurement. Parents had to cope with feelings of guilt and anxiety, whilst many trauma victims expressed anger and frustration.
 - The literature on the psychological consequences of altered appearance considers the dangers of social isolation and there has been some evaluation of strategies for dealing with staring, teasing and bullying in everyday life.
-

Meeting information needs

- Health professionals gave many examples of the information they provide to these patient groups.
- The literature and the focus groups provided evidence of several new initiatives in information provision such as bio-modelling and scar simulators.
- However, although some patients were very happy with the information they had received from their health professionals many more had experienced shortcomings, particularly in relation to their psychosocial needs and the more unpleasant consequences of surgery.
- The literature suggests that patients require more details about their condition and treatment options than they are usually offered.

The process of information giving

- It emerged from the focus group discussions and the literature that how and when information is given to patients is as important as the content of that information.
- Patients still regard their consultants as the main source of information, but several focus group participants were unhappy with their communication skills.
- Recent years have seen the emergence of clinical nurse specialists. Many patients and parents interviewed found them an invaluable additional information source. They are generally more accessible, have more time and see themselves as better communicators than doctors.

The production of NHS information materials

- The proliferation of both national and individual hospital guidelines for the production of patient information demonstrates the increasing importance being given to this aspect of healthcare at a policy level.
- However, despite the best intentions of many health professionals in the focus groups, they accepted that the actual quality of patient information varied greatly.
- Although a few were proud of the work they were doing in this area, more professionals felt that problems of time and resources prevented them from doing as much as they would like to do.

The role of the voluntary sector

- Both patients and health professionals used information produced by charities and patient organisations. In most cases this was to supplement information provided by the NHS, but in a few instances it seemed that it was used to plug a gap, particularly regarding psycho-social concerns.
- Patients and parents generally spoke very positively about the support they received from these organisations, but a few expressed reservations about the quality and appropriateness of some of their information material.

The internet

- The internet is now a major source of health information and the vast majority of patients and parents in the focus groups had used it to search for information on their own or their child's condition at some point.
- Professionals also recognised the power of the internet, albeit reluctantly in some cases.
- Concerns were expressed about the reliability of the information found there, but generally patients felt able to judge trustworthiness for themselves.

The media

- Concerns were also expressed about the reliability of the media as a source of health information. Both patients and professionals were aware that sensationalism and misinformation could lead to unrealistic expectations.
- On the other hand, several television documentaries have been broadcast on the subject of disfigurement during the course of this research and many patients thought that when sensitively produced, such programmes can increase social awareness and promote public understanding.

Peer support

- Contact with others in a similar situation to themselves was highly valued by virtually all the patients in the focus groups. They felt that the information exchanged in this way was qualitatively different from that provided by clinicians and this appears to be confirmed in the literature.
- Peer support is usually organised through the voluntary sector, but some health professionals described ways in which they facilitate contact within the healthcare setting.
- There were a few patients who preferred to cope on their own and found support groups patronising.

Information seeking behaviour

- The literature suggests a growing trend towards better informed patients who expect a greater role in decision-making about their own health care. This was reflected in the focus groups, although it should be remembered that the patients who took part probably represent the more actively engaged.
- There were instances when participants thought too much information at the wrong time might actually increase rather than allay anxiety and a few patients deliberately chose not to look for information.
- Some professionals appreciated the skill involved in judging how much to offer and when.

2 Introduction

2.1 Research aims

In September 2003, the Picker Institute began a three year research programme to investigate the information needs of patients with conditions that affect appearance, that is, they cause disfigurement and/or visible loss of function. The aims of the study were to:

- assess the need for information
- provide an overview of what is currently provided
- highlight gaps and weaknesses
- make recommendations for the improvement of the information available.

The investigation was in three parts:

1. An in-depth qualitative study of patients' information needs, preferences and experiences (Report I)
2. A review and assessment of existing information materials (Report II)
3. A questionnaire survey providing a wider assessment of the information needs of people with disfiguring conditions (Report III).

The three parts of the research are reported separately, together with a short Summary Report of the whole project (Report IV), drawing out key conclusions and presenting recommendations.

This report describes the findings of the qualitative study and the review of previous research. The study reported here involved interviews with patients, health professionals and representatives of the voluntary sector. Thirteen focus groups and ten one-to-one interviews were conducted. The research has provided an insight into the information needs of this group of patients and the complexities of the information exchange between patients and clinicians.

2.2 Background and objectives

There are an estimated 400,000 people in the UK with a disfiguring condition that seriously affects their quality of life (Office of Population 1988). The reasons for disfigurement range from congenital disorders to accidents and disease. One million people a year seek treatment for facial injuries caused by accidents, falls or assaults. Mouth cancer is the sixth most common cancer with nearly 2,000 new cases per year. About 2,000 babies are born each year with severe defects such as cleft lip and palate or conditions associated with craniosynostosis (Facial Surgery Research Foundation 2004). Although visible disfigurements like these may cause the most serious psychological and social distress, patients with any form of disfiguring condition and accompanying loss of

function, will need a range of resources to make successful adjustments to their altered body image and thereby enhance their recovery.

Information is a key resource. Whatever their condition, patients, their carers and families need reliable, high quality and accessible information at every stage of their journey from initial concern through diagnosis and treatment to rehabilitation. Patients with disfiguring conditions can theoretically look to a number of sources for information. They are treated by a multitude of health professionals including maxillo-facial, plastic and orthopaedic surgeons, dermatologists, oncologists, psychologists, occupational and speech therapists. Numerous support groups and charitable organisations exist to assist patients and raise awareness, for example, Changing Faces, CLAPA (Cleft Lip and Palate Association), Headlines, RAFT (Restoration of Appearance and Function Trust), the Psoriasis Association, the British Red Cross and BACUP (the British Association of Cancer United Patients). Private companies offer information and advice on prosthetics and skin camouflage products.

However, research suggests that many patients find access to information difficult and feel that they miss out on what they need. Leeds Teaching Hospitals carried out a study of the needs of its oral and maxillofacial cancer patients (Feber 1997). They found that patients were often unable to take in much information when they had just been given a diagnosis of cancer; there was no opportunity for patients to be given information between the initial outpatient visit and admission for surgery; and there was no local self-help group to refer patients to. In another small study, families attending a special scald injury clinic at Newcastle Royal Victoria were interviewed and asked to complete a questionnaire. Although 27 of the 28 families felt they had been adequately prepared for discharge, none knew about a return to school programme, only two knew about support groups and none knew about the burned children's camp (McKenzie et al 2005). A recent audit of treatments for atopic eczema in secondary care in Sheffield showed that on a first visit less than 5% of patients had received any explanation of the causes of eczema or any demonstration of how to apply treatments (Ransome and Ward 2000). Any assessment of information needs should consider not only content, but also how and when information is provided. Disfigurement can affect people of all ages and information needs will vary accordingly. Information needs also change and fluctuate over time. Disfigurement and loss of function may impair the way information is received. Information should therefore be available in a variety of mediums and make the most of new technology.

There is another dimension to the information needs of patients with disfiguring conditions. The way we and others see us is central to our notion of self. If that self-image is threatened by disfigurement, patients often experience a considerable degree of psychological distress. Society places great emphasis on appearance and therefore anyone with an unusual appearance can be subjected to teasing, stares, hurtful comments and discrimination. Various studies have considered the way psychosocial factors can influence patients' capacity to cope with their condition (Burr and Gradwell 1996; Newell 2002; Thompson and Kent 2001). Anxiety, depression and avoidance tactics are all common and can adversely affect health outcomes. Some patients complain of negative judgements when in contact with health professionals which inhibits their requests for information, particularly for psycho-social support (Garlick 2000).

The Bristol Royal Infirmary Inquiry was set up to inquire into the management of the care of children receiving complex cardiac surgical services at the hospital. The report made

several important recommendations regarding the provision of information for patients (Kennedy 2001). Information should be available in a variety of forms, tailored to the individual and based on current available evidence. Furthermore, the public should be helped to find reliable sources of information on the internet. In 2004 the Department of Health launched a programme of action to improve access to health information for everyone (Department of Health 2004). However, the extent to which these recommendations and initiatives will impact upon patients with disfiguring conditions and the health professionals who care for them, remains uncertain.

In September 2003 The Healing Foundation awarded the Picker Institute a three year research contract to investigate the information needs of patients with disfiguring conditions and their families, and assess how they are being met by the NHS, the voluntary sector and other means. The study has two main aspects: (1) the evaluation of existing information materials and information giving practices and (2) the development and application of an information needs questionnaire for patients with conditions that affect their appearance. The development of the questionnaire will be based upon the findings from a search of the relevant literature published within the last ten years and from a series of consultations with patients, health professionals and representatives of the voluntary sector. In addition to informing the development of a survey instrument, the focus groups and interviews conducted in this consultative stage have enabled the exploration of more complex themes and issues around patient information. It is in recognition of these complexities that we present this report of our qualitative research.

3 Methods of Investigation

3.1 Focus groups: Recruitment

Thirteen focus groups and ten one to one interviews were conducted in England and Scotland between August 2004 and September 2005. In consultation with The Healing Foundation, the following patient groups were selected as representative of the various types of disfiguring conditions:

- Congenital disorders: cleft lip and palate; craniofacial conditions
- Accident: burns; amputees
- Disease: head and neck cancer; cancer of the eye; amputees
- Skin conditions: vitiligo.

Patients and carers were recruited to focus groups and interviews via leading charities in the field with the exception of three interviewees who were recruited with the help of the producer of a television documentary. In addition to the structured focus group discussions, one researcher observed a group session at a family weekend organised by a burned children's camp charity. Although not tape recorded, hand-written notes were taken during the discussion and provide additional qualitative evidence to this report. One focus group was conducted with representatives from five voluntary organisations that support patients and carers.

Six specialist centres are collaborating with this study. Each centre has been chosen in consultation with The Healing Foundation based on their expertise in the clinical areas where disfiguring conditions are treated. The six centres are:

- Oxford Radcliffe Hospitals NHS Trust: head and neck cancer
- Mid Yorkshire Hospitals NHS Trust: Pinderfields Burns Centre
- St John's Institute of Dermatology, London: skin conditions
- Great Ormond Street Hospital for Children NHS Trust, London: craniofacial and cleft lip and palate
- South Manchester University Hospitals NHS Trust: Wythenshawe Hospital Burns Centre: burns
- Moorfields Eye Hospital, London: cancer of the eye.

Health professionals were recruited to focus groups via the collaborating specialist centres and professional associations.

3.2 Characteristics of participants

There were 36 patient and carer participants, 34 health professionals and five voluntary sector representatives. The characteristics of each group are set out in Tables 1, 2 and 3.

Table 1: Patient/carer participants

Patient group	No. of participants in group	One on one interviews	Age range	Location
Amputees	6 (4 male, 2 female)	0	27-58	Glasgow
Vitiligo	5 (1 male, 4 female)	1 (male)	29-58	London
Head & neck cancer	6 (1 male, 5 female)	1 (female)	63-83	London & Oxford
Burn injury	6 (2 male, 4 female)	0	34-50	Manchester
Craniofacial patients/parents	0	6 (1 male, 5 female)	21-57	Glasgow, Kent, Birmingham, Middlesex
Eyes	0	2 (female)	70 + 72	London
Cleft lip & palate patients/parents	3 (female)	0	43-45	Birmingham

Table 2: Professional participants

Clinical area	No. of participants in group	Professional group	Location
Dermatology	4 (female)	Nurse specialists	London
Head & neck cancer	2 (female)	Nurse specialists	Oxford
Plastic surgery	4 (female)	Nurses	Nottingham
Plastic surgery	8 (6 male, 2 female)	Consultants and registrars	Oxford
Burn care	5 (female)	Physiotherapists, OTs, maxillo-facial technician	Wakefield
Burn care	6 (1 male, 5 female)	Nurses, dietician	Birmingham
Craniofacial	5 (female)	Play specialist, nurses, psychologist, speech & language therapist	London

Table 3: Voluntary sector participants

Clinical area	No. of participants in group	Professional group	Location
Dermatology (2); cleft lip & palate; burns; generic	5 (1 male, 4 female)	Chief Executive; Information worker; Volunteer Development Co-ordinator; Volunteer; Head of Client Services	Oxford

3.3 Procedure for focus groups

Two female researchers with experience of running focus groups moderated the groups. The discussions and one to one interviews were recorded on audio-tape and transcribed verbatim. The groups were structured around the focus group topic guides (Appendix 1, 2 & 3).

Patient/carer participants were asked to discuss the following topics:

- Obtaining a diagnosis for their condition
- Information on treatment options and prognosis

- Information on self-care
- Information sources and information seeking behaviour
- Gaps in information
- Suggestions for the improvement of information provision

Health professionals were asked to discuss the following topics:

- The production of information materials
- Information given to patients
- Role of information providers
- Gaps and shortcomings in information provision
- Suggestions for the improvement of information provision

Voluntary sector participants were asked to discuss the following topics:

- The production of information materials
- Funding for information production
- Information given to patients
- The relationship between the voluntary sector and the NHS
- Gaps and shortcomings in information provision
- Suggestions for the improvement of information provision

Participants were invited to evaluate a range of information materials relevant to disfiguring conditions. The findings from this evaluation process are available in Report II.

3.4 Analysis

The findings have been analysed using the “framework approach” (Ritchie and Spencer 1994) which allows for the use of pre-set categories as well as the development of categories and themes from the data.

4 Findings

4.1 Information needs and how they are met

Previous research on patient information reveals the wide range of information needs common to all types of patients. In a King's Fund study into the quality of the information materials available, Coulter and colleagues found that patients need information for a variety of reasons (Coulter et al 1998). They need information to:

- understand what is wrong
- gain a realistic idea of prognosis
- make the most of consultations
- understand the processes and likely outcomes of tests and treatments
- assist in self-care
- learn about available services and sources of help
- provide reassurance and help to cope
- help others understand
- legitimise help-seeking and concerns
- identify further information and self-help groups
- identify the "best" health care providers.

In addition to these general concerns, different patient groups will also seek information that reflects the particular problems associated with their condition. The literature relating to people with disfigurement focuses primarily on the psychological aspects of altered appearance. However, in an article on the development of the Changing Faces information service, Clarke describes the results of a retrospective study of the information requests of adults and family members who had contacted the charity over a five year period (Clarke 2001). She divides the requests into two main categories: factual (e.g. diagnosis, prognosis, scarring, treatment options) and advice about support and coping (e.g. staring and teasing, bullying at school).

The information needs of cancer patients have been analysed more than any other patient group and within that research, some of the studies have looked specifically at the information needs of patients with head and neck cancer. A focus group study in the South West of England, found that virtually all of their study participants wanted information sheets in outpatient clinics and on hospital wards about support groups, treatment issues and specific problems in head and neck cancer (Birchall et al 2002). Other suggestions included information on complementary medicine and "good news" stories about patients. There was general agreement that better information about radiotherapy should be provided. Another focus group study with ten head and neck cancer patients in Leeds found that although the majority expressed satisfaction with the information they received, they wanted more information on a range of things including: radiotherapy side effects, alternative treatments, research, financial help, the healing process after brachytherapy, eating problems, the recovery process and fatigue (Feber

2003). The National Cancer Alliance canvassed the views of head and neck cancer patients in a discussion group of ten (National Cancer Alliance 2002). Although based on only a small sample, the results provide a very detailed description of the variety of information needs such patients express. They also indicate that some health professionals may underestimate the full impact of the disease in order to protect patients. This leads to further anxiety when patients experience more severe or longer lasting problems. Ziegler and colleagues carried out the first comprehensive review of research to explore head and neck cancer patients' experiences of surgery, their information needs and their views on decision-making (Ziegler et al 2004). They found that the psycho-social and functional problems faced by these patients were not reflected in the type of information given to patients before surgery.

Diagnosis

The patients in our focus groups expressed both the general information needs shared by all patients and others related to their specific conditions. It also became apparent that the needs changed over time as the patient moved through the treatment process to rehabilitation and self-care. Trauma patients talked of their need for basic survival information on initial admission to hospital.

If you have a large injury at the time of your primary treatment, you're not really in a position to ask questions....it's going to be doing what's necessary to keep you alive and sort of preserve your limbs.

Burns patient

Accurate diagnosis is crucial for all patients accompanied by information about the nature of the condition and its consequences. However, in the case of the head and neck cancer patients, diagnosis was not always straightforward and as one patient pointed out, while the doctors are still unsure, they have to be very careful in the way they present the information. Another patient accepted that it was difficult for them to tell her how severe her disfigurement would be until they had ascertained how far the cancer had spread.

At one point you started off with tonsillitis and then you think you might have an infected lymph node.....and then you suddenly find out you've got a malignant tumour.....and obviously you have to be careful about what information you give at each of those stages.

Head and neck cancer patient

Some of the focus group participants expressed a desire for very basic information about their condition which they felt should be provided automatically without them having to ask for it. This was particularly true of the vitiligo patients several of whom thought that health professionals often trivialised their condition leaving patients to search for information themselves.

She [GP] said, "It's not on your face, it doesn't matter so go away."

Vitiligo patient

This lack of support for skin diseases was confirmed by evidence from the literature search which revealed that dermatology patients can wait up to six months for an outpatient appointment and during this time have to manage their condition on their own, often lacking the information to do so (Gradwell et al 2002).

In evaluating the care at the Nottingham Cleft Lip and Palate Unit, Martin found that parents whose child had been diagnosed pre-natally were unsure of what a cleft lip looked like (Martin 2005). Although they were given reassurance, they received no real information and were concerned that their child might have other problems. The parent of a child born with craniosynostosis interviewed for this study was very angry about the way she found out about her son's condition.

I mean to find out about craniosynostosis on a website without being told by a doctor and just reading that on his discharge leaflet, I don't think that's right.

Craniofacial parent

Treatment

The parents of children with craniofacial conditions and cleft lip and palate need information to enable them to make decisions about surgery to improve function, and also sometimes for purely cosmetic reasons. This is particularly onerous when the decisions are made on behalf of someone else.

So we thought if they don't fix his head, he's going to get bullied at school.

Craniofacial parent

These parents also wanted to know about the long-term developmental implications of their child's condition.

I can remember thinking I wonder if he'll be able to sing, silly things like that.

Cleft parent

As children with congenital disorders grow up, they have to make decisions for themselves and one young woman expressed her own information needs.

Questions about the anaesthetic, what I'll look like after surgery....pain....how long will I be under?

