

Evaluation of functional outcomes (speech, swallowing and voice) in patients attending speech pathology after head and neck cancer treatment(s): development of a multi-centre database

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Abstract

Since April 1997, in Melbourne, Australia, speech pathologists have collaborated to establish a prospective database of functional outcomes of speech, swallowing and voice for patients undergoing head and neck cancer treatments.

Staff at eight acute care hospitals, all of which offer speech pathology for head and neck cancer services in Victoria, are contributing data, collated centrally, in an agreed pro forma.

Early results are given (after 12 months' data collection). The implications for clinically-based research, and the future potential for benchmarking outcomes – by expansion of the rehabilitation database beyond the current participating sites – is discussed.

This paper outlines the rationale of establishing the database is multicentred, and explores some of the complexities involved, including the challenges inherent in long-term accurate data collection in the head and neck cancer patient population. This work represents the development of an appropriate, usable tool for data collection on functional outcomes.

Key words: Speech-Language Pathology; Deglutition; Head and Neck Neoplasms; Treatment Outcome; Databases

Introduction

Rehabilitation services in the form of Allied Health intervention (speech and language therapy; physiotherapy and occupational therapy) are often costly and the outcomes are unknown with little/no widely-used predictors of rehabilitation outcomes available. The speech pathology service provision for speech, voice and swallowing rehabilitation after head and neck cancer treatments is patchy and, to date, there has been no large scale study in Australia evaluating current practice and outcomes.

Against this background, many patients are selected for speech pathology interventions in rehabilitation that may prove to be ineffective, and many others do not achieve maximal rehabilitation services, but receive services that do not necessarily meet their needs, or are never referred for rehabilitation.

'Success' in cancer treatments is often defined as mortality or whether or not the underlying pathology is controlled. As Morton¹ stated, this is often inappropriate as a patient does not seek treatment on the basis of a diagnosis, but rather on the nature

of their symptoms. This conflict can lead to the paradox of a medically 'good result' but an unsatisfactory outcome from the patient's perspective.

Enderby² points out that outcomes in this area are often measured exclusively on the basis of impairment³ that is used in most health services as a measure of change. This function concerns the loss, or abnormality, of any anatomical, physiological, psychological structures or functions – but is only one measure of outcome and focuses on the somewhat limited medical model of illness, presenting disease and its process in terms of aetiology, pathology and manifestation.⁴

A more helpful model, specifically in rehabilitation, might be to examine the sequence underlying health phenomena. This model defines the relationship between impairment, disability and handicap.

Disability reflects the consequences of impairment in terms of functional performance or activity levels by the individual, and represents disturbances at a personal level.

Handicap is concerned with the disadvantages experienced by the individual as a result of impairments and disabilities. Such handicaps reflect interaction with, and adaptation to, the individual's surroundings. Therefore, handicaps can only be defined in terms of the circumstances in which disabled people find themselves in relation to peers and society, and not according to the individual alone.

A fourth aspect might be added to this model: distress. There has been much work in assessing outcomes of patients, but largely with those who have undergone surgical procedures, using the dimensions of disability and distress.⁵

This model of disability is potentially important in assessing outcomes in a meaningful way for people who have been diagnosed with cancer of the head and neck and who have undergone treatment processes.

Although functional outcomes of treatment in terms of speech, swallowing and voice status are important and relate to overall patient satisfaction with cancer treatment, there is little systematic inclusion of these parameters in most reported studies of treatment outcomes. There is no clear information about the effect of cancer (let alone the effect of treatment) on speech and swallowing and there is little in the literature about the effectiveness of speech pathology in rehabilitating these patients post-treatment.

Rationale for study

There is a need to examine outcomes of the speech pathology service for the rehabilitation of patients, much of which is costly and unproven in terms of value to patient/carer. There is a need to provide an evidence-base for practice in the current Australian health service that, against the background of cash shortage and over-demand on resources, needs to develop a reliable means to audit outcomes from treatment provided.

This study seeks to address the gap between examination and evaluation of current rehabilitation services to head and neck cancer patients, using speech pathology settings in Victoria, Australia. This is innovative clinical research with the potential to radically evaluate clinical practice in this area.

