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Medical audit

Surgeon information giving practices prior to laryngectomy: a national survey

ND Stafford[1], RJP Lewin[2], P Nash[2], GF Hardman[3]

[1]*Academic Surgical Unit, Department of Head & Neck Surgery, Hull Royal Infirmary, Hull, UK*
[2]*Department of Health Studies and* [3]*Centre for Health Economics, University of York, York, UK*

Prior to the proposed development of a pretreatment counselling package for patients with cancer of the larynx or pharynx, a study was undertaken to determine current information giving practice prior to laryngectomy. A postal questionnaire was sent to all UK ENT consultants registered in the *Medical Directory*. The response rate was 88%, with 48% meeting the study's entry criteria. Counselling practice varies widely. Surgeons report an average of 15 min available for discussion with the patient: 84% gave the diagnosis and discussed the treatment options at the same consultation. The size of the department, as measured by cases seen per year, did not correlate with the consultation time although it did with the numerous different issues discussed. Whilst the survey supports the need and desire for an appropriate counselling package, many surgeons feel that they alone know what the patient's information needs are.

Key words: Laryngectomy – Cancer – Services – Survey – Counselling

In 1996, 5071 new cases of carcinoma of the larynx and pharynx were reported in England and Wales.[1] Over the same period, approximately 796 patients underwent a total laryngectomy as treatment for cancer of the laryngopharynx. Although an established and effective treatment for advanced disease, this operation carries with it serious potential long-term sequelae, over and above the acute complications that can occur after any major upper aerodigestive tract surgery. Chronic morbidity can result from one or more of the following: (i) loss of voice; (ii) swallowing problems; and (iii) coping with a permanent tracheostomy.

The 5-year survival figures for T4 laryngeal cancer treated by laryngectomy vary between 25–50%.[2,3] This figure falls to less than 10% for patients with T4 pyriform fossa cancer.[4] It is, therefore, not surprising that patients with laryngeal cancer also frequently suffer significant long-term psychological morbidity as a result of their treatment. The psychosocial effects of laryngectomy can be profound, with approximately 30% of patients

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Correspondence to: Prof. ND Stafford, Academic Surgical Unit, Department of Head & Neck Surgery, Alderson House, Hull Royal Infirmary, Anlaby Road, Hull HU3 2JZ, UK

manifesting clinically significant levels of depression. If these burdens were not enough, many patients also harbour a continuing concern regarding the possibility of recurrence of their disease. The overall risk of suicide in head and neck cancer patients is approximately 1%.[5]

It has been demonstrated in other patient groups that the psychological morbidity following treatment of cancer can be improved by appropriate patient counselling. In a review of the literature on psychosocial aspects of head and neck cancer, Pryn *et al.* commented that the psychosocial adjustment of a substantial number of patients was poor and counselling efforts had not kept pace with the medical management of laryngeal cancer.[6] DeBoer demonstrated that the head and neck cancer patients' perception of the quality of the information that they received is positively related to a number of important rehabilitative outcomes.[7] The study looked at three patient groups: those with T_1 laryngeal tumours treated by radiotherapy, those treated by laryngectomy and those undergoing composite oral cavity or oropharyngeal resection. Open discussion of the illness in the family, social support and perceptions of adequate information from the specialist were the most important predictors of positive rehabilitation outcomes. Indeed, high appreciation of information given by the specialist correlated positively with more self-confidence in oral presentation, fewer specific head and neck and psychosocial complaints, fewer feelings of depression, and greater self-esteem. At a time where there is a drive to treat head and neck patients on a multidisciplinary basis, the presence of other team members such as radiotherapist, specialist nurse, dietician and speech language therapist is vital in order that the patient can obtain advice about their condition and treatment from as many perspectives as possible.[8] The frequent lack of input from more than one member of the head and neck team to such crucial consultations must be to the patient's disadvantage. Tobias expressed the opinion that treatment decisions should be far more thoroughly discussed before implementation than is currently the case.[9] The perceived quality of information giving has been linked to a number of post-surgery outcomes and the King's Fund survey[10] revealed that many patients believe themselves to be poorly supported. Such resentment may foster the conditions in which litigation becomes more likely. Whilst in the past patients could have been expected to remain ignorant of possible alternative treatment strategies, with different levels of psychosocial morbidity and quality of life expectations, many patients now have access to electronic databases such as PubMedline and patient-led 'support groups' on the Internet.

Methods and Results

Before developing a counselling package for patients diagnosed with cancer of the larynx or pharynx who may be treated by surgery, we conducted a postal survey of all consultant ENT surgeons who undertook laryngectomies in NHS hospitals in the UK. The intention was to find out the actual current practice of information giving and what surgeons thought should be current practice given more appropriate circumstances. In view of the Calman Hine philosophy that bigger centres provide better cancer services, it was also of interest to us to see whether the size of the caseload had any influence on the quality of information given.