Craniofacial patient

The health professionals interviewed felt that they provided a great deal of information to patients about treatment options and surgical procedures, and listed many of the topics covered in their different clinical areas.

We have a series of information leaflets that we can give to them about tissue expansion, artificial skin, reconstruction, steroid injection.

Burns professional

Pain relief, reflux, how to manage dry mouth, post radiotherapy stoma care ...managing symptoms and what they can expect from a particular surgery.

Head and neck cancer professional

There were cases when patients had received good information about their surgery and treatment. One head and neck cancer patient spoke of the detailed nature of the

information she was given about her surgery and another described the information she received from the radiotherapy department as “fantastic”.

However, evidence from both the literature search and the focus groups demonstrates there is little room for complacency. A postal survey of all UK ENT consultants sought to identify current information-giving practices prior to laryngectomy (Stafford et al 2001). Of the 254 surgeons who responded, 79% thought that patients should routinely have a second consultation before starting treatment, but only 64% provided one. When seeing patients before surgery, 40% failed to discuss routinely the cure and survival rates for the different treatments available. Stafford and colleagues concluded that “surgeons continue to feel that they know what is best for the patient.” Many clinicians in this study felt that it would be unprofessional not to provide good information.

The process of consent effectively starts.....in the clinic. You're not being professional putting a patient on an operating list for an operation without explaining to them what it involves, what they're going to go through, what they can expect and what the potential risks and complications are.

Plastics professional

However, a focus group participant who had undergone surgery for eye cancer, was not given the most fundamental information about the nature of her surgery until she was going into the operating theatre

“S, I don't think you understand about your operation.” She says, “What they will be doing is, they will be taking.... your lower eyelid as much as they need, plus some of your top eyelid.” So that's the next trauma that I've had to live with because I wasn't expecting that.

Eye patient

Researchers at the Queen Victoria Hospital in East Grinstead sent out questionnaires to the parents of 478 children in the care of the regional cleft team (Jeffery and Boorman 2001). Although there was a high level of satisfaction with the care received, 33% thought they had insufficient or no knowledge about cleft lip and palate and its treatment. Several parents in the focus groups had experienced occasions when surgical information was inadequate.

We didn't know how it was going to affect his life, whether he'd need more operations because they don't tell you that.

Craniofacial parent

An older focus group participant who had been born with a cleft lip and palate felt that quite naturally most of the information was geared to children. However, this meant that older people, who might be unhappy with the care they received in the past, were left largely unsupported.

I do think there is a big gap for those people who have grown up with the stigma of the condition that they and their families happened to know very little about.

Cleft patient

Side effects of treatment

The literature and the focus group research suggest that health professionals tend to underplay the unpleasant side effects of treatment and surgery. A Canadian study which looked at the information needs of patients who had undergone head and neck surgery found that most patients who had difficulties in speaking, swallowing and breathing as well as altered appearance, had not received information about these problems before surgery (Glavassevich et al 1995). One focus group patient had a similar experience:

Well will I be able to eat?and he just said "Yes you'll be able to eat" and I was happy in that knowledge but the actual reality of it was that I couldn't, so re-learning, you have to re-learn eating and drinking.

Head and neck cancer patient

There may be good reasons for not wanting to alarm patients unnecessarily if outcomes are uncertain, but for those who do suffer pain they were not expecting, the lack of advance information can be a cause of resentment.

"This pain I'm left with" and he said, "Sometimes it happens, you know." I said, "Well you should have warned me about it."

Eye patient

In many cases it seems that doctors simply do not know the reasons for the pain that patients are left with following surgery or are unable to do anything about it. The problems faced by clinical staff when deciding how much to tell patients are highlighted by one interviewee who commented about the amount of detail given to her before surgery, but is still left with unexpected discomfort.

It was pointed out in horrific detail before I signed the consent form all of the side effects....and I have been very lucky that I have got away without that happening....but I have had nearly a year of painand I didn't expect that.

Head and neck cancer patient

Managing expectations

Information is essential if patients are to form realistic expectations of what the future will hold. In coping with a condition that will affect their own or their child's appearance, focus group participants wanted realistic indications of how they or their children were going to look.

When they are first born, that is the main worry...what are they going to look like and if somebody came along and explained that to you, to be honest that's probably what you'd be more interested in than anything else.

Cleft parent

Several people talked about the dangers of forming unrealistic expectations of reconstructive surgery and amputees knew they could not all look like Heather Mills. But the widespread confusion between reconstructive and cosmetic surgery can fuel such expectations further. As a recent report on cosmetic surgery pointed out, cosmetic procedures are widely advertised and promoted in ways that would be unacceptable for other surgical interventions (Expert group on the regulation of cosmetic surgery 2005).

This is perhaps what lay behind one patient's view that his injuries could be easily addressed.

When I came into this situation, I was told plastic surgery and you automatically think they can wipe it clean, but they can't.

Burns patient

Conversely, the parent of a badly burned child had limited expectations of the reconstructive process and was surprised when more could be achieved.

The consultant looked at [child's] hand and said, "I'm not happy with that." I didn't know that.

Burns parent

Although it is not always possible to provide the answers patients and their carers want, the health professionals did acknowledge that it was part of their job to manage these expectations by providing good information and ensuring that it has been understood.

A lot of them do have unrealistic expectations and particularly in burns, what I've found is a lot of patients aren't aware that their skin is going to be scarred for life.....they've either been told early on when it's perhaps too early and they're too much in shock to really take it on board or it hasn't been really explained to them quite enough.

Burns professional

Prompted both by a desire to provide better information, but also in some cases to avoid litigation when cosmetic results fail to satisfy, various studies have considered the value of visual information in helping patients gain a better understanding of how they or their children will look after surgery. A prospective trial to assess the utility of bio-modelling in craniofacial surgery found that bio-models were invaluable in illustrating probable outcome to the parents of 40 children with complex abnormalities (D-Urso et al 1998). In our focus groups, parents and professionals expressed an interest in technology that would help patients visualise the probable outcomes of surgery and hence enable them to make decisions about further treatment.

There's some technology.....that can give you an idea of how that person would have looked from nothing....they would be able to give you an idea of an image of how she would look....because you could then make an informed judgement on whether this was worth doing.

Craniofacial parent

What children actually want is to stick an image on the computer and change it and say this is how you will beyou can do it for plastic surgery, you can do it for soft tissue and in private practice, apparently it's done all the time.

Craniofacial professional

In a study involving patients attending the plastic surgery department at Pinderfields Hospital, the value of a scar simulator was tested using a questionnaire (Beale et al 2002). Understanding of scar appearance prior to seeing the simulator varied considerably but afterwards, 73-90% reported an improved understanding of how their scar was likely to look at different stages of the recovery process.

Prosthetics

The National Amputee Statistical Database recorded that 5,443 amputees were referred to the prosthetic centres in the UK in 1999-2000. Of these, just 4.7% were upper limb amputees. The participants in our focus group were a mixture of upper and lower limb amputees and the reasons for their amputations included trauma, bone cancer and congenital conditions. In a continuing education article for Nursing Standard, Gibson argues that patient information is an essential part of pre-operative nursing care for people about to undergo an amputation (Gibson 2001). It is the nurse's responsibility to assess the understanding of the condition, the proposed surgery and the rehabilitation plan. She believes that although educational materials are useful, they should only ever be a supplement to talking through concerns and anxieties with the patient. But one focus group participant was not happy with the information provided by health professionals:

It was never explained that this was not my final leg. I thought this was it, this stupid blow-up thing.

Amputee

The literature research revealed the wide range of needs reported by people with amputations and prostheses: gait re-education, donning and doffing techniques, functional activities, prosthesis use, the management of the interface between socket and residual limb, reduction of skin irritations and care of the remaining limb (Larner et al 2003; Legro et al 1999). A wide cross section of the focus group patients talked about issues relating to prostheses: amputees, cancer sufferers and the parent of a burn survivor. All these patients wanted to know not only the different types of prostheses available, and how to use them correctly, but also where they could obtain the best prosthetic service. One head and neck cancer patient thought there were only five people in the country capable of making a good facial prosthesis. There was general frustration amongst the amputees about the lack of information about new developments in prosthetics.

You are never really told about developments. You might be given this limb that suits you fine it is comfortable it is functional, but if something evolves that could potentially give you a better of quality of life I think you should be told about that.

Amputee

Patients in the head and neck cancer and amputee focus groups felt that a guide to prostheses along the lines of the Consumers' Association's Which reports would provide much needed information on where to find good quality prosthetic care. One young man who had been referred to Let's Face It having had surgery to his lower jaw, wanted to know if he could get a prosthetic beard and discovered it would only be available through a theatrical company.

I think we need a Which Guide! Which Limb! Just I suppose on the different components whether that is sockets, feet or whatever, knees whatever just to give you some kind of run down. Maybe the experiences of people who have used them and what it is actually like for them rather than what is on offer.

Amputee

Legro et al felt that more patient information about what can be expected would help people to feel it is acceptable to complain when something is wrong. This was reflected in a comment by one focus group participant.

I wasn't aware that it [obdurator] could be adjusted, so it was pinching everywhere and hurting everywhere and I thought I can't face all this continual pain because I didn't realise it could be adjusted.

Head & neck cancer patient

For two patients it was very important to be able to choose whether they wore a prosthetic or not. An amputee felt very strongly that he should not have been made to feel that wearing an artificial limb was a necessary part of his rehabilitation. For him, it became like "a vast ball and chain around my life." Similarly, a patient who had suffered cancer of the eye found that her prosthetic eye was heavy and uncomfortable and she prefers to express her own individuality by wearing eye patches that she has designed herself.

Self-care and rehabilitation

Several patients described the difficulties of leaving the safe environment of the hospital. For many, this was the first time they really became aware of their need for information to help them adjust to their condition. Patients who had experienced a loss of function, wanted information about the rehabilitation process and the likely impact on their quality of life, but this had not always been available.

Nobody really explained to me that the shit was going to hit the fan when you got home in real terms, you know nobody sat me down and said this is where you are going to need the support.

Amputee

The National Burn Care Review recognised the inadequate provision for burns rehabilitation post discharge from the acute hospital setting. It recommends the creation of a multidisciplinary and multi-specialty service offering treatment to a variety of trauma patients. The idea was supported by Collings in the AB Wallace Lecture to the British Burn Association who felt that with the help of staff at such a centre, patients could learn to become their own therapists (Collings 2004). Some studies have looked at other ways of educating burns patients and their parents about self-care. A randomized single-blind evaluation of a discharge teaching book for paediatric patients found that although the book improved knowledge about burn care, other factors, particularly ethnic background and language, had more influence (Jenkins et al 1996). Another study considered the effects of enhanced patient education on compliance with silicone gel sheeting and burn scar outcome (So et al 2003). The results demonstrated that detailed multi-media education improved compliance and resulted in a better scar outcome. In a follow-up of paediatric scalds at the Royal Victoria Infirmary in Newcastle, researchers found that all parents remembered being given information about scar care; 68% about scar massage, 78.5% about sun protection, 36% about silicone and 71% about pressure garments. The information was retained and parents were satisfied they could ask questions (Toland-Mitchell et al 2005).

Certainly a lack of information about care at home led to unnecessary anxiety for one patient in the burns focus group when the colour of her skin changed after washing and

parents sometimes felt a little guilty about bothering busy professionals with seemingly small problems. One burns nurse who had attended a support group meeting admitted that she was surprised by the number of issues parents raised post discharge.

The things that I got back from the parents then completely surprised me...you kind of close your eyes don't you, once they've left the ward.

Burns professional

The parents of small children with congenital disorders talked about the complex caring regime they are responsible for at home. They regarded information as essential in helping them to deal with a wide range of problems including breathing difficulties, toileting and feeding and certainly two focus group participants had found it inadequate. However, there were many patients in the focus groups who received useful information which enabled them to cope better after they had left hospital.

I think it's called Care of your Eye. It's aftercare anyway....but it does describe what it will look like, what your eye will look like to yourself after surgery and how to cope with it, how to clean it and eventually when you get an artificial eye what to do with that and then when to start using eye makeup if you want.....which was helpful.

Eye patient

New research

Patients with long term conditions often need to keep up to date with new treatments and surgical techniques that may benefit them. Several patients mentioned the importance of being given such information when it becomes available and one parent chose to remain at a particular specialist centre, even though it was a long way from home, because she felt that it was where any new pioneering work would be carried out. This same centre provides research material to parents and carers, but another mother interviewed felt that the internet was the only way to access such information:

So we've got to ourselves do a bit of research, but the only place you can do it I think is on the internet, we haven't been given any information about it.

Craniofacial parent

The relevance of new research was flagged up by one Burns patient. Contrary to what she had been told in the early stages of her recovery, she had recently learnt that not only would she be able to have children, she could also benefit from the hormonal changes in pregnancy.

I was told ...basically.... don't have any children.....Only in the last few years they have discovered that the hormone stretches skin regardless.....so in an ideal world straight after the birth, use the skin.... and get rid of all the scar tissue.

Burns patient

Parents of children with congenital conditions have a particular need for information on the latest developments in genetics. One young woman with Apert's Syndrome had done her own research on the internet about the chances of passing her condition on to her children.

Primary and non specialist care

Patients discharged from specialist centres often have to rely on health professionals in the community to provide continuing care. However, there were many complaints from patients in the focus groups about their lack of knowledge. Health visitors, district nurses and GPs were criticised for not being sufficiently informed to address the problems associated with particular conditions. Even the health professionals interviewed were concerned about the lack of knowledge amongst their non-specialist colleagues.

They've had input from other health professionals like their GP and their district nurses who don't specialise specifically in plastics, but have a little bit of knowledge and they give them information that may not be accurate.

Plastics professional

Vitiligo sufferers expressed particular dissatisfaction with the information available at primary care level where most initially seek treatment and at one craniofacial centre, they endeavoured to fill the knowledge gap in primary care by sending articles and information leaflets to the children's GPs.

At a family weekend organised by a burned children's camp, parents discussed the difficulties they had when they used local emergency services.

If [daughter] cuts herself badly, the GP or local A&E won't touch it because of her skin, so we have to go back to [burns centre]. Recently she broke her leg. The local A&E didn't realise that scarred tissue doesn't swell up and therefore didn't realise that her leg was broken.

Burns parent

They suggested that they could be provided with an information sheet which they could show to other clinical staff when necessary, for example, if their child needed medical attention while on holiday. A lack of professional knowledge also affected the parents of children born in general hospitals. In some cases, it seemed that they were better informed than the clinicians.

The midwives, they were terrible and the junior doctors because she was born in the middle of the night....they didn't have a clue what was wrong with her, they asked me whether I was on drugs.

Craniofacial parent

For example, breastfeeding, you would have some midwives who would say you can breastfeed...but as a mother I know that it is impossible.

Cleft parent

In a survey carried out prior to the reorganisation of cleft services the Cleft Lip and Palate Association found that hospital staff lacked knowledge and denied parents vital explanations to help them cope with the birth of their child (Cleft Lip and Palate Association 1996). Furthermore, this placed the burden of seeking out information on the parents themselves, which only added to the stress they were already experiencing. As a consequence, CLAPA embarked upon a programme to raise awareness of cleft lip and palate amongst health professionals, but owing to constraints on time and resources,

were not able to target all the health professional groups originally identified (Cleft Lip and Palate Association 1999).

The information needs of families and carers

The information needs of the parents of children with congenital disorders and burns have been discussed above, but there are other occasions when families and friends need information. In the extreme situation of a major trauma, it is often the families who require information, rather than the patient. In a study carried out in the US to identify family members' needs during the hospitalisation of patients with burns, researchers found that families have both physical and psychological concerns about the patient and in the case of paediatric patients, pain and skin graft worries have high priority. The findings emphasised the importance of communication and reassurance between the burn team and family members (Thompson et al 1999). This was also reflected in comments made in the Burns patients' focus group.

Your brain's not good at taking in information when you've just gone through such trauma, but if your family can take it in for you and support you through it.

Burns patient

Head and neck cancer nurses talked about visual information they provided which could be shown to family and friends to avoid the necessity of lengthy explanations. A head and neck cancer patient spoke of her mother's desperation to know everything about the condition and the ease with which relatives are forgotten when attention is focused on the person who is ill.

Information needs outside the health sphere

In investigating the information needs of disabled children, Beresford and Sloper found that they extend beyond medical information to knowing how to manage daily living (Beresford and Sloper 2000). Parents of children with congenital disorders emphasised the need for information about education and schooling.

Will he be able to go to school....can they be educated?

Craniofacial parent

Some centres have developed programmes to assist a return to school after hospitalisation or at important stages of the child's schooling.

We were talking in our team about the information we give to schools and particular transition points, sort of secondary transfer or starting primary school because sometimes because children look different, people underestimate their abilities.

Craniofacial professional

However, in a survey of teachers of children undergoing scar management programmes at the Welsh Centre for Burns, 85% of the 13 teachers who responded did not feel that they were provided with adequate information about a burn injury to enable them to support a child on return to school (Brown et al 2005).

For other patients in the focus groups, daily living means having access to very basic information about how to survive financially when work is not possible. Information

about benefits and allowances can often seem complex and confusing. One amputee felt that this was one of the biggest challenges for him.

Disability allowance - if you are going to qualify for that how do you go down and apply for that? But you get so much different information in terms of registering disabled.

Amputee

It may be that this sort of information is best provided by a multi-agency approach. One interviewee is actually helping other parents to access information on benefits and educational statementing by promoting an early support family pack produced by the Department for Education, SureStart and the Department of Health.

So in there, you've got all the information you need....about your benefits...education, who to write to, how to write to the people you need to write to, things that you're entitled to, extra help that you might need.

Craniofacial parent

Interestingly, it was this interviewee who chose not to search for medical information about her child's condition.

Gaps in information provision

The Manual of Cancer Service Standards states that patients must be provided with adequate verbal and written information about treatment and support services. To find out how these needs are being met by cancer professionals, The British Association of Head and Neck Oncology Nurses (BAHNON) Committee circulated a questionnaire to all its members in January 2004 in order to identify what information resources they provide to patients. Although there was only a 17% response rate, returns were received from 59 members working in 25 cancer networks. Of these, 88% offered written information to their patients. This included more nationally than locally produced material (80% to 50%). The perceived gaps in information provision included: tests and investigations, treatment options, care and recovery after treatment, appliance care, emotional and psychological support, support groups.