Various attempts at evaluation of treatment outcomes in terms of quality of life (QOL) in head and neck cancer patients have been made.⁶⁻¹⁴ These usually involved sub-groups of the cancer patients – e.g. longitudinal study of laryngeal cancer patients, or small numbers of patients who have undergone experimental organ-preservation protocol⁷ but there has been no systematic evaluation of functional outcomes of speech and swallowing in a large number of treated head and neck cancer patients, as assessed by the patient and speech pathologist (with agreement score), nor correlation of these swallowing and speech outcomes with overall patient perception of QOL.

Because of the difficulty in researching outcomes of speech pathology intervention in rehabilitation of head and neck cancer patients due to a plethora of

interacting factors, many of which are not able to be controlled, it was initially planned to undertake a two-year pilot study to examine speech pathology services and rehabilitation outcomes in Victoria and, once the database methodology had been shown to be appropriate and/or refined, a later stage would be to (a) extend the study into qualitative assessments of patient experiences of cancer care and (b) to 'benchmark' outcomes of cancer care in Victoria, Australia (which has eight centres offering multi-modality treatment) with other, perhaps larger, cancer centres e.g. in the UK, where more patients are treated.

Aims

This project aims to:

- (1) establish in Victoria a collaborative demographic database of patients who undergo treatments for head and neck cancer with a view to examining patterns of treatment and morbidity (speech, swallowing, voice, quality of life (QOL) resulting from such treatments;
- (2) measure quantitatively the speech and swallowing sequelae from existing cancer treatments in Victoria;
- (3) measure objectively (i.e. quantitatively) outcomes from existing rehabilitation practices in Victoria;
- (4) correlate these results with an examination (using well-established qualitative research methodology) of how well treatments have met the needs of patients and carers, specifically by auditing speech pathology practices.
- (5) The eventual aim is to obtain measures and predictors of 'good functional outcomes' from mapping prospectively the path of rehabilitation of head and neck cancer patients.

This paper describes the methods and results of the first two aims above.

Materials and methods

Subjects

All head and neck cancer patients who attend speech pathology rehabilitation provided at eight main cancer centres in Victoria were to be entered into the project. The data collection for this project was prospective, over two years, having commenced in April 1997, with a following year to finish data collection by April 2000, when final results were analysed. There were no exclusion criteria in terms of age, site, extent of cancer – all attendees of speech pathology services with a diagnosis of head and neck cancer were included in this study.

Method

A collaborative speech pathology database of patients who had undergone treatment(s) for head and neck cancer was developed over six months, by speech pathologists in Victoria, to prospectively examine the functional outcomes (of speech, swallowing and voice) in head and neck cancer patients and to provide a profile of referral pattern and

PATIENT'S FIRST VISIT

Is the patient having surgery?

Yes

No

WAIT until surgery is completed

Is the patient having radio- and/or chemotherapy

Yes

Pre-therapy assessment
Fill in
DIAGNOSIS and
STATUS forms

No

WAIT until radio and/or chemotherapy treatment is completed

Post-surgery assessment
Fill in DIAGNOSIS
SURGERY and
STATUS forms
(prior to discharge or at 14 days whichever is first)

Post-DXT/chemotherapy assessment
Fill in RADIO/CHEMO
SURGERY (if required)
and STATUS forms

After 3 months

3 months post therapy assessment
Fill in: STATUS forms

After 6 months

6 months post therapy assessment
Fill in: STATUS forms

After 12 months

12 months post therapy assessment
Fill in: STATUS forms

FIG. 1
Schedule of forms to be completed.

service provision. Data was recorded immediately post-treatment and at three, six and 12 months. This was collected in clinics externally and collated centrally by the database manager at La Trobe University. In order to identify the morbidity resulting from surgery, radiotherapy and other interventions, a model of data entry was agreed whereby the speech and swallowing data at differing time points in differing treatment regimes could be collected (Figure 1).

This study was prospective, and divided into three phases: Phase 1: to establish and trial a multi-centre database of patients and therapies undergone; Phase 2: a description of clinical and speech pathology practices in rehabilitation of head and neck cancer patients; Phase 3: an evaluation of practice outcomes.