The surgeons were identified from the *Medical Directory* and were sent a questionnaire previously piloted on local surgeons. Those not responding received two reminder letters. Of 529 questionnaires sent out, 467 (88%) were returned, of which 195 did not meet the entry criteria because; the surgeon did not perform major laryngopharyngeal surgery (155), had retired (36), had moved or had already returned questionnaire (12), had no time to complete it (3), had died (3), objected to unsolicited questionnaires (2), had no interest in the subject (1), or was on long-term sickness absence (1). A total of 254 questionnaires were analysed. Surgeons reported having an average of 15 min (mode 15 min, SD 7.4 min, range 1–45 min) available for discussion with each patient. This time was regarded as adequate by 124 (49%), inadequate by 107 (42%), and very inadequate by 23 (9%). The number of professionals in the head and neck team was not related to whether or not the individual surgeon thought the patient's consultation time was or was not adequate. Of the total, 213 (84%) surgeons gave the diagnosis **and** discussed the treatment options at the same consultation; 201 (79%) thought that patients should routinely have a second consultation if time allowed before starting treatment, but only 163 (64%) routinely provided one. Surgeons who did discuss cure and survival rates with patients (55%) took significantly longer over the consultation compared with those who did not (a mean of 17 min compared with a mean of 12 min; $P = 0.002$). Those who only discussed the issues if asked by the patient to do so (29%) provided a mean time of 13 min for the consultation. The length of the consultation was not related to whether or not treatment options were discussed at the time that the diagnosis was given. When seeing patients prior to treatment, approximately 40% of surgeons failed to discuss routinely the cure and survival rates for the treatments available.

The size of the department, as judged by the number of cases seen per year, did not correlate with the number

Table 1 Matters covered during consultation

	Yes n (valid %)	No n (valid %)	If the patient asks n (valid %)
Do you discuss the cure and survival rates for each of the possible treatment options with every patient?	140 (57)	31 (13)	73 (30)
Do you routinely tell patients about the effects of each of the possible treatment options on the following aspects of quality of life:			
Swallowing difficulties?	222 (89)	16 (6)	10 (4)
Speech production?	252 (100)	0 (0)	0 (0)
Altered appearance?	217 (87)	19 (8)	13 (5)
Problems in communicating with others?	230 (93)	11 (4)	7 (3)
Saliva production problems?	128 (52)	95 (39)	23 (9)
Possible effect on relationship?	52 (22)	133 (55)	56 (23)
Common complications?	231 (93)	11 (4)	7 (3)
Further medical procedures that may be required?	142 (58)	61 (25)	40 (17)
Post-treatment pain?	148 (60)	64 (26)	32 (13)
Daily routines required for speech devices?	146 (62)	70 (30)	20 (9)
Psychological sequelae (*e.g.* depression, embarrassment)?	93 (38)	97 (40)	52 (21)
Day-to-day activities (*e.g.* swimming)?	145 (58)	52 (21)	52 (21)

of ancillary staff (professions allied to medicine, PAMS) included in the information giving process or with the time given to the individual patient. However, it did correlate with the amount of information given in terms of issues covered.

Table 1 provides a summary of the frequency with which various issues are covered during what is often the patient's sole pre-treatment consultation.

The extent of the advice routinely given to patients regarding various aspects of treatment and the surgeon's

Table 2 Current advice giving, information that should be given and attitude to the involvement of others

	Yes (%)	No (%)	If the patient asks (%)
Do you discuss the cure and survival rate for each of the possible treatment options with every patient?	57	13	30
Do you think our material should state these?	56	37	6
Do you routinely tell patients about the effects of each of the possible treatment options on the following aspects of quality of life:			
Swallowing difficulties?	89	6	4
Speech production?	99	0	
Altered appearance?	87	8	5
Problems in communicating with others?	92	4.5	3
Saliva production problems?	52	39	9
Possible effect on relationship?	22	55	23
Common complications?	92	4	3
Further medical procedures that may be required?	58	25	16
Post-treatment pain?	60	26	13
Daily routines required for speech devices?	62	30	8
Psychological sequelae (*e.g.* depression, embarrassment)?	38	40	21
Day-to-day activities (*e.g.* swimming)?	58	21	21
Should our material discuss the effects of the different treatment options on the following aspects of quality of life:			
Swallowing difficulties?	94	4	2
Speech production?	99	1	0
Altered appearance?	92	5	3
Problems in communicating with others?	95	2	3
Saliva production problems?	82	12	5
Possible effect on relationship?	71	16	13
Common complications?	94	5	1
Further medical procedures that may be required?	75	16	10
Post-treatment pain?	85	9	6
Daily routines required for speech devices?	87	7	5
Psychological sequelae (*e.g.* depression, embarrassment)?	80	10	10
Day to day activities (*e.g.* swimming)?	91	3	6

Table 3 Which aspect of the initial information giving and discussion would the surgeon be prepared to delegate to other members of staff (e.g. nurse, speech and language therapist) if they were using evidence based information leaflets and decision aids designed to convey risk and benefits?

