



Audit

The information needs of head and neck cancer patients prior to surgery

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Objective: To describe the common themes in the experiences and expressed information needs of patients undergoing head and neck surgery.

Summary background data: Patients who suffer head and neck cancers and undergo surgery often report considerable psychological distress and impaired social functioning. To optimise survival, the decision about what treatment option to follow is often made quickly, with little support in terms of counselling or the provision of information. There is inadequate previous work exploring the content and delivery of information required by patients at this time.

Patients and Methods: Participants included patients who had undergone surgery for head or neck cancer ($n = 29$) and their immediate relatives who were present at the initial consultation with the surgeon ($n = 13$). Patients were recruited from out-patient departments in two hospitals in the north of England. All interviews were conducted in participants' homes and were guided by a semi-structured interview schedule devised both from literature and a pilot study.

Results: Whilst most participants felt well informed about the surgical procedure they were undergoing, many reported feeling unprepared for the long-term lifestyle changes that occurred. Information, support and advice throughout the 3–6 months postoperative period was reported to be inadequate. The majority of participants did not ask any questions and did not perceive there was a choice regarding treatment. Individuals who wanted to take an active role in decision-making reported difficulties accessing information to enable them to do so.

Conclusion: The findings of this study emphasise the need for individualised information provision defined not exclusively by the surgical procedure.

Key words: Cancer – Head and neck – Laryngectomy – Information

Head and neck squamous cell carcinoma (HNSCC) comprises approximately 4% of all solid tumours in the UK. Because of the anatomical site of this disease, long-term problems with morbidity are disproportionately large when compared with tumours at other sites. Difficulties with speech, swallowing and physical appearance are all

common results of surgical, and indeed radiotherapeutic, treatment. The largest subgroup of HNSCCs is cancer of the larynx and pharynx for which the overall 5-year survival is of the order of 25%. It is, therefore, not surprising that this patient group frequently suffers significant long-term psychological morbidity.¹ The relationship between

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psychological distress and head and neck cancer has previously been attributed largely to image disturbance and functional difficulties inherent in the disease and treatment process. More recent research suggests that unmet information needs may contribute significantly to psychological distress.² Considering the potential consequences of treatment for head and neck cancer and the poor long-term prognosis, relatively little previous work has been undertaken to explore head and neck cancer patients' information needs.

The National Cancer Alliance³ held a discussion group for 10 patients who had undergone surgery for head and neck cancer. All respondents said they wanted information to be readily available and be provided by a specialist professional who had good communication skills. Edwards⁴ reported that information giving for patients with head and neck cancer is generally poor. In the postal questionnaire conducted by Stafford *et al.*² only 55% of surgeons routinely discussed cure and survival rates for each possible treatment, even though such information is an integral part of obtaining informed consent and clinical risk management of such patients.

Patients and Methods

A total of 42 people participated in structured interviews, 29 of whom were patients. Of the 29, 14 had previously undergone a laryngectomy, 9 had undergone radical neck dissections and 2 had had oral cavity or oropharyngeal tumours treated surgically.

Thirteen relatives or close friends of the patient who were present at the consultation where consent for surgery was sought and agreed to participate also took part. The experience of head and neck surgery patients at the time they are asked to consent to surgery and their possible information needs at this time are not known. Moreover, the aim of the study was principally to explore the characteristic experiences and needs of patients prior to constructing instruments for a more representative survey. For these reasons, probability sampling was neither possible nor necessary. Purposive sampling was employed. This is an accepted non-probability method of sampling that aims to achieve adequate numbers of respondents to describe common aspects of the experiences and views of a group where inadequate research had previously been undertaken.

The numbers needed were decided on during data collection on the basis of the point at which data become 'saturated' (*i.e.* when no new themes emerged from the data). An independent review of transcripts was undertaken to ensure sampling adequacy and showed saturation had occurred after 29 patients and 13 relatives/friends had been interviewed.