Most of the perceived inadequacies emerging from the focus group discussions concerned a failure to provide information rather than a general lack of information materials per se. However, there were some instances where gaps in resources were highlighted. One health professional mentioned the lack of specific information for the different types of head and neck cancer.

If you've got a head and neck patient, someone who's had a reconstruction of the nasal area, there is actually nothing specific to give them ...guidelines of where to go, camouflage, scar management or anything like that. It's always done on an adhoc basis.

Plastics professional

Dermatology nurses wanted to be able to offer a range of information that is not currently available in their hospital.

General skin care, but particularly because I am dealing with a lot of people with leg ulcers and weeping eczemathenhosiery and sort of the need for exercise and you need to have a balanced diet and balance between rest and exercise, what compression is, why they need it, what their options are and just a little bit mainly about the different products that they use as well.

Dermatology professional

For the parent of a child with craniosynostosis, one of the main difficulties had been the lack of information about feeding problems and a health professional working in the same area was concerned that they were not doing enough to inform young people with learning difficulties about their options.

Children with Apert's have a higher incidence of learning difficulties and helping adolescents to choose on top of learning difficulties, it's terribly hard and I think we could do it better.

Craniofacial professional

Although not highlighted in the focus group discussion, the information sheet which provoked most interest in the evaluation exercise, concerned phantom pain. There are several illustrations in the literature of shortcomings in the information provided to amputees about phantom pain. Parallel focus group studies with patients and health professionals working in amputation care in Scotland found that there was strong desire for information amongst patients: the variability and type of pain, the likely duration, the causes and treatment options. (Mortimer et al 2002; Mortimer et al 2004) However, few of the professionals interviewed fully understood phantom pain or the problems associated with it. Patients wanted information before or shortly after amputation, but there was uncertainty amongst the professionals about who should provide this information and an acknowledgment that practices were inconsistent. The authors recommended that information giving should be standardized by developing protocols for a minimum set of information that all patients undergoing amputation should receive at the different stages of rehabilitation. In another study which looked at the role of primary care in supporting those with phantom pain, it was found that GPs tend to underestimate the prevalence, intensity and duration of phantom pain (Whyte and Niven 2004). They recommended a wider role for other primary care professionals in supporting patients with this problem.

Information to support psychological readjustment

It is in the area of psycho-social readjustment that there appears to be a real shortage of information although as one professional interviewee pointed out, it is important to maintain a distinction between information giving and counselling.

My role the majority of the time isn't about information giving at all.....there are a lot of so-called facts, there are an awful lot of opinions, my jobis helping people adapt that to their needs.

Craniofacial professional

There is a great deal in the literature about the psychological consequences of disfigurement. It is not within the scope of this research study to explore this in depth, but only in so far as it affects patients' information needs. Certainly, patients and carers in all focus groups were very vocal about their psychosocial needs and most talked of the

various emotional reactions they had experienced in the course of their treatment and rehabilitation. Parents had to cope with feelings of guilt as well as anxiety and fear for their children.

As a parent it's all the guilt and the fear of how the child is going to cope as he or she becomes aware of the deformity and how other people are going to react to him or her.

Cleft lip and palate parent

But one of the strongest emotional responses was anger and several patients talked about this, particularly those who had suffered traumatic disfiguring injuries. One woman who had survived major burns accepted that this could make life very difficult for her family.

There are some days when I can be very difficult to the children, very difficult to him as well. I've had problems with my tantrums, I can throw things, I can be angry.

Burns patient

In their research into the information needs of disabled young people, Beresford and Sloper list a number of psycho-social issues that generate information needs (Beresford and Sloper 2000):

- dealing with negative emotions
- living with physical symptoms
- living with unanswered questions
- dealing with parents
- dealing with peers
- managing at school
- managing other social situations
- living with restrictions on lifestyle
- maintaining a positive attitude
- planning for the future.

Evidence from the literature search suggests that only a minority of disfigured people report any meaningful contact with health professionals about their disfigurement (Newell 2002). Professionals also accepted that the Health Service is often ill-equipped to provide the necessary psycho-social support for patients with disfiguring conditions. Where resources permit, psychologists form part of the multi-disciplinary teams in specialist centres and are involved in patient care at the outset.

Within the craniofacial unit there is a psychologist that's attached, so every patient will be assessed as they come through the clinic.

Plastics professional

However, in most cases trusts lack these resources to provide good psychological support and are only able to provide it after problems have emerged.

I think we've got a bit of a shutting the door after the horse has bolted situation because we have a clinical psychologist...if patients are developing signs of

problems with altered body imagewe can wheel him in....but that's probably too late then.

Burns professional

A few health professionals felt that raising these issues could sometimes do more harm than good and that it was actually better to wait to see if patients developed psychological problems first. Indeed, the association of psychological support with some kind of mental illness can lead patients to reject it when it is offered. The same patient who had suffered severe burn injuries and who recognised that her angry tantrums caused problems for her family, was very uncomfortable with the idea of receiving such help.

Seeing psychologist at the hospital was very embarrassing to me....I would refuse my husband to come in with me because it was like am I insane, am I nuts?

Burns patient

One plastic surgeon saw his role as making patients less disfigured and therefore less likely to need psychological support.

I mean there are exceptions you know, but if you've got a big skin cancer hanging off here, you know a great big, black, manky sweaty, smelly thing and you suddenly end up with a bit of scarring on your face, you think you've won the lotto, so it's not really relevant to us.

Plastics professional

But for many of the patients in our focus groups, surgery left them facing major readjustment problems and there was a general consensus that information to support psychosocial rehabilitation was lacking within the health service.

If someone had given me a leaflet or actually sat and given me 10 minutes and said "There's a process that you're going to go through" ...for some professional to actually acknowledge this ghastly inheritance that we have with facial disfigurement, that we withdraw within ourselves and that that is part of the process and that is natural.

Head and neck cancer patient

I think there hasn't been much done for the parents.....because from the time the baby is born until ...the child realises what they've got....all the psychological aspect is probably borne by the parents. I don't think there's much information on that yet.

Cleft parent

One of the most difficult points for patients was when they saw their changed appearance for the first time.

One day I just saw myself, either in a mirror or what, I just saw without the bandages, my nose was twisted, this was all horrible and just like that I went downhill into a depression and it was like hitting a brick wall.

Head and neck cancer patient

In his book, *Changing Faces: the challenge of facial disfigurement*, James Partridge devotes a whole chapter to what he has called "the mirror moment." (Partridge 1990). He

believes that the timing of this moment can critically affect the whole recovery process and that the patient should ideally be supported by a family member, friend or health professional when it happens. Unfortunately, it seems that it does not always happen in such a considered manner. One Burns patient caught sight of his reflection accidentally.

It was six weeks before I looked in a mirror and that was by accident. They had me stood up, propped me up against the sink and putting dressings on my legs and I just happened to look up into the mirror above the sink.

Burns patient

Furthermore, some of the professionals who are with patients at this point in their recovery do not always feel up to the task.

I just felt out of my depth being the one that had to take her to the mirror.....and not knowing what the consequences might be.

Burns professional

Disfigurement is often seen as less of an issue for male patients. Parents of young boys born with a cleft lip and palate are apparently told not to worry because "he can always grow a moustache". This has implications for information provision as one male focus group participant commented.

I think they should have straightaway said about cosmetic camouflage and because you are a guy and you feel embarrassed about it they should overlook that, they should say look this is on offer if you need it.

Vitiligo patient

Dermatology professionals felt that cancer patients received better psychological support than patients with skin conditions. This may be true in a relative sense, but a number of studies point to dissatisfaction amongst head and neck cancer patients. A focus group study in the South West found that professionals tended to concentrate on details of surgery and patients wanted more information on psychological difficulties (Edwards 1998). A review of the literature on the information needs of head and neck cancer patients highlighted the fact that the psychosocial and functional problems faced by patients were not reflected in the type of information they received before surgery (Ziegler et al 2004). One of the parents in the focus group on cleft lip and palate felt that health professionals were more comfortable dealing with medical information than psychological aspects.

A lot more of the information is based on the treatment in the medical aspect of it rather than the psychological side effects.

Cleft parent

In an article on the psychological aspects of scarring, Atkinson speculates that the reason nurses may concentrate on the healing of the wound rather than its effect on body image, is because they feel they can do something tangible with a scar, but are out of their depth dealing with other issues (Atkinson 2002). This was echoed by comments from burn care professionals who felt inadequately trained for the kind of demands placed upon them

Because the patients turn to us don't they, they're in a bit of a mess emotionally....and nobody's really addressed that and it's actually us they speak to and it's not really our remit to do that...I'm not trained.

Burns professional

Clarke and Cooper surveyed specialist nurses working in burns and head and neck cancer in order to investigate their training needs. (Clarke and Cooper 2001) They found that whilst they are the health professionals usually considered to be the most appropriate to offer psychosocial support, both groups rated their skills in the social rehabilitation of their patients as significantly lower than their skills in physical rehabilitation. In some cases, psycho-social needs will not become apparent until long after patients have left hospital. The parent of a severely burned child knew that this was an issue he would have to face in the future but was uncertain how he would begin to address it.

This is where I need the counselling for her, but at what age do I start? How will I know? Will she tell me?

Burned children's camp

In the last in a series of 12 articles for the BMJ, Amy Acton, executive director of the Phoenix Society for Burns patients in the US, argues that addressing issues around altered appearance and the long-term implications of staring and social isolation, should be part of the discharge process (Acton 2004). The National Burn Care Review states that in preparing patients for discharge, every patient and family should have discussed how to deal with staring and that this can be facilitated with written advice in the form of a self-help guide. Newell and Clarke evaluated the effect of such a leaflet based upon principles used in cognitive behavioural therapy (Newell and Clarke 2000). The study compared disfigured individuals with psychological difficulties, some of whom received the leaflet and some who did not. The leaflet contained an explanation of the nature of anxiety and its relationship to altered appearance. It then outlined a range of strategies for dealing with these anxieties in everyday life. The leaflet was considered helpful by most participants, but the authors felt that detailed one-to-one support would probably be necessary for those experiencing high levels of psychological distress.

A young interviewee who was born with a craniofacial condition suggested that cards could be provided explaining why he looked different. He could then offer them to people who stared. The mother of a young child with Apert's Syndrome wanted guidance on how to support the child's older brother.

I wanted some practical information about what to tell [sibling] because he's starting school...he is going to get people saying, "Oh your sister"... and all the rest of it.

Craniofacial parent

Amongst the health professionals in our focus groups there was tendency to rely on the voluntary sector to provide help in coping with social encounters – Changing Faces being the charity most often mentioned.

I'd refer them to Changing Faces. I know what they do but they are a Charity that's prepared to offer some sort of support for people who have this sort of thing and frankly we don't have the time to do that so it's an exit route that the patients may find useful.

Plastics professional

Summary

In this section we have considered the type of information patients with conditions that affect their appearance need and the extent to which health professionals caring for them meet those needs. There appears to be a growing awareness amongst professionals that more and more patients now expect to be fully informed about all aspects of their condition. However, it also seems that this does not mean that patients are always given this information or made aware of it when they need it. In the next chapter we look at the importance of how and when information is given.

4.2 The process of information giving

Both patients and professionals recognised the importance of how information is given.

It's very, very important the way that you are told information.

Craniofacial parent

Patients still regard their doctor as the main source of clinical information. However, the manner in which information is communicated varies tremendously. A review of research on the giving of bad news quotes the journalist John Diamond who died in 2001 of throat cancer (Fallowfield and Jenkins 1999). He described the way in which doctors communicate difficult information as "somewhere between the mawkish and the unnecessarily brusque". The reviewers believe that although no two patients will respond in the same way to difficult news, the way in which information is given can substantially influence the patient's emotions, beliefs and attitudes towards the future. Kim and Alvi sent questionnaires to head and neck cancer patients in order to evaluate their thoughts and concerns (Kim and Alvi 1999). The results indicated that patients wanted their doctors to be truthful and use simple, unambiguous terms rather than complex medical terminology. Several focus group patients illustrated this point well.

They didn't mention the word cancer, it was a malignant tumour. Well that means if it's a malignant tumour, that's cancer, but they don't say the word, they are discreet but you know by then that you've got cancer.

Head and neck cancer patient

It frightens the life out of you because you don't know what they're talking about....

Cleft patient

My surgeon said "Do you think you can cope with the morbidity"? And I can remember saying "Well what's morbidity?"

Head and neck cancer patient

Some of the participants we interviewed felt that doctors communicated well:

They judge very, very carefully I think and they give people information and options on a really individual basis.

Craniofacial parent

However, more people expressed dissatisfaction with the way they were given information. This often centred on the lack of time for discussion and the tendency of doctors to underestimate both the physical and emotional impact of the condition upon the patient. For one patient, there appeared to be a failure to communicate the most essential information adequately.

Because nobody mentioned losing the eye or offered me anything to read or discussed anything with me before he said, "Well we'll have to have the eye out, now let me get my diary and let me see when I can do it," sort of thing.

Eye patient

Lack of time is widely recognised as one of the main barriers to good communication. The ENT surgeons mentioned earlier reported having an average of 15 minutes to discuss diagnosis and treatment options prior to laryngectomy (Stafford et al 2001). Some of the patients also appreciated that although they received good clinical care, the doctors did not have time to consider how they were coping in their everyday life.

However, there were indications in some of the focus group comments that professional attitudes might also adversely affect the information giving process. The trivialisation of their condition experienced by vitiligo sufferers has already been referred to, but the professionals themselves revealed a certain disdain for their patients, particularly in burns.

When we get a nice family, all the girls on the other ward are like, "Oh my God, they are not your typical family.....they're interested, they ask questions."

Burns professional

Assimilating information

Some studies have investigated the way patients retain and recall information given to them. Godwin looked at the recall of women undergoing breast reduction (Godwin 2000). A total of 38 patients were given information as part of the informed consent process. Six days after surgery they were asked to recall this information. The average number of facts recalled was just three out of the 12 mentioned. Despite this, 97% thought the consent procedure was adequate.

The professionals we spoke to seemed quite concerned about the patient's ability to assimilate information, particularly when being given a difficult diagnosis or on initial admission. The ability to judge just how much has been taken on board was viewed as a particular skill and they emphasised the importance of providing written information to take away and of reinforcing information through repetition.

If they can't take it in, well I will see you tomorrow and we can work through it again and they have time to think about questions.

Dermatology professional

Patients and parents also accepted that there were times when they were unable to absorb the information they were given, even to the extent of completely misinterpreting what they are being told.

I wasn't ready to hear anything negative....it still amazes me to this day that I could have interpreted those results as being alright, but I did.

Craniofacial parent

Consistency of information

Participants in nearly all the professional focus groups seemed particularly concerned to ensure that information was consistent when patients might see many different clinicians during the course of their treatment. However, very few patients seem to have experienced problems with conflicting information or advice.

I think one of the things we find as well is that families are coming backwards and forwards so the communication and the consistency is really important.....I think that's really important, not to confuse things.

Craniofacial professional

Responsibility for information giving

The large multi-disciplinary team approach is increasingly used in specialist centres. It encourages better communication between professionals and means that patients spend less time going from one specialist to another. When all the members of the team come together for a consultation, it can be an intimidating experience for the patient, although others seem to enjoy the attention.

I call it the "circus trip"....because I'm in the middle and there's loads of people looking at me.

Craniofacial patient

I felt like the star of the show in my chair.

Head and neck cancer patient

One parent found it far less intimidating if it took place in her child's room on the ward rather than in the general consulting rooms, because then it was on her territory. A lot of information is exchanged on these occasions and patients can find it difficult to remember everything. Those familiar with the process have learnt how to deal with it so that they get the most out of this opportunity to talk to the specialists responsible for their care, such as making a list of questions to ask beforehand or taking someone with them.

...because if one of you doesn't remember something, the other one will.

Craniofacial parent

The health professional focus groups were made up of a wide range of different disciplines including consultants, registrars nurses, speech therapists, occupational therapists, physiotherapists, a dietician, a prosthetist and a psychologist. Whilst patients usually saw the consultation as the main source of clinical information, they frequently

turned to these other health professionals on an individual basis to meet additional information needs.

In an article on the role of the clinical nurse specialist in head and neck cancer, Semple argues that one of the main benefits of the post is the continuity of care it provides from initial diagnosis, through treatment planning, treatment and follow-up in the community (Semple 2001). In addition the clinical nurse specialist can offer emotional and psychological support to encourage adjustment to altered body image and provide information, advice and education for patients and carers. Although she focuses on her own clinical area, Semple believes the concepts can be applied to other specialities as well. The emergence of the clinical nurse specialist role certainly appears to have been of great benefit to many of the patients interviewed. They were often viewed as better communicators than the doctors.

What tended to happen was that Mr C would see me and give a quick run down of what was going to happen and then we would be shunted into the side room with one of the clinical nurses to be given an expanded version. He was the nuts and bolts and they were the soft fluffy bits.

Head and neck cancer patient

I find it easier to talk to [clinical nurse specialist] but that's because I've built up a bond with her.....so I've talked to her about most things, about my fears and that, and bits and bobs with my surgery more than I can with the surgeon.

Craniofacial patient

But they also tend to be more accessible, have more time to spend with the patients and sometimes can even visit patients or parents at home.

Yes, she [nurse] made it quite clear that I could ring her at any time if I was worried about anything.

Eye patient

A clinical nurse specialist came down...she was absolutely fantastic and they've got it spot on.

Craniofacial parent

Clinical nurse specialists themselves recognise their role in clarifying complex medical information, enabling patients to ask questions, and interpreting information they get from elsewhere. They generally see themselves as better communicators than the medical staff.

No disrespect to our surgeons, but a lot of them don't have very good bedside manners.

Plastics professional

One focus group patient bemoaned the lack of clinical nurse specialists for amputees.

I think in the surgeon's area I think they can tend to be a bit aloof a bit distant; the nursing staff are all very helpful. But I think generally they do what they can but there is not anybody, you know you hear about cancer nurses and you hear about neuro nurses and things like that but you don't hear about amputee nurses

Amputee

Other professionals also play an important role in information giving. Tilley describes the reliance of patients and their families on the occupational and physical therapists for advice and information in both the acute phase of burn management and in some cases, for many years to come (Tilley et al 2000). This was reinforced by comments made in the focus groups.

A lot of these things come out and a lot of questions and lots of things that perhaps they feel they haven't been told. We're in the firing line really aren't we as physios and OTs?