Data design, collection and analysis

Three versions of the data entry forms underwent trial before the final version was agreed.

It was agreed that there would be a maximum of four initial data entry forms for each speech pathologist to complete: diagnosis, surgery (if appropriate); radiotherapy/chemotherapy (as necessary); and status forms (both therapist and patient completed). At three, six and 12 months, status forms were again completed by both speech pathologist and patient (see Figure 1 for data entry points).

Results

Phase 1

All data were collected manually by the individual speech pathologist and coded by the database manager for entry onto the central computerized database, using MS Access database.

Diagnosis forms included details such as: status of disease; primary site of cancer; TNM status; current planned treatment(s).

Surgery forms included data with respect to: surgical intent; operative procedure; grade of tumour; structures sacrificed; peri-operative morbidities. Chemo/radiotherapy forms included data about: intent of course; regime; whether planned therapy was completed; toxicities.

Patient status forms included ratings of: activity; recreation; pain; employment; health; appearance; speech; taste; respiration; overall quality of life (QOL) and comparative quality of life (C-QOL). These forms were completed by the patients while waiting for speech pathology sessions or, where patients were no longer attending therapy, at follow-up of three or six months, the forms were sent, completed and returned by post (Appendix 1).

Clinician status forms (i.e. rated by speech pathologists) were based on the Enderby² therapy outcome measures (TOM) and scored, using a five point scale, impairment (speech, swallowing); disability; handicap; distress (Appendix 2).

Inclusion of a 1–10 swallowing severity scale, ALSSS, previously developed and used with patients with motor neurone disease, was also scored.¹⁵

When patients transferred centres, examination of intra-clinician reliability using the clinician status forms was performed, and this indicated where confusion or disagreement had occurred – discussion and clarification at the regular (three monthly) database meeting ensued, resulting in better levels of agreement. Voice status was rated – modes included laryngeal, oesophageal and tracheo-oesophageal (TEP) speech – and whether or not an augmentative or alternative communication source was used.

Phase 2

One hundred and fifty-eight (123 male; 35 female) subjects were recruited in 12 months in 1997 from eight cancer centres in Victoria. Seventy-four of these patients had been seen previously but represented to speech pathology with ‘new’ problems following recurrence and further cancer treatment and 84 were referred having had no prior cancer treatment. As head and neck cancer is a notifiable disease in Australia, the Anti-Cancer Council of Victoria (ACCV) cancer registry recorded that there were 656 and 510 new cases of head and neck cancer in Victoria in 1994, 1995 respectively (latest years for which completed figures are available).

These figures excluded tumours of the nose and sinus but included tumours of the larynx, hypopharynx and oral cavity.

A range of single and combined modality treatments – surgery, radiotherapy and chemotherapy – was received by all the patients who were registered on the speech pathology database.

It was surprising to us that the referral rate to speech pathology was so low in each centre. In one centre (hospital 3) there was a higher referral rate to speech pathology than the ACCV had head and neck cancer patients registered for that centre. This occurred because patients who were referred for speech pathology had their cancer diagnosed (and thus were identified on the Anti-Cancer database by being registered) elsewhere, but in fact received speech pathology services at hospital 3.

Although we would acknowledge that not all head and neck cancer patients require speech pathology services, it would nevertheless seem that an approximate level of 16 per cent overall referral rate to speech pathology in Victoria was rather low.

The statistics provided by the Anti-Cancer Council of Victoria revealed the total number of registered patients and this was compared with the numbers who received speech pathology (see Table I). It can be seen that there was a low uptake for referral to speech pathology in many centres, with idiosyncratic patterns of referrals.

Regimes for cancer treatments have varied somewhat across patients, even when they apparently present with similar cancer staging and status. Interestingly, there is as much intra-centre variability as inter-centre variability in choosing the mode of radiotherapy or surgery regimes that were to be given to patients. This finding will be discussed in a later paper.