An interview schedule was devised from the literature, discussions with professional colleagues and pilot interviews

with patients and relatives. In exploratory interviews, it is important that the agenda remains relatively open. However, since the current study had a specific focus on experiences of consultation and information at the time of diagnosis and treatment decision, the guide questions and probes were relatively focal and asked respondents to describe their perceptions of what had happened during the interview when they were told their diagnosis and need for surgery, including how information was given to them, how well they felt they understood the information given, how involved they felt in treatment decisions and what other information they would have liked to have received.

Patients who met the study criteria were recruited from out-patient departments in the participating hospitals. Consent was sought at this time and the research officer arranged to meet and interview the participant in the patient's home. Appropriate consent to continue and to tape record interviews was again sought on commencement of the interview. The interviews were conducted according to the interview schedule and a sample of tapes and transcripts were independently examined to ensure consistency of interviewing approach and avoidance of leading respondents' replies or prematurely closing topics during the interview.

Data analysis occurred alongside data collection, using the method of constant comparison to assess the point at which data became saturated to the extent that no new themes were emerging. The principal form of analysis was content analysis to identify categories and themes emerging from responses to the open question elements of the interview schedule.

Results

A total of 42 people participated in the interviews of whom 29 were patients, 9 female and 20 male. Mean age of male participants was 65 years, mean age of female participants was 63 years.

Content of information

The type and amount of information individual patients wanted regarding surgery differed enormously and the information patients received did not reflect the diversity of their needs. In the majority of cases, patients appear to have been offered a package of information that seemed to relate exclusively to the type of surgery they were facing (Tables 1 and 2).

Interestingly, several patients found out they had cancer before the consultation in which the surgeon officially told them their diagnosis. Some patients reported overhearing discussions about their diagnosis during investigative procedures (Table 3).

Table 1 Topics participants wanted information about prior to surgery

Potential communication difficulties	10
Potential difficulties eating and swallowing	13
Psychological adjustment and coping	8
Time-scales to judge own progress against	7
Length of time hospitalised	10
Appearance after surgery	7
Support groups	3

Table 2 Opinions about and response to volume of information and manner presented

Opinions	
Too much information	6
Too little information	14
Unable to understand information	11
Wanted individualised information	18
Wanted truth and honesty	9
Response to information	
Felt shock numbness	18
Caused anxiety	6
Reduced anxiety	8
Facilitated coping	10

Table 3 Participants' perceptions of how adequately they were prepared for surgery

Ill-prepared for altered appearance	6
Ill-prepared for lifestyle change	6
Ill-prepared for functional difficulties	13
Ill-prepared for long-term adjustment	5
Adequately prepared for altered appearance	5

Many people were dissatisfied with the amount of information provided generally and expressed concern about not being able to control the information they received. Several patients said that although they did not appreciate the significance of the information they were given at the time, its significance became apparent during the recovery process.

Some patients felt there was a need to know of things that might happen so they could feel prepared. Others found information about uncertain possibilities difficult to deal with. This was particularly the case when it involved issues around diagnosis and prognosis.

Patients often reported difficulty absorbing information. This appeared to be related to the fact that almost all information about treatment was given during the same consultation as diagnosis (Table 4).

The way the information was given was significant for most patients. The use of medical jargon and technical terms often adversely affected the participant's ability to understand the information adequately. Often participants found it necessary to gain information from other sources such as the internet or support groups to help them to understand what they had been told in the consultation. When participants were asked how they felt about receiving information about treatment at the same time as diagnosis, most perceived there to be no alternative due to the urgency of much of the surgery.

In all but one of the cases, the diagnosis and the information about treatment was given by the surgeon. Frequently, however, there were several others in the room whilst the surgeon gave information. Several participants thought that this was unsatisfactory because of the lack of privacy and patients felt inhibited about asking questions (Table 5).

Very few patients chose to attend appointments alone. The majority of patients attended with relatives or close friends reporting primarily that they provided emotional support.

Most participants perceived there to be no choices to be made by themselves regarding treatment options but considered this to be the responsibility of the doctor. The few participants who wanted to be involved in decision-making experienced difficulty accessing the information that would have enabled them to do so (Table 6).

When participants were asked if they thought they had a choice about whether or not they had any treatment at all, most explained that they were aware if they did not have the treatment they would have died (Table 7).