Burns professional

The physios gave me a lot of information.

Burns patient

However, another study relating to the wearing of pressure garments, found that there were wide disparities between occupational therapists and their patients (Stewart et al 2000). The clinicians felt they had given a lot of information, but patients said they had received little.

It would seem that the success of the information exchange often hinges on the development of a good personal relationship. This can be formed with any health professional, but when it does not work, it can seriously hinder communication.

The main support really has come from the speech therapist...if I've got any problems or questions, I tend to ask her.

Cleft parent

Those conversations patients have with perhaps the nursing auxiliary care assistant where they probably say things to them that they probably wouldn't say to a more senior nurse.

Plastics professional

I don't like one of my specialist nurses. I find taking information from her quite difficult.

Head and neck cancer patient

One nurse was able to stand back and offer her patients another option if they did not like her communication style.

If I think somebody doesn't like the way that I try and say something...you can try and ask another nurse, maybe they want someone else to explain things to them.

Craniofacial professional

But there is evidence that doctors in particular find it difficult to accept that others can provide a better information service. The survey of UK ENT surgeons revealed that the

majority of surgeons were only willing to delegate certain aspects of information giving, for example, quality of life and psychosocial issues (Stafford et al 2001). Of those who responded, 60% thought that other staff should only be involved in the information giving process after the doctor and patient had reached a decision about treatment for their cancer.

Using the wrong person to convey information can give patients a totally false impression as is illustrated by this focus group example.

They thought that because the Chaplain was going to see them, that he was telling them something so awful that the nurses couldn't go in and tell them. So it's not just about the content of the information, it's who's delivering it.

Burns professional

The timing of information giving

It was recognised by both patient and professional participants that the timing of information giving is just as important as the way it is given. Feedback to Feber's report on oral and maxillofacial cancer at Leeds Teaching Hospitals, suggests that patients do not want too much information when initially given a cancer diagnosis because they will simply not be able to absorb it (Feber 1997) This seemed to be supported by some of the comments in our focus groups which implied that too much information too soon is not helpful. People need time to come to terms with what's happened to them.

If you've been badly injured and they give you a great big folder right at the start...you're not in a fit state to appreciate it.

Burns patient

You are bombarded by images that you don't want to see, there's pictures up on the wall of kids with Apert's.....and you're coping or not coming to terms with the fact that your child is going to look different.

Craniofacial parent

However, when the National Cancer Alliance sought the views of head and neck cancer patients, they found that all those interviewed wanted to know the scale of the challenge they faced at the outset (National Cancer Alliance 2002). Caress recognises that some patients are likely to have lots of questions at the time of their diagnosis, but that others may be too distressed or confused. (Caress 2003) The health professionals in our focus groups seemed acutely aware of this dilemma.

I find the hardest time is on the initial admission, there's so much information that you can give out but....at that stressful time, how much information will they take in, but then what do you hold back?

Burns professional

Information giving is a process, not a one-off event. Professionals in the focus groups talked about the importance of reinforcing information at every possible opportunity and mentioned a number of occasions when patients could access information when they needed it.

We have pre-op clinics which are run by the clinical nurse specialist and registrars, but that's also the time where we give them the information and there is time before the surgery for them to come back and there is a contact.

Craniofacial professional

I think the scar review clinics are a fantastic idea.....they're given information about all the different options.

Burns professional

Patients had differing views on the usefulness of some of these clinics.

I would still go every six months to see if there were any new treatments

Burns patient

I'm surprised that you are still going, [to the scar review clinic] because when I was going they were not telling me anything I wanted to hear.

Burns patient

The timing of information can either be determined by the clinicians – although as one professional participant pointed out, this could be seen as rather controlling – or left to the individual patient when they feel ready. As one of the parents commented, the ideal situation is to be given help and guidance in knowing where to find information when required.

The best thing to do is say to people there is all this information out there and you need to be given the skills to find the information....so you can go away and do it when you're ready to do it.

Craniofacial parent

Kemper and Mettler see information as important as any drug or surgery. They believe it should be prescribed like any other therapy at every point of the patient journey (Kemper and Mettler 2002). This approach would be appreciated by one focus group participant.

You go through stages of wanting to know about different things.... but if you could have incremental doses as you progress, that would be very useful.

Burns patient

Tailoring information

In their review of the literature on head and neck cancer patients' need for information, Semple and McGowan argue that information must be tailored to individual need rather than assuming what patients need to know (Semple and McGowan 2002). The health professionals in the focus groups recognised this need too.

There is sort of global information that applies to everybody...and then something specific can be tailor-made in much more of a circumspect way and perhaps that second sort of information is perhaps what is needed more.

Craniofacial professional

One of the difficulties with providing general written information in the area of reconstructive surgery appears to be the very individual nature of most cases.

A lot of ...information leaflets...wouldn't necessarily pertain to everything we do because the operation is tailored to a patient's requirement and problem, and a lot of them aren't quite so generic.

Plastics professional

Furthermore as patients respond to treatment in an individual way and at a different rate, information based on the general or average case can actually be misleading and discouraging.

You can't always say what a patient's scar is going to look like.....if they get delayed in terms of like in 6 months they're not at that stage, then they'll get disheartened and annoyed with themselves.

Burns professional

The health professionals in our focus groups appeared to make every effort to tailor information to the needs of their patients. This can mean writing things down for each individual rather than relying on pre-printed fact sheets or adapting the general information provided by the voluntary sector and making it relevant to the needs of the individual patient.

I have to be quite specific about what I highlight to the patient is relevant to them.....I don't just say, "Here's a book about radiotherapy".

Head and neck professional

Physiotherapists working in burn care talked about new software which enabled them to download and adapt information from the internet specific to the changing needs of individual patients.

Physio Tools have got loads and loads of exercises on the net....so it's got all the things that the physio would use and then you just click on it and it prints out which ones you want. So you just make it patient specific....you'd give the printed copy to the patients....and you can change it as and when the patient progresses.

Burns professional

The lack of tailored information was sometimes seen as a problem by patients. The mother of a child born with a cleft lip and palate gave an example of why general information material often fails to meet the specific needs of a particular patient.

I remember looking at the photos...in the hospital and I said to them, "Well, you've done a fantastic job....but they're all white babies, they've got their pointed nose and their rounded nose and this is me with an African child with an African nose, how is it going to turn out and be surgically mended?"

Cleft parent

For another mother, the fact that there was no other information available meant that she was given something individually targeted to her son's situation.

The neurosurgeon actually had to draw a picture, there was nothing available to just hand to me....so it made it more special to [son].

Craniofacial parent

Information in languages other than English

The National Consumer Council's report on Health Literacy recommended that bilingual workers or trained interpreters should be available to work with patients who, in addition to having limited English, also possess limited literacy skills (Sihota and Lennard 2004). A study of the information needs of Asian cancer patients in Leicestershire showed that even those who did speak English wanted to receive such important information in their first language - over half of the English-speaking Asian patients surveyed said they would prefer to discuss their illness in their mother tongue (Muthu et al 2004). There were few black and Asian patients in the focus groups, but one Asian Burns patient commented on the lack of information in languages other than English.

I think there isn't enough information for Asians.... ..it would be nice if there was some information maybe in another language for them.

Burns patient

Several professionals said that trusts are able to offer information in other languages on request. They gave examples of the various services they can offer to patients and carers whose first language is not English including interpreters, Language Line and translations of information materials.

We have a Cancer Information Centre where most of the national patient information is produced in different languages and larger text and audio versions.

Head and neck cancer professional

And we use Language Line and we've got interpreters full-time here so you can book face to face.

Craniofacial professional

We can always get something interpreted....we just contact our interpreter services. They take a little while, but we had someone from Somalia and we had got our information leaflet translated in a language that was recognisable to them.

Burns professional

However, it appears that not every hospital has the resources to do this.

It's quite hard because we cover such a wide area; there could be absolutely huge amounts of different languages coming in.

Burns professional

The format in which information is provided

The overriding preference from patients in the focus groups was to receive information verbally and face to face.

I find that doing things face to face is a lot more, I can take a lot more in, than if I have a leaflet or a pamphlet or something. Because as I say I tend not to read.

Head and neck cancer patient

You can give me a pile of leaflets and I probably won't ever read them so for me it's people, it's conversation.

Craniofacial parent

In the above mentioned report on the information needs of families with disabled children, Mitchell and Sloper highlighted the fact that parents continually emphasised that booklets, leaflets and videos are not enough by themselves. Personal contact with those providing the information was regarded as crucial. Gibson considers educational materials to be useful for those who have undergone an amputation, but only as a supplement to talking to patients about their concerns (Gibson 2001). Some patients and parents in the focus groups expressed a need to receive information in other formats, but this did not come across as a major issue. A head and neck cancer patient, who was interested in alternative therapies, had found an audio-tape from the Bristol Cancer Help Centre very useful and a young Burns patient was very keen to make use of new technologies.

I think any new technology should be embraced as a medium for spreading information....it wouldn't be hard to remake something like that [hospital admission video] in the format of a DVD so you've got a menu, you can go straight to the bit that you want to re-look at, as and when you're ready to process it.

Burns patient

The literature review revealed a growing body of evidence that suggests that additional information in another format can significantly assist patients, particularly on discharge from hospital when they are expected to manage aspects of their own care. Moreover, as suggested above, when people are anxious, they are less able to assimilate all the information received in a consultation. Johnson et al conducted a review of two trials which sought to determine the effectiveness of providing written information in addition to verbal information for the parents of children being discharged from a Canadian burns unit and a U.S. emergency department (Johnson et al 2003). They found that verbal and written information provided together appeared to be more effective for improving knowledge and satisfaction than only providing verbal information. Burns professionals in the focus groups felt that a leaflet would help educate patients about the importance of wearing pressure garments.

So if we could educate the patients somehow earlier on that these are the changes and although your skin is going to look good at a certain point, this is what happens after that and this is why it's so important to have your pressure therapy, andperhaps a leaflet early on would help our work in the future.

Burns professional

Semple and McGowan reviewed the literature on head and neck cancer patients' need for information (Semple and McGowan 2002). They concluded that patients can use written material for future reference, to revise information previously received and to help clarify misconceptions. The National Cancer Alliance has developed a teamwork file to provide information about cancer, its treatment and care in a flexible format which contains a guide to cancer and a personal health record. A similar approach is also being used in other clinical areas.

In complex needs we'll have a shared care folder.....usually it would have all of the contact telephone numbers and resources from within the hospital....the families

will often put in records of their craniofacial assessments....so if they go to a local A & E department, they've got all that information.

Craniofacial professional

One focus group participant liked this concept and thought it could be adapted to burns care. She compared it to the maternity notes given to pregnant women.

If you turn up at some clinic and say I'm pregnant, you get a folder with binders and samples and you get like this is what's going to happen to you. Why can't they just translate that model into burns... and just give you like a folder with things that you can insert.

Burns patient

Another focus group participant felt that basic self-care information could be provided in a more practical format than the usual sheet of A4 paper:

If it came in a little folder, a piece of card, you can put it on your pin board at home, magnet it onto your kitchen fridge or whatever.

Plastics professional

One of the recommendations in the recent Bristol Royal Infirmary Inquiry (Kennedy 2001) suggested that patients be given an opportunity to record consultations for their own use. A study at the Royal Liverpool University Hospital looked at the attitudes of eye cancer patients to audio-taped consultations (Ah-Fat et al 1998). A total of 94 patients attending an ocular oncology clinic were given an audio-tape of their initial consultation. The researchers then conducted structured interviews and administered a questionnaire. The results showed that 91% had listened to the tape at least once and of these 94% found it very or quite useful in helping them to understand their condition. Most thought it was a valuable aid to the consultation process. The Cochrane Collaboration recently reviewed 12 trials which examined the effects of giving cancer patients either audio-taped recordings or written summaries of consultations (Scott et al 2005). They concluded that most patients found these communication aids very useful and recommended that practitioners should consider offering them. Health professionals at one of our collaborating specialist centres have introduced their own version of this and another professional talked of taping nurse consultations.

What you do with the dictaphone is you take it to your consultation, you give it to the consultant ...they do a summary, what you get is a transcript basically of that summary.....I think it's a brilliant idea and it's a great way of looking back on things....so and so said this and they still haven't done anything about that so we need to ask that question.

Craniofacial parent

The nurse was very conscious of the tape being there.....it seemed a bit stilted, but then in terms of the content, the facts were there.

Plastics professional

Whilst professionals recognised this might aid information retention, both they and the patients had some reservations. Patients who had built up a good relationship with their specialists feared that it might compromise the openness and informality of their exchanges and were not convinced that clinicians would agree to it.

But I like to keep an open relationship with them.....it [tape recording] might put them on their guard more.

Craniofacial parent

Some professionals reflected on the legal implications for them if subsequent outcomes failed to conform to the taped discussion. There was also the simple issue of equipment to record and play back the taped material.

When appearance concerns are paramount, visual information is crucially important. The health professionals interviewed frequently mentioned the use of photographs as a useful tool – to inform patients and parents about likely surgical outcomes and to measure progress in the healing process. Burns patients wanted before and after photographs to help them visualise how their injuries will heal.

It would be nice to see a similar sort of quality of burn and see a picture of it two years later.

Burns patient

The Health Education Authority's review of 175 studies involving the use of video in health care found that its potential to inform patients was largely unfulfilled (Eiser and Eiser 1996). The authors felt that more use could be made of video in modelling self-care behaviours. Health professionals in the focus groups agreed:

I mean we're stuck with photos, but it has occurred to me that we should perhapsmake a short video of the child, get permission for them to speak a bit and then you get another dimension.

Craniofacial professional

I suppose if children in the video could see other children being happy and wearing the conformers and pressure garments and continuing normal life at school, that's going to give them a hell of a lot of confidence isn't it?

Burns professional

However, Eiser and Eiser also found that although videos can be used to reassure patients before treatment, they can sometimes raise anxiety. Opinion seemed to be fairly evenly divided over the value of video in the focus group discussions.

It [video] worried them more rather than got rid of their anxieties.

Burns professional

You are not always in the mood to read and stuff at that stage but the videoshelp.

Amputee

New technology can also facilitate the sharing of information between doctor and patient, provided both have access to it. One parent at the burned children's camp wanted to email a digital photograph of his child's laser patch test as he was not sure how it should look. He had attempted to describe it over the telephone as the hospital did not have the necessary software to receive the photograph.

Summary

The evidence from the focus groups and the literature suggests that the manner in which information is given to patients can be as important as the content of the information. Although many of the health professionals interviewed appeared to appreciate this, there was still a tendency amongst others to underestimate the value of good communication skills and many patients certainly felt it was an aspect of care which could be greatly improved. The next section considers the information production process within the NHS.

4.3 The production of NHS information materials

Quality concerns

In the focus group discussions it was the health professionals who raised issues around the quality of written information provided by the NHS.

A lot of information that we've got at [hospital] is a bit of A4 paper that's literally been ripped in half so you've got jagged edges down one side, it's been reproduced so many times it's got black dots all over it and it's embarrassing to actually give that out to a patient.

Head & Neck Cancer Professional

For a long time we have just produced an A4 sheet that somebody has typed out....it is repeatedly photocopied and becomes poorer and poorer quality....we changed hospitals over the last couple of years, some of them have still got the wrong hospital on.

Plastics professional

Although issues of reliability and quality were raised in connection with the internet and media, few patients voiced similar concerns about printed information. One patient said she had trusted a book about having an eye removed because it had the trust's name on it and pointed out the importance of updating information.

You know if I sort of read a book that I saw was published in 1973, I might think, "oh well I'm sure they've moved on a bit from then."

Eye cancer patient

In recent years several studies have highlighted the generally poor quality of health information, finding much of it to be irrelevant, unbalanced, patronising and written in language difficult for people to understand (Coulter et al 1998; Garlick 2003; Semple and Allam 2002). In its report, Better information, better choices, better health, The Department of Health recognised the importance of producing good quality patient information (Department of Health 2004). Indeed, recent years have seen a proliferation of guidelines within individual hospital trusts. Health professionals in our focus groups explained how these worked.

The Trust has written guidelines on producing patient information which specify how it's supposed to be, not only in terms of content but also how you must present it, how you must evaluate it.

Head and neck cancer professional

These days everything you want to produce has got to go from her [information manager] so that it's vetted and it's got the right format, so you can't produce your own leaflet in that sense, it's got to be rubber stamped, it's got to conform to however they want it in terms of layout and content.

Craniofacial professional

However, some clinicians seemed to find the process a hindrance rather than a support. They thought it was too lengthy and felt it took away their editorial control.

I know it mustn't be too high level.....but it was so basic, I wasn't even allowed to call an operation by its proper name. I think I'd put something like rhinoplasty...but I had to change it to nose job.

Plastics professional

Others expressed a certain cynicism about the role of an information co-ordinator and there was a sense amongst a few professionals that the production of patient information was not the most satisfying aspect of their job.

I'm sure there'll be somebody in the trust....because it's a managerial position so there'll be a least ten of them.

Plastics professional

For heaven's sake, there is nothing more boring than trying to do patient information leaflets.

Plastics professional

There was only limited awareness of the NHS Toolkit for Producing Patient Information (2003) which was developed to help those responsible for the production of written information for NHS patients and carers.

It's like there's this national guideline as well, isn't there?

Burns professional

Although patient involvement is recommended at every stage of the production process, the impact of the Toolkit in this regard did not always seem to have filtered down to grass roots level. Several professionals talked about different ways of engaging patients, but in most cases this was only to evaluate materials after they had already been produced.

And then once the final version is produced it's again circulated for comments and then sent out to patients for evaluation before we use it.

Head and neck cancer professional

She [nurse] has been doing a little survey on how patients find those leaflets, whether they're happy with the wording and the amount of information on them.

Burns professional

One health professional felt that there was a danger of producing too much information.

I think, I'm reaching at a point now where I thinkwe're quite proactive with information and we've reached a point now that if we start developing any more the patient's going to need a forklift truck to get out the hospital.