	Yes	No
They could help by discussing quality of life issues	93	7
They could help by discussing possible psychological sequelae	90	10
They could help by giving information about what will happen during treatment	84	12
They could help by giving the patient the diagnosis	10	90
They could help by giving survival information for various treatment options	9	87
They could help patients make decisions about their treatment	41	59
They could talk to the patients but they should not influence the patient's treatment choice	80	20
They should only be involved after the doctor and patient have made their decisions	60	40
If the pack met all the criteria you have stated above would you be likely to use it?	94	6

views as to what information should be given to patients in an information pack are summarised in Table 2. From Table 3, it is clear that the majority of surgeons are only willing to delegate certain aspects of information giving, such as quality of life issues and possible psychological sequelae after treatment. However, they do not feel that such information should influence the patient's choice of treatment. Indeed, 60% thought that other staff should only be involved in the information giving process after the doctor and patient had reached a decision regarding treatment.

Were a counselling package to be developed for this group of cancer patients, 94% of surgeons said they would use it if it met certain criteria. However, 37% did not feel that such a package should routinely discuss the issues of cure and survival.

Discussion

This survey appears to support the opinion of Tobias[9] and Edwards[10] that information giving for patients with head and neck cancer is generally poor. Particularly worrying is the fact that only 55% of the surgeons canvassed routinely discuss the cure and survival rates for each possible treatment. Providing this information is an essential part of obtaining informed consent, integral to clinical risk management and clinical governance.[11] A failure to provide such information is not only ethically questionable but, in the era of clinical governance, it may expose the Trust concerned to serious financial consequences. It must also be questioned whether 15 min is sufficient time for a true dialogue and hence for informed consent to be obtained. This is particularly so when it is common practice to tell the patient that they have a cancer with a low overall survival rate at the same consultation. Certainly, less than half of the surgeons regarded the consultation time available as adequate. However, more time may not be all that is required. The content of the information currently provided may not be meeting all of the patient's needs. Although the major long-term sequelae are discussed routinely with the majority of patients and issues such as postoperative pain and effects on daily living commonly covered, the discussion of psychological sequelae such as possible effects on relationships and mood are largely neglected.

In a survey of 100 cancer patients undergoing radiotherapy in Exeter, 22% had no memory of giving consent, 25% had no memory of being told of the side effects of treatment and none remembered being told about the possibility of a second malignancy.[12] Of course, patients may forget what they have been told, but it is the oncologist's duty to inform each patient appropriately.

A crucial part of the counselling process is providing patients with information regarding their proposed treatment and follow-up. For those patients with advanced disease, radiotherapy has a lower long-term survival rate but is less mutilating than surgery; therefore, patients may have a complex decision to make regarding this trade-off. Following laryngectomy, a number of authors have found that laryngectomees consistently report that they wish they had received more preoperative counselling and information.[13,14] It is notable that Pryn reported that 25% of patients did not know that they would be unable to breathe through their nose after laryngectomy.[6] This desire of the patient to be told more is in contrast to the observation by Stam *et al.*[15] that up to a quarter of 294 physicians reported that too much information might lead a patient to refuse surgery. That may well be so: McNeil *et al.*[16] observed that treatment choices were made on the basis of the patient's attitudes toward the quality as well as the quantity of survival. A previous study by the same group demonstrated that some patients with operable lung cancer would choose radiation therapy over surgery, even though the latter offered a higher probability of long-term survival.

The majority of surgeons begin what may be the sole pretreatment consultation by breaking the news to the patient that they have a cancer with a poor prognosis. Following receipt of such news, it has to be questioned how much further information a patient will take in. Patients with advanced disease may face a difficult choice between radiotherapy and surgery, which have different risks and different effects of subsequent quality of life. It has recently been questioned if the role of radiotherapy is always adequately presented.[17] Although surgeons reported that the obvious physical sequelae, *e.g.* voice production problems, were always presented, other common problems such as postoperative pain and the effects on daily living were less commonly discussed. The possible long-term psychological consequences of radical surgery were relatively neglected. These deficits are unlikely to be met by others because many of this group of surgeons have no access to counsellors or specialist nurses.[10]

Healthcare staff concerned with clinical risk management and clinical governance should ensure that the time and resources required to meet patients' information and psychosocial needs are available and that the giving of information is audited and routinely recorded.

Whilst this survey would appear to support the need and desire for the development of an appropriate counselling package for patients with cancer of the laryngopharynx, it also emphasises the fact that a truly multidisciplinary approach to the pretreatment management of these patients is still some way off. Surgeons continue to feel that they know what is best for the patient and it will be important to make any counselling materials acceptable to them, otherwise they will not be used.

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