There were some common themes in participants' psychological responses to their diagnosis and consequent treatment. Almost all attributed difficulties absorbing information to feeling in shock or dazed when told their diagnosis. Most participants had only a vague recollection of this time and it was not possible to determine accurately how long this period of shock or numbness lasted.

Participants varied in their desire to be given detailed information about their appearance; some reported that if they knew what they were going to look like, they would be

Table 4 Barriers to satisfactory delivery of information

Problematic use of medical jargon	12
Given at same time as diagnosis	18
Noisy environment	10
Not reinforced by written information	9
Others in room	6
Hearing problems	5
Lack of time	5

Table 5 Factors reported as enhancing satisfaction with information giving

Opportunity to ask questions	10
Attended appointment with a relative	11
Reinforced with written information	8
Felt able to control the interaction	12
Adequate time available for discussions	8

Table 6 Participants' perceptions of the decision-making process

No choice of treatment	16
Patient challenged doctors opinion	2
Advice offered by specialist nurse	4
Patient made choices about treatment	2
Patient thought doctor knows best/is expert	12
Lack of time for discussions	6

Table 7 Psychosocial impact

Shock/numbness	18
Onset of depression	6
Disruption to social life	6
Altered friendships/relationships	12
Disruption to career	15
Lifestyle change, no holidays, etc.	17
Difficulty adjusting to altered appearance	12
Isolation	8

Table 8 Physiological impact

Difficulty eating	16
Difficulty communicating	15
Weight loss	21
Pain	10
Loss/alteration of taste	8

even more frightened. Many elderly male participants said that their appearance was of little consequence and focused on the fact that the surgery would hopefully cure them of the disease.

Several participants explained how they became depressed or 'low' several months after the surgery because their relief at surviving the illness in the short term began to be over-shadowed by the fact that fundamental changes to their lifestyle had occurred. There was little professional support available to participants at this time (Table 8).

Discussion

Patients were almost always given the information about their treatment at the same time as they were told their diagnosis. This presented problems primarily with absorbing information, many patients reporting being unable to recall exactly what they were told. This appears to be common practice. A national survey of head and neck surgeons undertaken by Stafford *et al.*² found that the great majority gave information about treatment at the same time as the diagnosis.

Whilst the surgeon almost always gave the diagnosis, the role of the clinical nurse specialist was often to be present in the consultation room and provide the opportunity for further discussion following the consultation.

Often the information that was routinely provided focused on the functional difficulties that were likely consequences of surgery, including difficulty eating or loss of speech. There was a fundamental need for information to be given in a way that reflected the individual needs of the patient. The importance of individualised information provision had also been identified by The National Cancer Alliance,³ Scott and Lenert⁵ and Edwards.⁴ This study reinforces their recommendations that information should be

individualised for specific patients and not simply individualised to specific surgical procedures or diagnosis. Patients expressed unique needs that could not be predicted by the type of treatment they were facing.

This presents a number of difficulties for the information provider in terms of determining individual patient's needs. It seems that an accurate prediction of patient information needs by the surgeon would be unrealistic given the fact that they appear to be ever changing throughout the illness journey. Successful individualisation of information seems to occur when the patient is able to control the consultation in a way that enables them to access information they would find beneficial whilst avoiding information they may find detrimental. This suggests that further work should focus on what can be done by the information provider to enhance the patient's ability to control the type of information they receive. This may require information sources to be broadened and protracted along the course of the illness journey.

Conclusions

Whilst appreciative of their management, the patients in this study not only felt they were not getting all the information that they required, but that they were not receiving information in the way that would be most helpful to them. At present, a consultant ENT surgeon spends approximately 15 min giving the patient their diagnosis and discussing their planned treatment. It is essential that there should be more than one opportunity for the patient to discuss his or her management and that such consultations should occur in an appropriate environment. This study forms part of a programme of work leading to a general survey of patient information needs and the construction of a decision support package for patients. It is intended that this future work will further explore the potential for consultations and information accessing opportunities to be structured in a way that enables individual needs to be met.

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