Head and neck cancer professional

In addition to the NHS Toolkit and the guidelines within trusts, several other manuals now exist to help health professionals produce better health information (see Appendix 4). Numerous small studies have also considered the usefulness of particular information tools and some of these relate specifically to the clinical areas under discussion including: self-help leaflet for those experiencing social difficulties after disfigurement (Newell and Clarke 2000); leaflet for parents looking after a child's burn injury at home (Hibble et al 2005); ditto (Jenkins et al 1996) ; hand-out and video for burns outpatients (So et al 2003); educational booklet on oral cancer (Katz et al 2004); leaflets about birthmarks (Syed et al 2004)

Standardised information

Health professionals in the focus groups recognised that there was a degree of unnecessary duplication in the production of information materials. But many felt that this was unavoidable when surgical practices, terminology and facilities differ so much between the different specialist centres.

Well it's difficult because we've got our own care pathway and then say [hospital] has got their own care pathway.....our pathway's leaflets are probably different to theirs, we've not got a standard leaflet.....there are no guidelines.

Burns professional

Parents also appreciated the difficulties of producing standardised information when the craniofacial centres adopted different approaches.

For instance [specialist centre] do a zigzag suture when they do that so that it knits together in a different way and I think some of the regions are still doing straight line sutures.

Craniofacial parent

In addition to these differences, individual surgeons within the specialist centres will use different methods and even terminology varies from place to place.

Different consultants will graft straightaway and certain ones won't.

Burns professional

For all these reasons, many of those interviewed felt it would be impractical to produce standard information material across many subject areas.

Resources

Several factors can limit what information is produced. Information production is not often seen as a priority in NHS trusts and consequently time and money are not allocated to it. The BAHNON survey revealed that 14 of the 59 head and neck nurses who responded said that they did not have a budget or access to locally produced information

and four said local patient information was under review (Maidment 2004). Focus group professionals expressed similar constraints.

We haven't any support either so you write it, you design it yourself. I mean the communications department may help a bit but it is the time thing.

Dermatology professional

You know, you're thousands of pounds overspent on staffing levels...so patient information...

Plastics professional

There was also a suggestion that there was little professional incentive to produce information for patients.

I just know I don't have the time and I kind of nag junior staff to do it....They say, "Will I get a publication out of it?" Of course you won't.

Plastic professional

It appears that all this can lead to a rather adhoc approach to information production, even involving the friends of staff who are prepared to offer their services at a reduced rate.

I know someone who knows someone who's done a media degree and we were thinking of getting them in.

Burns professional

Summary

Despite efforts at a national level to improve the production and co-ordination of information for NHS patients, the focus group discussions suggest that there is still a considerable amount of work to do at a grass roots level, where quality varies tremendously from trust to trust. The next chapter looks at the vital role the voluntary sector plays in the provision of patient information.

4.4 The role of the voluntary sector

The purpose of information

Different charitable organisations address different information needs, but two main types of information were identified in the discussion group: medical information and practical advice about coping with a particular condition. Often charities will refer to other organisations for the kind of information they cannot offer. In addition, focus group participants mentioned other reasons why patients might come to them for information. One person talked about empowering patients by helping them to ask their clinicians the right questions and giving them the confidence to do so. Another stressed the fact that one of her charity's main functions was to reassure parents concerned about their child's treatment.

That is what people want; they want to know is this normal, is this what's happening throughout the country and should I be going somewhere else?

Voluntary sector

The “normality” theme was echoed by another participant from another patient organisation who felt that facilitating peer support was an important part of their role.

I thinksomething we can help with as opposed to the health professionals, we've heard of X number of people who have had similar experiences and putting them in touch with other people in their area who know how they feel, that it is normal.

Voluntary sector

When asked to identify the common information needs of patients with a wide range of disfiguring conditions, the voluntary sector representatives all highlighted the long-term psycho-social aspects and the important role that they have to play in addressing these concerns.

The thing that comes up most is, “how do I have a relationship with someone looking like this?”

Voluntary sector

They thought that patients often feel unable to ask their clinicians the questions that really matter and one participant felt that health professionals generally fail to understand the psychological consequences of disfiguring conditions.

Clinicians have a tendency to act as proxy for patients. They suppose they know what this particular condition means to a patient and they absolutely don't.

Voluntary sector

Some charities focus more specifically on psycho-social information than others. Changing Faces was seen as the leader in this field, but other organisations offer support via articles in magazines, drop-in sessions and helplines.

Relationship with the NHS

Charities and support groups are often key providers of specialist health information about a disease or condition. They can either complement information provided by the NHS or in some cases provide information where none exists within the NHS. The voluntary sector representatives interviewed were careful to distinguish their relationships with individual clinicians from their relationship with the NHS as a whole.

We've got a huge number of friends who are consultant dermatologists....we know them very well and they're very supportive of us, but I wouldn't count all that necessarily as quite the same relationship as the NHS.

Voluntary sector

Working with the NHS itself can be problematic. One participant talked of the battle between different voluntary organisations to get their information into the racks in GP surgeries. He suggested that one way around this would be for patient organisations to sell their services to the NHS, an idea that is gaining ground with policy makers.

Primary care trusts.....might pay the National Eczema Society, say, £5 a year for each patient they expect to have in 6 months and that patient would then have unlimited access to the Society's helpline and written materials.

Voluntary sector

Clinicians often assist in the writing of information materials provided by patient groups, but some of the focus group participants admitted that they could become too dependent on the same few who were prepared to devote time to this. The more academic style of writing favoured by some clinicians also meant that charities had sometimes to rewrite their material in a more user-friendly way.

They are horrendously busy and I think you fall into the trap of using the same ones because you know that they'll get back to you.

Voluntary sector

Quality concerns

There was a general feeling in the discussion group that the public trusted the voluntary sector and therefore the information that it produced. However, variations in quality are to be expected when the size and resources of individual charities vary so much. To address this concern within dermatology, one umbrella organisation which represents over 30 skin care groups sets quality standards for inclusion in its directory of conditions. All material, whether produced by a large charity like the National Eczema Society or a small charity operating from someone's kitchen table, has to be produced by a medical panel, be regularly updated and revalidated, and written in plain English.

Once they've satisfied us that they have done that to a proper standard, we will include it in the directory and that directory is replicated on the website.

Voluntary sector

Resources

Smaller condition-specific support groups can be quite fragile. Some of the voluntary sector participants talked of the difficulty of sustaining interest in these groups over a period of time. Activity can wax and wane often depending on the energy and commitment of one or two enthusiasts. This has resource implications. All the organisations represented in the focus group seemed to be prepared to accept commercial sponsorship, although participants stressed the importance of remaining independent.

We absolutely thrive on it...[but]...were we ever perceived to be in the pocket of the pharmaceutical industry, we'd be dead in the water.

Voluntary sector

It was emphasised that when commercial organisations provided the money for information material, it must not be to promote any products and the quality must be checked rigorously.

We don't want our name on something that isn't good.

Voluntary sector

One participant illustrated the difficulties posed by a lack of resources by describing how it had taken nearly three years to produce one booklet. The situation was further exacerbated by the time pressures experienced by the health professionals involved.

We're regional....the people I went to initially would only fund locally...so eventually by going to 2 different funders I got £1,000. We got professionals involved; each of those professionals ...had other jobs to do which were far more important.

Voluntary sector

Standardisation and duplication

Research participants representing the charitable sector seemed to have no problem with the duplication of information materials. They felt that as long as there was no contradiction, some duplication was actually quite valuable. It allowed for patients to access material in different ways and *probably covers little holes that are left by other things*. One representative of a small local support group felt that however good the information provided by larger national charities, patients will often want a more local input. This enables the introduction of named clinicians and particular clinical practices and *it suddenly becomes more friendly*.

Format

Charity representatives were generally more interested in the format of information than the patient and health professional groups. They all recognized the necessity of having a website, although at least one felt that their own website was ineffective. But there was also discussion about videos and CD Roms and the power of the visual image. One local support group for people with burn injuries had produced a video illustrating various aspects of after care which they planned to show to patients while they were still in hospital. The video format enabled them to demonstrate much more clearly what the patient can expect.

We could have given booklets on garments, but it's just a man standing like this...they want to see how it's fitted, why it takes so long to have this appointment.....and the pictures of the scarring changing over time.

Voluntary sector

The information officer of another patient organisation emphasized the importance of providing information in a variety of ways via leaflets, telephone and email helplines, and a website. The directory of skin disorders mentioned above is spiral bound. This is invaluable for consultants making it easier to make photocopies for patients and GPs, ensuring that they both get the same quality assured information.

Patient involvement

Voluntary organisations appear to involve their members in the production of information materials in different ways and at different stages of the process. One charity had parents and patients on its editorial board and some of their literature originated from ideas generated in user groups. Another held a clients' forum in 2004 to discuss what sort of information they wanted. But the information officer of another support group feared that they tended simply to react to patient feedback rather than involve members proactively from the start.

You think, "I've had a lot of enquiries about pregnancy, maybe we should do something, you know."

Voluntary sector

Culture and language

There seems to be only a limited attempt to meet the needs of non-English speaking patients. One focus group participant felt that political correctness could be taken too far, particularly when it involved the requirement to produce information in Welsh for use in Wales. This was expensive and placed a huge burden on the voluntary sector. It was acknowledged that even when written material was made available in other languages, this was not always the solution.

We have our feeding booklet, but it's not very effective....it's just words. I believe visual things are important and there are no pictures.

Voluntary sector

Focus group participants were aware that producing information materials and devising coping strategies that are culturally appropriate to all their members is highly complex. Evidence was also presented that illustrated the difficulties of translating information from elsewhere, in this case the Dutch Burns Foundation, into English.

One of the committee members has brought a book on burns back from Holland which he decided he wanted to translate for people.....what was fascinating was to see how the result was awful, so we've knocked that on the head.

Voluntary sector

Gaps in information provision

The voluntary groups themselves recognised that more needed to be done for young people. One of the generic disfigurement charities has recently held its first young people's council and is setting up a young people's chat room on its website. Another charity felt they needed to provide more targeted information for the very young, the middle school age and teenagers. One participant spoke of a very specific gap in the literature it provides:

Information on bone grafts for the older children, we don't have a booklet on that.

Voluntary sector

Internet and media

Like the health professionals, voluntary sector workers were ambivalent about the internet. Everyone recognized that it was now hugely influential, but there were concerns that it often fuelled unrealistic expectations or generated unnecessary anxiety amongst patients who then came to them for reassurance.

The internet's a wonderful thing, but sometimes a very dreadful thing....people will read something and it will stay in their head....and so you can spend quite a large part of a telephone call ...reassuring somebody that everything's alright.

Voluntary sector

Similar attitudes were expressed towards the media. One participant felt that their organisation had a good relationship with the media, but it also had to cope with the fall-out from some television programmes, particularly those featuring cosmetic surgery. There was however, praise for individual documentaries such as *The Boy Whose Skin Fell Off*.

Patients' and professionals' views of the voluntary sector

It should be noted that many of the patients in the focus groups were recruited via the voluntary sector and this should be taken into account when considering their views on charities and self-help organisations. Nevertheless, it was clear from the discussions, that the support and information provided by these charities is highly valued. Many of the health professionals in the focus groups also use information from charities to support them in their clinical roles. Indeed one of the charitable groups actually provides training for health professionals in the psycho-social aspect of disfigurement.

A nursing midwife...encouraged me to get in touch with CLAPA....they passed on all the information that they had at the time.

Cleft parent

The facial stuff, we sometimes maybe recommend Let's Face It, Red Cross and that kind of stuff.

Plastics professional

There are two national charities in the UK that provide general support and information to people on the basis of disfigurement rather than any particular condition. Although they may be able to offer less tailored information than the condition-specific organisations, patients thought that the psychological aspects of disfigurement were similar, irrespective of its cause.

They wouldn't have the same sort of pain issues in some of those different disfigurements, but as for the emotional reaction of other people...it's pretty much the same.

Burns patient

A survey of the first 70 clients to contact Changing Faces, the larger of these charities, found its information material easy to understand (87%), helpful (73%) and effective in stimulating individuals to try some of the coping strategies it recommends (69%) (Clarke 2001). Many in the focus groups also spoke positively about the charity.

Changing Faces seemed to be the one that worked for me.

Eye patient

One parent suggested she was referred to a charity because the psychological support provided by the NHS was unsatisfactory and a clinician in plastic surgery admitted that the voluntary sector is sometimes used as "an exit route" when they don't have the time to offer the patient such support. However, he was unsure about the extent to which patients followed up these referrals. In some cases, the lack of local or regional branches may make some charities inaccessible to patients. In formulating her strategy for the support of patients with oral and maxillofacial cancer at Leeds Teaching Hospitals, Feber

found that patients thought that London-based workshops were too difficult and expensive to get to (Feber, 1997).

There was a sense from a few of the health professional participants that the lack of any real alternative to the material produced by one or two charities could be problematic. Others seemed happy to refer patients to charities without having actually seen any of their information material.

But then I suppose we've got nothing to compare it to...we haven't got one [leaflet] made by a psychologist who works on the burns unit.

Burns professional

No, I've not seen any of the leaflets...I just know that these are groups and bodies that are helpful to patients.

Plastics – medical

Some charities do not produce a great deal of written information, but instead offer one to one support, counselling and advice through meetings and local contact points throughout the UK. Several head and neck cancer patients found these support networks an invaluable source of information.

I don't think we've looked anywhere else because we haven't felt the need once we belonged to Let's Face It.

Head and neck cancer patient

In addition to the pan disfigurement charities, there are a number of other patient organisations established to support people with different congenital disorders offering practical help and information on feeding, speech and hearing, and treatment. Some of these charities also have a campaigning role and can influence the way in which care is delivered. In 1996 the Cleft Lip and Palate Association contributed to the Clinical Standards Advisory Group's review of cleft lip and palate services in the UK (Cleft Lip and Palate Association 1996) and in 1999 it undertook a project to raise awareness of cleft lip and palate amongst frontline health professionals (Cleft Lip and Palate Association 1999). Focus group participants spoke very highly of the information it provides and the opportunity it offers for members to play a part in improving services.

Because of my involvement with CLAPA ...I have the benefit of being involved in a lot of the framework of the treatment pathways.

Cleft parent

Some of the condition-specific charities are small and under-resourced. They are run by highly committed individuals who often have to combine their involvement with a full-time job. It is perhaps therefore unsurprising that they cannot always meet the demands of patients and carers. For some of the participants in our focus groups, such organisations were a vital source of much-needed information, but for others their approach and style was less appealing.

I got on the website and phoned up ...and she told me an awful lot about it.

Craniofacial parent

I couldn't relate to them. They weren't local, they all seemed to be quite a lot older. their website was crap....it was hard to use, the links were poor, there wasn't that much information, it wasn't up to date.

Craniofacial patient

Although some voluntary organisations produce information which is specially targeted at younger people, this is not always the case. Some of the younger amputees did not find the videos produced by one charity entirely appropriate for their age group:

The videos would help, though the people in them are a wee bit old for us!

Amputee

The head and neck cancer patients in our focus groups were perhaps the best served in terms of voluntary sector information simply because the large national cancer charities are so well resourced and efficient. The British Association of Head and Neck Cancer Nurses' survey of its own members (Maidment 2004) revealed that the nationally produced information most commonly offered to head and neck cancer patients is produced by CancerBACUP, the National Association of Laryngectomy Clubs and Macmillan Cancer Relief. Health professionals spoke very highly of the information provided by the large cancer charities which was considered to be very clear and comprehensive. Nevertheless they emphasised the importance of reviewing material regularly to ensure its appropriateness and of supplementing nationally produced information with local information.

We all.....liked the format, we liked the way they were written. We each, you know, continue to review them, I don't just carry on using them.

Head and neck cancer professional

One patient liked the way NHS and voluntary sector information complemented each other.

The information from the radiotherapy department was excellent. Fantastic and also CancerBACUP. It actually discussed radiotherapy and the types of radiotherapy they would give for different cancers and what the side effects would likely to be.

Head and neck cancer patient

Another focus group participant raised the important issue of availability. There is obviously little point in patient organisations producing information if it is not readily accessible and visible to those who need it.

I went to [hospital], I didn't see any displayed so when I got called in by a dermatologist I said, "I take it you haven't got any leaflets for the Vitiligo Society." She said, "Well wait a minute" and she went into the next office and dug around somewhere and she said, "Yes we have"so I said "why haven't you got them on display?"

Vitiligo patient

Summary

There appears to be little doubt that without the voluntary sector, most patients would find it far more difficult to satisfy their information needs. Patient organisations offer an

alternative voice, interpret the information provided by clinicians and complement that information with practical advice on living with a disfiguring condition. Relations between the voluntary sector and individual clinicians are often very good, but participants were keen to distinguish these from their relationship with the NHS as a whole. When well-resourced and efficient like the large cancer charities, the information they produce can be highly sophisticated and of very high quality. However, at the other end of the scale, small, local charities, like the hospital-based burn survivor groups, struggle even to survive. Although most conditions which affect appearance are represented in the voluntary sector, there are very few who represent disfigured people as a whole. This limits the range of information available to patients on the particular issues associated with disfigurement.

4.5 The internet, the media and commercial information

The internet

In recent years the internet has become a major source of information on health. A quick Google search for head and neck cancer yields 2,830,000 results; even craniosynostosis provides over 73,000. In the face of such an overwhelming amount of information, the patient's dilemma is hardly one of insufficiency, but rather how to make sense of it all and what to trust. The issue of quality and reliability in internet health sites has spawned an industry in its own right with a multiplicity of evaluation tools and guides. It is not clear, however, that patients (or indeed professionals) employ any of these when searching on the web.

I just type in Apert's and see what comes up...

Craniofacial patient

I don't go to particular sites to be honest. I'd use a search engine and whatever gives me the information, I'd use.

Head and neck professional

The majority of the patients in the focus groups had used the internet at some stage to find out about their condition and treatment, some even setting up their own websites for local support groups.

Well I did the website for the group and that's got links to Changing Faces, the Phoenix Society, the British Plastic Surgeons site...there's children's sites as well, burns camps and stuff.....it's got links to all the other global information centres on burns. There's burns chat rooms, there's burns message boards, there's burns forums for people to discuss these things.

Burns patient

With the intervention of the internet, you type in one word and it gives you everything you want.

Cleft parent

A number of studies have assessed the quality of health information sites although few relate specifically to disfiguring conditions. One such study evaluated all the web sites on the internet search engine Yahoo relating to burn scar treatment and management (Bohacek et al 2003). Using their own quality assessment tool, they grouped the websites

into 3 categories: commercial, academic and non-profit organisations. Of the 88 websites evaluated, the majority (77%) were commercial, 8% academic and 15% organisational. Information was found to be poor in the majority of commercial sites and excellent, very good or good in the majority of others. A similar study assessed the impact of the internet on the availability of information on wound care management (Bovill et al 2001). The largest proportion of sites accessed were commercially based (32%) and 23% specifically targeted patients mostly by advertising. The found that extensive searching was required to identify relevant information and concluded that an increase in the quantity and quality of wound care society sites was necessary to balance the commercial influence and improve patient education. Hu et al compared skin disease internet sites and found that most sites contained product information (Hu et al 2002). They concluded that until standards are introduced to regulate online information, patients are in danger of obtaining misinformation and buying ineffective products.

Patients in the focus groups recognised that information obtained from the internet cannot always be trusted and can vary in quality. But rather than deter people from using the internet, it simply meant that they used different sites in different ways.

If it was some important information that I needed to assess, I wouldn't necessarily take that from a website because I would want to know whether it was accredited or whether the information had been properly looked at or reviewed. But for general stuff, just reading other people's experiences, basically knowing what [son] might need doing in the future and the pros and cons of the different things that will be available to him, just really evaluating.

Cleft parent

I would use internet only for information not for trusting as far as treatments go.

Vitiligo Patient

Indeed, as Powell et al has suggested, perhaps the main difference the internet has made is in the quantity rather than the quality of information. The quality of information has always varied (Powell et al 2003). The way in which the focus group participants judge the reliability of the information on the internet appeared to be very subjective.

I'd just think that's not for me, it's not a matter of whether or not I trust it...it would be the style or the pictures, it would be just instinct more than anything.

Craniofacial parent

Some health professionals recognised the importance of the internet and accepted it as a fact of life.

There's so much available on the internet, it's the first thing people do these days, after a consultation is go home and find something themselves.....

Plastics professional

Patients are generally becoming more internet friendly and they often come with some form of information already that they've looked on the Internet and seen various bits and pieces.

Plastics professional

They also used the internet for their own medical education and to provide information to patients. It offers a major advantage over the traditional dusty piles of outdated leaflets that clog up cupboards and filing cabinets on wards and in outpatient departments.

If there's a diagnosis that a patient's been given that I haven't dealt with for a while then I'll look it up [on the internet] just to kind of refresh myself as well.

Head and neck cancer professional

If you can download stuff and give out to patients as and when rather than have to keep stockpiles of leaflets.

Burns professional

However many other professionals expressed misgivings about the increased use of the internet and were reluctant to refer patients to it. Concerns ranged from unfiltered information causing anxiety in patients and an increase in workload for clinicians.

I think the Internet is good for some things but I think it causes quite a lot of panic and the amount of patients that I've actually said to when they phoned up and said, "You know I'm looking on the Internet" and I've said, "OK, that's fine, I want you to stop doing that now".

Head and neck cancer professional

If someone's been on the internet, my heart sinks..... they've read everything about melanoma and it's all been the wrong stuff and they want this and they want that and they don't know anything about it really, but they've got completely panicked.

Plastics professional

The US domination of the internet means that much of the information patients find will inevitably be American. Patients and professionals had differing views as to its usefulness when many of the treatment and surgical approaches are different from those in the UK. It seemed that patients' views were largely subjective – what seemed a little over the top to one, was user-friendly to another. For one mother it was not the medical information that mattered, but the contact with families in a similar situation to her own.

Teeters Page you get lots of links.....and I was very aware that it would be very different in the States....and that the surgery would be different...but that wasn't what I was looking for...I wanted to find other people who were living that life.

Craniofacial patient

However, it should not be forgotten that not everyone has access to the internet or chooses to use it and a minority of patients in the focus groups preferred to get their information in other ways. The predominant socio-economic profile of some of the patient groups may also influence internet use.

I doubt many of the families have got computers or know how to get on the internet to be honest.

Burns professional

One way round this would be to provide internet access on the ward as suggested by one of the health professional in the focus groups.

The media

Although the media is acknowledged as a potentially important source of health information, in the literature on disfigurement, it is more often condemned for the way it stigmatises and pressurises us all to conform to an idealised appearance. Writing in the BMJ, McGrouther sees facial disfigurement as the last bastion of discrimination and suggests that if the media approached gender or sex in the way they portray those who look different they would be subject to prosecution (McGrouther 1997). One of the focus group participants echoed this theme.

I think Hollywood has got a lot to blame before because their perception of amputees is around baddies in movies, it is around Long John Silver, it is around Captain Hook, it is around the one armed man in the Fugitive. That is about the whole kind of image of disabled people. As far as I can remember there has not been a goody in a movie who has been an amputee.

Amputee

However, during the time that this study has been running, several television documentaries have addressed the issue of disfigurement. (Being Terri, ITV 2003; What Are You Staring At? BBC 2003; To Change My Child's Face, BBC 2004; In Your Face, BBC 2004; Face Transplant, C4 2004; The Boy Whose Skin Fell Off, C4 2004; When Your Face Doesn't Fit, BBC 2005; New Face, New Life, BBC 2005). Reactions to these programmes have varied. A review in The Observer newspaper, reports that The Boy Whose Skin Fell Off (a film about recessive dystrophic epidermolysis bullosa) divided the medical community (McKie 2004). Research charities like DebRA, which supports sufferers of the condition, approved of the film, but many doctors felt it was too explicit. There is, they suggest, a delicate balance to be struck between raising awareness and generating anxiety. Being Terri, a film about a little girl with 90% burns, was viewed by four million viewers and hundreds contacted the programme makers, inspired by her and her father's courage. Over three million viewers watched In Your Face, a documentary about birthmarks. Some of those who contacted the BBC expressed their admiration for the young woman who featured in the programme and her determination to overcome her lack of confidence.

Patients in the focus groups acknowledged that television could be a very powerful way to increase people's understanding of what it is like to live with a disfiguring condition.

I think anything that raises awareness of it would be helpful....when they had cases on these hospital programmes....lots of people came up to me and said, "Oh I didn't realise they had to have an operation like that."

Cleft parent

Other patients used the media as an additional source of practical information and advice.

Not only watching. I do read as well and if you read on a Tuesday or a Wednesday like the Daily Mirror, the Daily Express, they have a lot of articles as well on burns, disfigurement.

Burns patient

Responsible broadcasters now increasingly provide a support service to accompany their programmes and this can be very useful in pointing the way to other sources of information.

I've phoned the BBC Action Line...and what a service! Brilliant! So maybe that's it; instead of giving poor information, give a telephone number out and say phone this and they will point you in the right direction.

Plastics professional

Both patients and professionals were very aware of the shortcomings of the media. Patients felt that there was a danger of sensationalism and misinformation.

It has to be presented in the right fashion, it has to be not sensationalist, it has to be not gruesome....the only thing you want as a result of doing something like that is more understanding.

Craniofacial patient

Professionals were concerned that the current media interest in cosmetic surgery and celebrity disfigurement could lead to unrealistic expectations of reconstructive surgery which in turn impacts negatively on psycho-social rehabilitation.

I mean the media has a lot really to do with it, even television; it's like Space Odyssey 2005 where nobody would ever have a scar.

Plastics professional

I have had a 33 year old lady breaking her heart in front of mebecause she saw an article on [Heather Mills] doing what she does, ...and this ...lady who had just become an amputee 2 years ago thinks she is getting that leg and thinks she is going to look like Heather MillsIt creates a false expectation.

Amputee

Commercial information

Commercially produced information was not a major topic in any of the focus group discussions except in relation to the internet (see above). A few burn survivors referred to new research being carried out by commercial organisations which they followed in the hope of finding solutions for their own problems.

My Skin, a Sheffield companythat have got skin cell technology to make new skin.

Burns patient

But more focus group participants were concerned about the possible bias of commercial information and the danger of putting too much trust in the treatments they offered.

Pharmaceutical companies that are trying to sell these caps even to the public, we're having to try and warn people off because we've been told they're so dangerous.

Craniofacial parent

Amputees realised that even information on artificial limbs provided by the NHS had a commercial origin.

It is not impartial.....that is the whole point...all the stuff is commercially based because even though it is an NHS limb it has come from those who sell the component to the NHS.

Amputee

Commercial sponsorship could offer a solution to the problem of funding the provision of patient information within the NHS. Most of the professionals interviewed were prepared to consider this provided there were safeguards.

If you use a certain company a lot, will they want something back, as in terms of using their product or something, but if it's an understanding that you're using the stuff anyhow and we're looking for funding and they say yes, get it while you can.

Burns professional

Summary

The amount of information now available to patients from sources outside the NHS has grown dramatically in the past few years. Most of the health professionals interviewed accepted, albeit reluctantly in some cases, that their patients will inevitably be influenced by what they find on the internet or hear through the media. Many of the patients in the focus groups appreciated these additional information sources and although they may not always exercise the most rigorous quality controls, they have developed their own techniques for filtering and interpreting information. The following chapter looks at the way in which patients share information between each other.

4.6 Peer support

There was overwhelming emphasis, particularly from patients, on the importance of meeting with and talking to other patients who had undergone similar experiences to their own. This was seen as being as important as information provided by clinicians.

I've got as much information from other mothers as I have from the medical team.

Craniofacial parent

To be somebody that's been through it.....there's a qualitative difference in the information you get.

Burns patient

Professionals recognised the importance of peer support and sometimes actually facilitated this within the hospital setting although some of them were keen to emphasise that this was not an easy option and has to be carefully thought through and planned.

[the clinical nurse specialist] is looking into getting burns buddies, that's what they call them in America, but we're looking for a more British name of burns patients going on the ward to newly burnt people..

Burns patient

It could be a good thing or a bad thing...some parents could scare people off and others probably wouldn't give enough information or aren't capable of giving the information that's needed.

Craniofacial parent

In an article describing the development of a peer visitation programme for pre-operative amputee patients, Fitzgerald argues that such schemes allow the patient to speak directly with someone who has had a similar experience, enabling him/her to share feelings and concerns when clinicians may find it difficult to empathise (Fitzgerald 2000). Feber's focus group research with head and neck cancer patients in Leeds revealed that they wanted access to expert patients who have been through the same experience themselves and can give very specific advice on the recovery process and tips on coping (Feber 2003).

Amongst our own focus group participants, it appears that this kind of peer support usually came from the voluntary sector.

There was one particular girl last year who wanted more information about other children with burns....she went to the National Burns Children's Camp and found it very, very beneficial.

Burns professional

Patients gained reassurance, emotional support and practical advice from other individuals in the same or similar situation to themselves. It also enabled them to share information.

I think it's interesting and it's useful to talk to other people who have had a similar experience because they know what they're talking about, they've gone through things that you're going through and they've often got very practical, helpful advice.

Burns patient

Because we do meet on a regular basis it rather encourages you to look for information, to follow it up and bring it and to share that.

Burns patient

Peer support offers continuity of care to patients and their families after they have left the protected environment of the hospital.

I think the support groups are good for peopleto know that they are there so that once they are home, ..they are not completely set adrift.

Amputee

Peer support, whether organised by the health service or the voluntary sector, has to be timely and appropriate and is not necessarily valued by everyone. Feber found that in her head and neck cancer focus group, patients felt that support groups were for "other people". They recognised that they could be helpful, but that that they could also have a negative effect, bringing people down by dwelling on the difficulties. This attitude was shared by some of the patients in our focus groups who for various reasons chose to cope in their own way and perhaps felt too vulnerable to join a group.

I shy away from things like support groups I would never join a support group. I would find it a bit patronising.

Amputee

And I didn't see how talking to other people about how they had coped with it would actually be of any use to me, me coping with it because their experience of it would be different to my experience of it.

Head and neck cancer patient

I was quite keen to meet and speak to other families and [husband] didn't want to do that at all, he found the whole thing far too scary...

Craniofacial parent

Summary

Although not all the patients in the focus groups were interested in meeting and learning from others in a similar situation, the vast majority found the support they received from fellow patients to be indispensable. Although clinicians can provide the medical information they need, it seems that people who have faced the same problems can really know what it is like to cope with a disfiguring condition. The last section of the report compares the different attitudes patients express towards information and information seeking.

4.7 Variations in information seeking behaviour

Demand for information

The focus group discussions provided an indication of how information seeking behaviour can differ. Several participants actively sought information and this proactive approach seemed to be driven by a range of different factors. The mother of a child with a cleft lip and palate wanted to understand the condition better so she could rid herself of the guilt that she felt; a woman with vitiligo started researching her condition because she did not believe the health service could give her the information she wanted; the grandfather of a child with a craniofacial condition found becoming more informed helped him to cope.

He [grandfather] went on the internet very quickly and found all this stuff and that's how he copes.

Craniofacial parent

Attitudes towards information can also change over time as patients recover and become less willing to simply accept what they are told by their doctors.

You were told and you took the information, but now looking back at what knowledge we had, I always ask now can they do it better, that's why I do the research by looking at these programmes to gain a knowledge of what's going around, what's new.

Burns patient

Some groups revealed an almost desperate desire for any information that might reduce their suffering. A Burns patient said she'd "got to watch" anything on television about burns and a young man with vitiligo recommended anyone in a similar situation should

Gather as much information as you can, ...and get counselling, don't be ashamed, ask for help, if you don't get help from one doctor, go to another, until you are actually satisfied.

Vitiligo patient

On the other hand, some felt too much information might be unwelcome and difficult to deal with, especially if this involved the graphic details of a surgical procedure, for example. Others thought they might not have gone through with surgery if they had been told the consequences beforehand.

I think had they told me how I was going to look after the surgery then I probably would have been on a bike and on my way home.

Head and neck cancer patient

One patient who had had an eye removed did not think of looking for any additional information because she trusted her doctors to tell her what was wrong. A few actively rejected the opportunity to acquire information and again there were various reasons for this. A young man with a craniofacial condition did not want to be reminded of all the operations and procedures he had already endured, the mother of a very young child with Apert's syndrome simply wanted to be given time with her daughter to come to terms with her situation and a head and neck cancer patient wanted to cope with the disease in her own way.

I kept on being offered sources of information. I wasn't really that interested.

Head and neck cancer patient

The traditional differences between male and female attitudes towards information were apparent in some of the interviews and focus groups. Two of the mothers interviewed talked about their husbands being reluctant to seek out information and support, preferring to deal with it privately as a family.

We definitely deal with the situations differently, whether that's because I'm a female, he's a male.....not necessarily wanting to be involved or show that much interest and dig out for stuff like I would want to.

Cleft parent

The Cambridge University Informed Patient project acknowledges that although information can alleviate anxiety in some patients, for others "ignorance is bliss" (Detmer et al 2003). Some of the health professionals interviewed claimed that certain types of information could do more harm than good.

Well, we've got to consider that some people just don't want the information; they're scared by the whole prospect.

Plastics professional

But there is a risk that professionals underestimate patients' ability to cope with information which leads them to censor what they tell patients.

They could be reading that and absolutely, you know, frightened and you know, being terrified at the prospect of having all these different types of radiotherapy, so I have to be quite specific about what I want them to read.

Head and neck cancer professional

However, there is a growing body of evidence that suggests patients want quite detailed and specific information, even if it is unpleasant. In a focus group study with head and neck cancer patients, researchers found that, in direct contrast with the above comment, patients wanted “the horrible nitty gritty” about radiotherapy as preparation for both the treatment and its aftermath (Birchall et al 2002). Recognising how much information patients want and then supporting them in coming to terms with that information, is a difficult skill to acquire. Perhaps that is why some clinicians seem to adopt a less complicated approach, particularly when it comes to the implications of disfigurement.

I'm not aware that there's a groundswell of our patients who seem to require this sort of assistance and that's probably because we're not looking for it.

Plastics professional

Shared decision-making

Shared decision-making has been defined as “a process in which patients are involved as active partners with the clinician in clarifying acceptable medical options and in choosing a preferred course of clinical care” (Sheridan 2004).

It has been argued that the desire for greater involvement is restricted to younger and better educated patients (Krupat 2000). However, there appeared to be no particular correlation between age and class and the desire to take a more active role amongst the patients in the focus groups.

It is having the courage and the confidence to tell your consultants this is what you think, this is what you want. I have always thought the attitude that I have had towards my surgeon is that he is a contractor and that I think has coloured how he has dealt with me.

Head and neck cancer patient

The relationship between me and the two GPs is brilliant....they don't get annoyed with me because they know that I've got a bit of knowledge about it.

Burns patient

Some of the health professionals interviewed were sceptical about the extent to which patients want such an active role.

A significant proportion of our patients say that very thing to us. “I'm sure you'll do your best doctor” and you can see the shutters come down when you try to explain some of the intricacies and details of what you're going to be doing, they don't want to know, they just want to be, to hand themselves over to you.

Plastics professional

Asking questions

One of the most important aspects of the information process is the ability to ask the right questions. Some patients obviously found this more difficult than others. The mother of a child with craniosynostosis felt that coping with her child during a consultation left little time to ask questions.

You see [son] doesn't like anything going near his head.....so you spend all your time struggling with him and by the time that you're ready to do it, it's like "See you in a year."

Craniofacial parent

A burns nurse thought that the less assertive parent could easily allow themselves to be dominated by the consultant.

They can just get railroaded and....they'll just accept everything that's said and you stand there thinking, "No, you should question things more and ask why this is being done."

Burns professional

But several focus group participants had acquired the confidence over many years of treatment and found that the surgical team responded accordingly. Several others had learnt the value of writing down their questions in advance.

I've learned over the years to be very enquiring and I ask questions about everything and they don't see it as something I shouldn't need to know, they're always happy to take the time to answer my questions.I think they're brilliant at that.

Craniofacial parent

The informed patient

There clearly was a growing recognition amongst the health professionals interviewed that patients were becoming better informed and more likely to ask questions, but it seems that not all clinicians respond positively to these changes.

She had been down to the library, she'd been on the internet, she had looked at the type of implants they were going to use...the types of incision that could be done... and she had rang round all the local plastic surgery units....it got to the stage where she was nearly telling the consultant how to do the operation.

Plastics professional

Although one plastic surgeon was keen to point out that having a lot of information was not necessarily the same thing as having a good understanding, the patients interviewed were generally very well informed. However, in most cases this was because they had been coping with their own or their child's condition for several years and had gradually built up their knowledge base over time. This knowledge was reflected in the way they spoke:

Luckily, it escaped my hands and face and my face healed, which happens a lot if it's only a splash injury – the face does heal quite well.

Burns patient

Some patients and parents demonstrated a very sophisticated way of searching for and using the information they found. Different sources are used for different types of information and this information is then used in consultations with clinicians to obtain more information and aid decision-making. For example, conferences are seen as an

opportunity to meet people researching a particular condition and the internet is used as a way of finding out how others have coped, but also to prepare for a consultation.

If I was going to a consultation, really just to prepare myself for the sort of questions that I might want to ask the surgeon.

Cleft parent

In some cases, parents claimed they were actually teaching the clinicians.

I taught them how to put the NG tube down, the doctors couldn't even put the NG tubes down. What are we teaching them? The care, how they're developing.

Craniofacial parent

Cultural factors

Macmillan Cancer Relief has recently published two toolkits to help health professionals provide culturally sensitive and appropriate information to black and Asian people affected by cancer (Macmillan Cancer Relief 2002, 2004). The project steering group discovered two main areas of concern. On the one hand health professionals lacked an understanding of the specific information needs of these communities and on the other, black and Asian communities held certain misperceptions about cancer. Cultural taboos were found to exist which impeded access to information and support services. Although there were only a few black and Asian focus group participants, there was evidence that cultural issues can affect attitudes towards information about disfigurement. Two focus group participants expressed the particular problems they faced when coming to terms with disfiguring conditions.

Asians have a very big taboo with disfigurement.

Burns patient

I have an African background.....deformity is viewed as an abomination....they attribute it to a curse.

Cleft parent

In the case of this mother, such beliefs led her to seek out information on the causes of cleft lip and palate for herself.

I wanted to understand it better just to rid myself of the guilt of thinking it's probably my fault.

Cleft parent

Health Literacy

The National Consumer Council defines health literacy as "the capacity of an individual to obtain, interpret and understand basic health information and services in ways that are health-enhancing." (Sihota and Lennard 2004) The health professionals in the focus groups felt that not only do patients have varying levels of information needs, but their capacity to understand and interpret information can also differ widely. This is all the more pertinent in clinical areas like burns and head and neck cancer where the patients tend to come from more socially and economically deprived backgrounds, and amongst congenital disorders which may affect learning abilities. These difficulties were

recognised by the health professionals in our focus groups, but although those working with children seemed to tailor the information to the child's development level, there was less evidence that this was the case with adult patients. The problem can be further compounded by patients' reluctance to admit they cannot read.

I'm gob-smacked because he'd got through the whole of the surgery without actually revealing it.

Head and neck cancer professional

Some parents either don't care or they don't have the knowledge or the understanding to see why it matters what you're telling them.

Burns professional

The importance of normality

There does appear to be some correlation between a patient's attitude towards their condition and their attitude towards information seeking. Inevitably, focus group participants are self-selecting and tend to be drawn from those patients who identify themselves quite closely with their condition – this is even more so when groups are recruited via support and self-help organisations. However, there were a few individuals interviewed who clearly wanted to get on with their lives despite the difficulties they faced. For these people, there was a limit to how much information they wanted to be given or the number of procedures they wanted to put themselves or their children through. This attitude was most clearly expressed by the mother of a young child with Apert's who valued her relationship with another mother in the same situation because they gave each other normality and who did not want to be identified according to her child's condition.

We've been thrust into this situation.....ten years ago what I wanted was three kids and a house, a lovely husband and that's what I still want. I don't want to know about Apert's, I don't want to live a life that's run by medics... I don't want to sit and look at information on the internet every day....I'm sure some people do, but that's not where I get my comfort.

Craniofacial parent

Summary

Patients in the focus groups expressed a variety of views about their information needs. Although, the general trend was towards greater demand and an increased willingness to search for information themselves, the level of need varied between individuals and at different stages of their treatment. A number of factors clearly influence this, including cultural differences and the ability to understand and interpret information. Although the majority of those interviewed appeared to want a greater role in decision-making about their care, some had experienced the anxiety that information can bring and a few deliberately chose to limit the amount of information they sought.

5 Discussion

General information needs

A wide range of causes lead to disfigurement and loss of function. In order for the aims of the research to be realisable, we have inevitably been forced to limit the number of conditions considered. Even within the clinical areas we were able to investigate, information needs are extremely varied and complex. On the one hand, these patients share many of the same information needs as any other patient group. As the literature and focus groups demonstrated, they will need information on diagnosis, prognosis, treatment options, the implications of their condition, coping mechanisms, self-care and support groups. In addition to these general information needs, each individual condition will generate very specific information issues and many of these have been described in the main findings. What remains to be discussed is the extent to which disfiguring conditions give rise to common information needs. What kind of information needs do burn survivors and head and neck cancer patients, for example, share?

Information needs common to disfiguring conditions

The research highlighted two main issues common to disfiguring conditions. Firstly, there is a need for information that will help patients and those caring for them visualise how they will look following treatment or as they grow up. Secondly, there is an overriding need for information that will enable them to adjust psychologically to their appearance. From the evidence assembled at this stage of the study, it seems that much more could be done to address both these needs. Patients and clinicians were very aware of the dangers of forming unrealistic expectations regarding treatment, which in turn could impact negatively on psychological readjustment. Most information continues to be verbal or written. Although there are issues around getting permission to use patients' photographs, perhaps more could be done to offer visual indications of the recovery process. New technology may help address this problem in the future, but at the moment, scar simulators and bio-modelling are only used in a limited way. The availability of psychological support for this group of patients is extremely variable depending on the resources of individual hospital trusts and many professionals expressed concern about their lack of training for the demands placed upon them. This makes the need for basic information on how to cope with the emotional reactions and social difficulties many will experience even more important, yet few of our patients had received such information except via one particular charitable organisation.

Continuing information needs

All the conditions under discussion have long-term implications. The information needs of the patients interviewed changed over time, but did not necessarily diminish. Individuals talked about the importance of "being in the loop" so that they were kept up to date with any new research or developments that might improve their quality of life. This can present a problem for clinicians and other health professionals who have to prioritise their work, and place a greater burden on the patient to remain informed. Regular review clinics and support groups can offer a solution, but not all patients choose to access them even when they are available.

Meeting information needs face to face

The primary way in which health professionals continue to inform their patients is verbally in consultations. The medical staff interviewed clearly thought this was how patients should be informed and the patients generally endorsed this. However, this form of information provision, essential though it is, relies entirely on the communication skills of the clinicians involved and all the evidence indicates that these are infinitely variable. It is not surprising, therefore, that some of the patients interviewed had had very good experiences and others felt that their information needs had been very inadequately satisfied. Information provision is a two-way process. Patients need to be able to talk to their clinicians about their concerns, articulate the problems they are experiencing and provide feedback on treatment regimes. Professionals need to be able to assess how much and what information a patient can understand and assimilate at any particular time. When diagnoses and outcomes are uncertain, this can be very difficult to judge correctly and there is perhaps an understandable reluctance to provide detailed information about unpleasant side effects and complications if they may not even arise. Although the demand for information is generally growing, some medical staff clearly have not recognised this or risen to the challenge. The research does however suggest that the development of the clinical nurse specialist's role has done a great deal to improve this situation. It appears that they play a key part in the clarification, interpretation and tailoring of information that patients might otherwise find overwhelming and complex.

Supplementary information

Most of the professionals we interviewed wanted to provide better information to their patients and several were actively producing printed and audio-visual materials. A few centres had developed quite sophisticated production and evaluation processes, although no-one appeared to involve patients from the beginning as recommended in many guidelines and toolkits. However, many good intentions seem to be leading nowhere owing to the lack of time and resources. Despite evidence from the literature that verbal and written information together provide a more effective way of informing patients, a few, mainly medical staff, did not see supplementary information as a priority. There remains the problem of who will write this material if those with the expert knowledge to do so fail to recognise its importance. The availability of alternative formats also seems essential when a loss of function may have compromised a patient's ability to access written information. Department of Health initiatives in information provision do not seem to be reaching those at ward level. Efforts to reduce the amount of duplication may appear sensible, but there is still some opposition to the standardisation of information in areas like plastic surgery where clinical practices differ from hospital to hospital and even surgeon to surgeon.

The voluntary sector

Patient organisations have proliferated in the UK in recent years, but there are still only a very few that address the needs of patients with disfiguring conditions directly. This obviously restricts the amount of choice patients have when looking for information and support outside the NHS and burns patients in particular have virtually no alternatives to the self-help groups attached to the individual burn centres. With the exception of the large cancer charities, most of the organisations in the field have limited resources and inevitably this affects what they are able to provide. Nevertheless, those patients who use

voluntary groups appear to value the support very highly. Many charities enjoy good relationships with individual clinicians, but there is perhaps scope to explore ways in which their relationship with the NHS as a whole might be made more effective.

The internet

No discussion about health information can ignore the huge amount of material now available through the internet. Indeed it could be argued that the problem no longer seems to be one of shortage but of overload. Professionals may fret about the quality and reliability of this information, but patients generally seem to have benefited from its availability. There are problems however. Not everyone has online access, the sheer amount of information can be overwhelming, much of it is US dominated and there is a risk of undue commercial influence. On the other hand, the flexibility the internet offers, allowing patients to choose the timing and extent of their information searches, makes it ideal for patients whose information needs may change daily and over time. For patients affected by disfiguring conditions, the visual content is very helpful and for those who may find social encounters difficult, the ability to search anonymously is an added advantage. For all these reasons, it might seem that more use could be made of the internet within the health service. The development of cancer information centres with internet access staffed by professionals who can act as information guides could perhaps provide a model for other clinical areas such as burns and skin conditions.

The information process

The research indicates the extreme complexity of the process involved in the giving and receiving of information. What perhaps emerged more strongly than anything else is the importance of the way in which patients and clinicians engage in this process – or in a few cases, choose not to engage. In circumstances where the very way in which patients see themselves has been fundamentally affected, this exchange is particularly sensitive. Some health professionals clearly manage this situation well, but the evidence from the research and the focus groups implies that many more do not. To add to the complexity, the huge amount of information available outside the health service means that patients can become their own information managers. But the extent to which they will want or be able to take on this additional responsibility remains uncertain. In this rapidly changing environment, the provision of health information will have to become far more flexible to meet the growing sophistication of many patients whilst addressing the needs of less active information-seekers and also to allow for the fact that patients can and do demonstrate both characteristics at different times.

6 References

- Acton, A. (2004) "When we leave hospital: a patient's perspective of burn injury" In *British Medical Journal* 329: pp.504-506
- Ah-Fat, F G, Sharma, M C, and Damato, B E (1998) "Taping outpatient consultations: a survey of attitudes and responses of adult patients with ocular malignancy" In *Eye* 12: (5) pp.789-791
- Atkinson, A (2002) "Body image considerations in patients with wounds" In *Journal of Community Nursing* 16: (10) pp.
- Beale, R, Dachtler, J, Rhodes, N, and Southern, S (2002) "Use of a scar simulator to aid patients' understanding of postoperative scar outcome" In *British Journal of Plastic Surgery* 55: (5) pp.458-459
- Being Terri* (2003) Anglia TV
- Beresford, B and Sloper, T. (2000) *The information needs of chronically ill or physically disabled children and adolescents* Social Policy Research Unit, University of York)
- Birchall, M, Richardson, A, and Lee, L (2002) "Eliciting the views of patients with head and neck cancer and carers on professionally derived standards of care" In *British Medical Journal* 324: pp.
- Bohacek, L., Gomez, M., and Fish, J. S. (2003) "An evaluation of internet sites for burn scar management" In *Journal of Burn Care Rehabilitation* 24: (4) pp.246-251
- Bovill, E. S., Hormbrey, E, Gillespie, P. H., and Banwell, P. E. (2001) "Accessing wound care information on the internet: the implications for patients" In *Journal of wound care* 10: (2) pp.23-26
- Brown, L, Evans, J, and Tucker, K (2005) *Developing the school re-integration programme at the Welsh Centre for Burns* British Burns Association)
- Burr, S and Gradwell, C (1996) "The psychosocial effects of skin diseases: need for support groups" In *British Journal of Nursing* 13: (5) pp.1177-1182
- Caress, A-L (2003) "Giving information to patients" In *Nursing Standard* 17: (43) pp.47-54
- Clarke, A (2001) "Managing the psychological aspects of altered appearance" In *Patient Education and Counseling* 43: (3) pp.307-311
- Clarke, A. and Cooper, A. C. (2001) "Psychosocial rehabilitation after disfiguring injury or disease: investigating the training needs of specialist nurses" In *Journal of Advanced Nursing* 34: (1) pp.18-26
- Cleft Lip and Palate Association (1996) *Review of current treatment for young children with cleft lip and palate* Cleft Lip and Palate Association)
- Cleft Lip and Palate Association (1999) *Raising awareness of cleft lip and palate amongst frontline health professionals* Cleft Lip and Palate Association)

- Collings, M. J. (2004) "Reflections on rehabilitation: the AB Wallace Lecture to the BBA Conference April 2003" In *Burns* 30: (1) pp.49-56
- Coulter, A, Entwistle, V, and Gilbert, D (1998) *Informing patients* King's Fund)
- D-Urso, P. S., Atkinson, R. L., Lanigan, M. W., and Earwaker, W. J. (1998) "Stereolithographic (SL) bio-modelling in craniofacial surgery" In *British Journal of Plastic Surgery* 51: (7) pp.522-530
- Department of Health (2004) *Better information, better choices, better health* (London, Department of Health)
- Detmer, D. E., Singleton, P. D., MacLeod, A., Wait, S., Taylor, M., and Ridgwell, J. (2003) *The informed patient: study report* (Cambridge, Judge Institute of Management, University of Cambridge)
- Edwards, D (1998) "Head and neck cancer services: views of patients, their families and professionals" In *British Journal of Oral and Maxillofacial Surgery* 36: pp.99-102
- Eiser, J. R. and Eiser, C (1996) *Effectiveness of video for health education: a review* (London, Health Education Authority)
- Expert group on the regulation of cosmetic surgery (2005) *Report to the Chief Medical Officer* Department of Health)
- Face Transplant* (2004) Channel Four
- Fallowfield, L. and Jenkins, V. (1999) "Effective communication skills are the key to good cancer care" In *European Journal of Cancer Care* 35: (11) pp.1592-1597
- Feber, T (1997) *Oral and maxillofacial cancer: a strategy for support* (Leeds, Leeds Teaching Hospitals)
- Feber, T (2003) *A qualitative analysis of the information needs of patients undergoing treatment for head and neck cancer using focus groups* University of Leeds)
- Fitzgerald, D. M. (2000) "Peer visitation for the preoperative amputee patient" In *Journal of Vascular Nursing* 18: (2) pp.41-44
- Garlick, W (2003) *Patient information: what's the prognosis?* (London, Consumers' Association)
- Garlick, W. (2000) *Matching service provision to patient need* Consumers' Association)
- Gibson, J (2001) "Lower limb amputation" In *Nursing Standard* 15: (28) pp.47-54
- Glavassevich, M, McKibbon, A, and Thomas, S (1995) "Information needs of patients who undergo surgery for head and neck cancer" In *Canadian Oncology Nursing Journal* 5: (1) pp.9-11
- Godwin, Y. (2000) "Do they listen? A review of information retained by patients following consent for mammoplasty" In *British Journal of Plastic Surgery* 53: (2) pp.121-125
- Gradwell, C, Thomas, K S, English, J S C, and Williams, H C (2002) "A randomised controlled trial of nurse follow-up clinics: do they help patients and do they free up consultants' time?" In *British Journal of Dermatology* 3: pp.513-517
- Hibble, V, Lyne, D, and Thomas, C (2005) *To audit the effectiveness of written information and written advice given to patients and their families at the West Midlands Paediatric Burns Service* British Burns Association)

- Hu, W, Siegfried, E C, and Siegel, D M (2002) "Product-related emphasis of skin disease information online" In *Archives of Dermatology* 138: (6) pp.775-780
- In Your Face* (2004) BBC 1
- Jeffery, S. L. A and Boorman, J. G (2001) "Patient satisfaction with cleft lip and palate services in a regional centre" In *British Journal of Plastic Surgery* 54: pp.189-191
- Jenkins, H. M. L., Blank, V., Miller, K., Turner, J, and Stanwick, R. S. (1996) "A randomized single-blind evaluation of a discharge teaching book for pediatric patients with burns" In *Journal of Burn Care Rehabilitation* 17: (1) pp.49-61
- Johnson, A, Sandford, J, and Tyndall, J (2003) "Written and verbal information versus verbal information only for patients being discharged from acute hospital settings to home" In *Cochrane Database of Systematic Reviews* (4) pp.
- Katz, M R, Irish, J C, and Devins, G M (2004) "Development and pilot testing of a psychoeducational intervention for oral cancer patients" In *Psycho-Oncology* 13: (9) pp.642-653
- Kemper, D. W. and Mettler, M (2002) *Information Therapy* Boise ID: Healthwise Inc)
- Kennedy, I (2001) *Report of the Inquiry into the Care and Management of Children Receiving Complex Heart Treatment between 1984 and 1995* Bristol Royal Infirmary Inquiry)
- Kim, M K and Alvi, A (1999) "Breaking the bad news of cancer: the patient's perspective" In *Laryngoscope* 109: pp.1064-1067
- Krupat, E. et al (2000) "The practice orientations of physicians and patients: the effect of doctor-patient congruence on satisfaction" In *Patient Education and Counseling* 39: (1) pp.49-59
- Larner, S., Ross, E. van, and Hale, C. (2003) "Do psychological measures predict the ability of lower limb amputees to learn to use a prosthesis?" In *Clinical Rehabilitation* 17: pp.493-498
- Legro, M. W., Reiber, G., Aguila, M. del, Ajax, M. J., Boone, D. A., Larsen, J. A., Smith, D. G., and Sangeorzan, B (1999) "Issues of importance reported by persons with lower limb amputations and prostheses" In *Journal of Rehabilitation Research* 36: (3) pp.155-163
- Macmillan Cancer Relief. (2002) *Macmillan Black and Ethnic Minority Toolkit: 1. Effective communication with South Asian people affected by cancer.* Macmillan Cancer Relief
- Macmillan Cancer Relief (2004) *Macmillan Black and Minority Ethnic Toolkit: 2. Effective communication with African-Caribbean and African men affected by prostate cancer.* Macmillan Cancer Relief
- Maidment, I. R. (2004) *Patient information for patients living with Head and Neck Cancer* Modernisation Agency)
- Martin, V (2005) "Prenatal cleft lip and palate parent programme - phase 1 and 2" In *British Journal of Midwifery* 13: (2) pp.90-100
- McGrouther, D. A. (1997) "Facial disfigurement - the last bastion of discrimination" In *British Medical Journal* 314: (7086) pp.991-

- McKenzie, A, Cubison, T, Toland-Mitchell, F, Johnson, L, Ponniah, A, Sanger, L, and Reid, C (2005) *Multidisciplinary follow-up after scald injury - outreach issues and conclusions* British Burns Association)
- McKie, Robin (2004) *Diary of death is too graphic* The Observer
- Mortimer, C. M., MacDonald, R. J. M., Martin, D. J., McMillan, I. R., Ravey, J., and Steedman, W. M. (2004) "A focus group study of health professionals' views on phantom sensation, phantom pain and the need for patient information" In *Patient Education and Counseling* 54: pp.221-226
- Mortimer, C. M., Steedman, W. M., McMillan, I. R., Martin, D. J., and Ravey, J. (2002) "Patient information on phantom limb pain: a focus group study of patient experiences, perceptions and opinions" In *Health Education Research* 17: (3) pp.291-304
- Muthu, K. D., Symonds, R. P., Sundar, S., Ibrahim, K., Savelyich, B. S. P., and Miller, E. (2004) "Information needs of Asian and white British cancer patients and their families in Leicestershire" In *British Journal of Cancer* 90: (8) pp.1474-1478
- National Cancer Alliance (2002) *Head and neck cancer patients: views and experiences* National Cancer Alliance)
- New Face, New Life* (2005) BBC 1
- Newell, R (2002) "Living with disfigurement" In *Nursing Times* 98: (15) pp.34-35
- Newell, R and Clarke, M. (2000) "Evaluation of a self-help leaflet in treatment of social difficulties following facial disfigurement" In *International Journal of Nursing Studies* 37: pp.381-388
- Office of Population (1988) *Census and Surveys* Office of Population)
- Partridge, J (1990) *Changing Faces: the challenge of facial disfigurement*. Changing Faces
- Powell, J. A., Darvell, M., and Gray, J. A. M. (2003) "The doctor, the patient and the world-wide web: how the internet is changing healthcare" In *Journal of the Royal Society of Medicine* 96: (2) pp.74-76
- Ransome, S and Ward, S (2000) "Information and support for people with eczema" In *Nursing Standard* 14: (20) pp.43-44
- Ritchie, J. and Spencer, L. (1994) "Qualitative data analysis for applied policy research" In Bryman, A. and Burgess, R. G. (Ed) *Analyzing Qualitative Data* (London, Routledge)
- Scott, J. T., Harmsen, M., Pictor, M. J., Entwistle, V. A., Sowden, A. J., and Watt, I. (2005) "Recordings or summaries of consultations for people with cancer" In *Cochrane Library* 3: pp.
- Semple, C (2001) "The role of the CNS in head and neck oncology" In *Nursing Standard* 15: (23) pp.39-42
- Semple, C J and Allam, C (2002) "Providing written information for patients with head and neck cancer" In *Professional Nurse* 17: (10) pp.620-622
- Semple, C J and McGowan, B (2002) "Need for appropriate written information for patients, with particular reference to head and neck cancer" In *Journal of Clinical Nursing* 11: (5) pp.585-593

- Sheridan, S. L. et al (2004) "Shared decision making about screening and chemoprevention: A suggested approach from the US Preventive Services Task Force" In *American Journal of Preventive Medicine* 26: (1) pp.56-66
- Sihota, S and Lennard, L (2004) *Health literacy: being able to make the most of health* (National Consumer Council)
- So, K, Umraw, N, Scott, J, Campbell, K, Musgrave, M, and Carlotto, R (2003) "Effects of enhanced patient education on compliance with silicone gel sheeting and burn scar outcome: a randomised prospective study" In *Journal of Burn Care Rehabilitation* 24: (6) pp.411-417
- Stafford, N D, Lewin, R J P, Nash, P, and Hardman, G F (2001) "Surgeon information giving practices prior to laryngectomy: a national survey" In *Annals of the Royal College of Surgeons of England* 83: (6) pp.371-375
- Stewart, R, Bhagwanjee, A M, Mbakaza, Y, and Binase, T (2000) "Pressure garment adherence in adult patients with burn injuries: analysis of patient and clinician perceptions" In *American Journal of Occupational Therapy* 54: (6) pp.598-606
- Syed, S B, Moulton, B, Linward, J, and Soon, K (2004) *Producing high quality information on vascular birthmarks for children* (London, Great Ormond Street Hospital for Sick Children)
- The Boy Whose Skin Fell Off* (2004) Channel Four
- Thompson, A. and Kent, G. (2001) "Adjusting to disfigurement: processes involved in dealing with being visibly different" In *Clinical Psychological Review* 21: (5) pp.
- Thompson, R, Boyle, D, Teel, C, Wambach, K, and Cramer, A (1999) "A qualitative analysis of family member needs and concerns in the population of patients with burns" In *Journal of Burn Care Rehabilitation* 20: (6) pp.487-496
- Tilley, W, McMahon, S, and Shukalak, B (2000) "Rehabilitation of the burned upper extremity" In *Hand Clinics* 16: (2) pp.303-318
- To Change My Child's Face?* (2004) BBC2
- Toland-Mitchell, F, Sanger, L, and Johnson, L (2005) *Multidisciplinary follow-up of paediatric scalds - therapy and psycho-social perspectives* (British Burns Association)
- What Are You Staring At?* (2003) BBC 2
- When Your Face Doesn't Fit* (2005) BBC One
- Whyte, A. and Niven, C. A. (2004) "The illusive phantom: does primary care meet patient need following limb loss?" In *Disability and Rehabilitation* 26: (14-15) pp.894-900
- Ziegler, L, Newell, R, Stafford, N, and Lewin, R (2004) "A literature review of head and neck cancer patients information needs, experiences and views regarding decision-making" In *European Journal of Cancer Care* 13: pp.119-126

7 Appendix

7.1 Topic guide for patient focus groups

Introduction

Explain that the purpose of the group discussion is to:

- Ascertain the information needs of patients with [condition].
- Ascertain what information is currently available to them.
- Establish how this information is disseminated
- Evaluate specific information materials currently available about [condition].

The Picker Institute Europe is an independent organisation working with healthcare providers to improve the quality of care from the patient's perspective.

Picker has been asked to undertake a research project on behalf of The Healing Foundation, a national charity established to champion the cause of people living with conditions that affect their appearance. We'll be talking to health professionals and running 10 focus groups amongst different patient groups.

The discussion should last about 2 hours. It will be tape recorded to make the analysis easier, but it will remain anonymous – all names will be removed and no comments will be attributable to an identifiable individual. We'll go round the table once to introduce everyone and then start the discussion.

Background information

Introduction: As you know everybody in this group is here because they have had or are being currently treated for [cancer/burns/dermatological condition/congenital disorder]. The main purpose of the discussion is to talk about information material.

Diagnosis

Who did you first talk to when you thought something was wrong/had the accident?

Which medical professional did you see? (*Probe: GP; hospital doctor, nurse, friend, relative etc*)

What information were you given about your condition at that stage – by the doctor, nurse etc?

Did you use any other information sources such as PALS or hospital information centres?

Was it the right kind of information for your needs at the time?

Was it too little/too much information?

How was it given to you? (*Probe: verbal, written, referrals to other sources of information*)

What did you need to know?

Treatment

How were you informed about the treatment you would receive? (*Probe: by whom, when, verbal, written*)

Were you given information about different treatment options?

Were you told about the possible outcome of the different treatments? (*Probe: loss of function*)

Were you told about the cosmetic consequences of the different treatments? (*Probe: disfigurement, scarring*)

Did you use any other sources of information about treatment? (*Probe: internet, media, family and friends, support groups, neighbours*)

What information were you given about any further treatment/surgery you would require?
When were you given this information? (*Probe: scar reviews, treatment plans*)

Self-care

What information was provided when you were discharged? (*Probe: care of wounds, possible complications, what to do if condition worsens*)

Who gave you this information and how? (*Probe: doctor, nurse, other – verbal, written, other*)

Was any information provided about the psycho-social aspects of living with a condition that affects your appearance? (*Probe: getting back to work, school, coping with stares and comments, intimate relationships, social situations*)

Were you given any information about voluntary organisations/support groups?

What information did you obtain from other sources such as magazines, TV etc?

Information: general

Which information sources have you found most useful and why? (*Probe: health professionals, books and leaflets, internet, media, support groups, family and friends*)

How do you like to get your information? (*Probe: verbally, written, audio-visual, interactive*)

How easy was to find information?

.....

Could you trust all the information you found?

What would help you trust information?

The kite system perhaps?

How easy was it to understand the information?

How have your information needs changed over the course of your condition/since the accident?

How well informed do you feel you've been during the course of your condition/since the accident?

When would you have liked more information? What kind of information?

Has a lack of information led to any problems?

Have you ever received conflicting information from different health professionals?

Where should information be available? (*Probe: hospital, GP surgery, library, internet, TV, other*)

Completion of Questionnaires about Information Materials

Participants will be asked to study different information materials relating to their condition. They will then be asked to complete a short questionnaire for each piece of information material.

Reactions to information materials

Which did you prefer overall? Why?

Which did you least prefer? Why?

Overall, which factors make good information material?

Future Possibilities

Have you heard of Digital TV?

Do you like the idea of patient-held electronic medical records?

Have you heard of Health Space on the net?

Good Information

Can you give examples of information which you have found useful?

Conclusion

Ask for any other comments. Thank everyone for their participation.

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7.2 Topic guide for health professionals focus groups

Introduction

Explain that the purpose of the group discussion is to:

- Ascertain what information is currently offered to patients
- Establish how and when this information is given to patients
- Evaluate specific information materials currently available about [condition].

The Picker Institute Europe is an independent organisation working with healthcare providers to improve the quality of care from the patient's perspective.

Picker has been asked to undertake a research project on behalf of The Healing Foundation, a national charity established to champion the cause of people living with conditions that affect their appearance. We'll be talking to health professionals and running 10 focus groups amongst different patient groups.

The discussion should last about one hour. It will be tape recorded to make the analysis easier, but it will remain anonymous – all names will be removed and no comments will be attributable to an identifiable individual. We'll go round the table once to introduce everyone and then start the discussion.

Locally produced information

Do you produce your own information for patients?

If not, why not? (*Probe resources, time, editorial processes*)

If you do, what format is this in? (*Probe: written, video, audio, multi-media, on-line*)

What topics are covered? (*Probe: treatment options, surgical outcomes, after-care, psycho-social support, support groups*)

Who is responsible for co-ordinating the production of information material? (*Probe: clinical staff, information department, PALS etc*)

Are you happy with the way the process for producing local information works? (*Probe: too much interference from trust; trust guidelines; editorial committees*)

Do you check to see if something suitable already exists?

Do you involve patients in the production and or evaluation of information material? (*Probe: how this is done*)

Do you provide information in languages other than English?

Are you happy with the standard of information produced? (*Probe: consistency, style, currency*)

What funding is available to support the production of information material? (*Probe: from the trust, from commercial sources, from charities*)

What are your views on commercial sponsorship?

Nationally available information

Do you offer patients any nationally produced information?

If so, who are the main producers of this material? (*Probe: charities, professional organisations, commercial organisations, NHS etc*)

What are the strengths and weaknesses of this material? (*Probe: relevance, accuracy, clarity, objectivity*)

If you don't offer any nationally produced material, why not? (*Probe: resources, lack of knowledge of what's available*)

Do you use the internet to obtain patient information?

Do you refer patients to the internet?

Have you any favourite websites?

Overall

How well informed are patients before you see them? (*Probe: information they have found on the internet, from friends and family*)

Would you like to offer patients more information?

On what topics? (*Probe: treatment options, surgical outcomes, after-care, psycho-social support, support groups*)

Giving information to patients

When do you offer information to patients? (*Probe: diagnosis, treatment planning, discharge, outpatients etc*)

Who gives information to patients? (*Probe: consultants, junior doctors, nurse specialists, psychotherapists etc*)

Is there a central place where patients can obtain information? (*Probe: hospital library, reception area, outpatient area etc*)

What is the balance between verbal and other types of information?

Do you keep a record of consultations for patients? (*Probe: diaries, audio-recordings*)

Are there any barriers to giving information to patients? (*Probe: lack of time, language problems, fear of creating inducing anxiety*)

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General

Do you think it's possible to produce standardized patient information?
(Probe: central resource; content bank)

How necessary is it to tailor information to individual patients and for individual clinical settings?

To what extent do you think you are an interpreter of information rather than a provider of information? *(Probe: correcting misunderstandings, guiding patients to other information sources, information overload)*

Future possibilities

How much are you aware of the NHS Knowledge Service and NHS Direct Online?

Canvass opinions on:
National Content Bank
NeLH
Digital TV
Commercial information systems eg Patient Line

Completion of Questionnaires about Information Materials

Participants will be asked to study different information materials relating to a particular condition. They will then be asked to complete a short questionnaire for each piece of information material.

Reactions to information materials

Which did you prefer overall? Why?

Which did you least prefer? Why?

Overall, which factors make good information material?

Conclusion

Ask for any other comments. Thank everyone for their participation.

7.3 Topic guide for voluntary sector organisations

Introduction

Explain that the purpose of the group discussion is to:

- Ascertain what information is currently offered to patients
- Establish how and when this information is given to patients
- Evaluate specific information materials currently available about a range of disfiguring conditions.

The Picker Institute Europe is an independent organisation working with healthcare providers to improve the quality of care from the patient's perspective.

Picker has been asked to undertake a research project on behalf of The Healing Foundation, a national charity established to champion the cause of people living with conditions that affect their appearance. We have been talking to health professionals and patients.

The discussion should last about one hour. It will be tape recorded to make the analysis easier, but it will remain anonymous – all names will be removed and no comments will be attributable to an identifiable individual. We'll go round the table once to introduce everyone and then start the discussion.

Information produced by the voluntary sector

Do you produce your own information for patients?

If not, why not? (*Probe resources, time, editorial processes*)

If you do, what format is this in? (*Probe: written, video, audio, multi-media, on-line*)

What topics are covered? (*Probe: treatment options, surgical outcomes, after-care, psycho-social support, support groups*)

Who within the organisation is responsible for co-ordinating the production of information material? (*Probe: staff/volunteers/clinicians/etc*)

Are you happy with the way the process for producing information works? (*Probe: editorial committees*)

Do you check to see if something suitable already exists?

Do you involve members in the production and or evaluation of information material? (*Probe: how this is done*)

Do you provide information in languages other than English?

Are you happy with the standard of information produced? (*Probe: consistency, style, currency*)

What funding is available to support the production of information material? (*Probe: from the trust, from commercial sources, from charities*)

What are your views on commercial sponsorship?

Do you use instruments to quality check information material produced? (*Probe: DISCERN etc*)

Overall

How well informed are patients/members before they contact you? (*Probe: information they have found on the internet, from friends and family*)

Would you like to offer patients/members more information?

On what topics? (*Probe: treatment options, surgical outcomes, after-care, psycho-social support, support groups*)

General

Do you think it's possible to produce standardized patient information? (*Probe: central resource; content bank*)

Are you able to tailor information to individual patients and for individual clinical settings?

To what extent do you think you are an interpreter of information rather than a provider of information? (*Probe: correcting misunderstandings, guiding patients to other information sources, information overload*)

Relationship with the NHS

What is your relationship with the NHS as far as patient information is concerned? (*Probe: plugging a gap in the provision of patient information*)

Do you work collaboratively with the NHS?

How important is it to produce information independent of the NHS?

Future possibilities

What is the role of the voluntary sector as provider of patient information in the future?

Do you have any suggestions about how patient information production/dissemination might be improved in the future?

How much are you aware of the NHS Knowledge Service and NHS Direct Online?

Canvass opinions on:
National Content Bank

NeLH
Digital TV
Commercial information systems eg Patient Line

Completion of Questionnaires about Information Materials

Participants will be asked to study different information materials relating to a particular condition. They will then be asked to complete a short questionnaire for each piece of information material.

Reactions to information materials

Which did you prefer overall? Why?

Which did you least prefer? Why?

Overall, which factors make good information material?

Conclusion

Ask for any other comments. Thank everyone for their participation.

7.4 Guidelines and toolkits

Title	Publisher	Description
Lynda Jackson Macmillan Centre and the Mount Vernon Cancer Centre procedure for producing written information	Mount Vernon Cancer Network	12 point plan on 2 A sheets (2003)
EQIP: Ensuring Quality Information for Patients	GOSH	30 page assessment tool and quality check (2004)
How to produce information for children and families	GOSH	12 page support tool (2004)
Toolkit for producing patient information	NHS	24 page booklet including templates (version 2 Dec. 2003)
Raising the Standard: Information for Patients	The Royal College of Anaesthetists and The Assoc of Anaesthetists of GB (www.rcoa.ac.uk)	144 page book + CD. Principles, samples of current practice and new text (2003)
Involving consumers in the development and evaluation of patient information	Centre for Health Information Quality	Fold-out topic bulletin (1999)
Guidelines for Reviewers of Health Information	Centre for Health Information Quality	4 page booklet (2002)
How to produce information for parents, children and young people	Birmingham Children's Hospital	13 page booklet (2003)
Macmillan Black and Ethnic Minority Toolkit: 1 Effective communication with South Asian people	Macmillan Cancer Relief www.macmillan.org.uk	40 page ring-binder format (2002)
Macmillan Black and Ethnic Minority Toolkit: 2 Effective communication with African-Caribbean and African men affected by prostate cancer	Macmillan Cancer Relief	56 page ring-binder format (2004)
DISCERN	British Library and The University of Oxford www.discern.org.uk	6 page instrument for judging the quality of written information (1997)
Producing information about health and health care interventions: a practical guide	Health Services Research Unit, University of Aberdeen	45 page book (2003)
Good Practice Resource Pack for cancer self help and support groups	Cancerlink www.cancerlink.org	Ring-binder format with section on giving information
The plain English guide to writing medical information	Plain English Campaign www.plainenglish.co.uk	11 page guide downloaded from internet
Improving the patient and carer experience across Cancer Services Collaborative "Improvement Partnership"	NHS Modernisation Agency	14 page quick guide to ensuring that cancer patients and carers are offered high quality information
Improving Communication in Cancer Care	NHS Modernisation Agency	13 page document setting out basic principles in communication improvement

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