TABLE I

COMPARISON OF TOTAL NUMBER OF REGISTERED HEAD AND NECK CANCER PATIENTS IN VICTORIA WITH THOSE WHO WERE REFERRED TO SPEECH PATHOLOGY IN 12 MONTHS

Hospital	New cases in database 1997/8	1995 Anti-cancer Council data	Percentage
1	4	17	24
2	5	29	17
3	8	2	400
4	18	36	50
5	10	173	6
6	17	45	38
7	13	40	33
8	5	13	38
Other	4	276	1
Total*	84	510	16

*Anti-cancer Council cases may have been notified by more than one hospital which is why total is not a sum of hospitals' data.

In assessing the 84 'new' cancer patients, Tables II, III, IV indicate the cancer treatments given, with oral, pharyngeal and laryngeal cancers respectively shown by T-stage. There was no more consistent pattern of treatment when the N-stage was included, thus has not been provided in these Tables, although the N-stage was considered when evaluating whether or not this staging had a basis for formulating treatment regimes. Table V, for completeness, is included to demonstrate treatments for other sites in head and neck patients (these were mainly patients with neck disease).

Of the 158 patients who had new or recurrent cancers and were recorded on the database, 141 patients had either surgery alone or surgery and radiotherapy as their chosen mode of cancer treatment. Of these patients, two died before three months' follow-up data were obtained, thus it was possible only to report on the status of the remaining 139 patients at three months' post-treatment. Ninety-eight status forms were eventually returned from

both the speech pathologist and the patient and analysed. The data on these 98 patients' are reported in the remaining section of this paper.

Quality of life (QOL), comparative quality of life (C-QOL) at three months post-treatment

Assessments of comparative QOL by cancer site and treatment in all patients (those undergoing new and recurrent treatment) revealed there to be significantly different perceptions of patients' C-QOL at three months' post-treatment, depending on whether surgery alone or surgery and radiotherapy treatment regimes were chosen. Forty-eight per cent of patients who were treated by surgery alone reported worse C-QOL (c.f. 71 per cent who had undergone surgery/radiotherapy). Twenty-four per cent of patients reported the same C-QOL (19 per cent surgery/radiotherapy) and nine per cent better (10 per cent surgery/radiotherapy). This is perhaps not surprising as the more extensive treatment may well have engendered worse morbidity and thus these patients experienced a worse QOL (Table VI).

Swallowing status at three months post-treatment

Three months after cancer treatment finished, both treatment groups presented with similar morbidity in swallowing. Only 12 per cent post-surgery patients had normal eating habits (13 per cent post-surgery/radiotherapy). Sixty-nine per cent of post-surgery patients required food consistency changes (i.e. vitamised diet) compared to 71 per cent post-surgery/radiotherapy. In both groups, 16 per cent patients had no oral feeding and relied totally on a percutaneous endoscopic gastrostomy (PEG) or naso-gastric tube feeding to meet their nutritional needs (Table VII).

Speech intelligibility at three months post treatment

In terms of speech intelligibility, at three months after cancer treatment finished, 63 per cent of

TABLE II
TREATMENTS FOR ORAL CAVITY CANCER: PATIENTS WITH NO PREVIOUS CANCER TREATMENT

Treatment	T Stage					Total
	T1	T2	T3	T4	X*	
Radiotherapy	1	1	0	0	0	2
Surgery	0	8	3	7	0	18
Surgery and radiotherapy	0	2	2	3	2	9
Total	1	11	5	10	2	29

*X is unknown or not stated in records.

TABLE III
TREATMENTS FOR PHARYNGEAL CANCER: PATIENTS WITH NO PREVIOUS CANCER TREATMENT

Treatment	T stage					Total
	T1	T2	T3	T4	X*	
Radiotherapy	0	1	1	0	0	2
Radiotherapy and chemotherapy	0	0	1	0	0	1
Surgery	0	0	2	2	0	4
Surgery and radiotherapy	0	4	3	8	1	16
Surgery, radiotherapy and chemotherapy	0	0	1	0	0	1
Total	0	5	8	10	1	24

*X is unknown or not stated in records.

TABLE IV
TREATMENTS FOR LARYNGEAL CANCER: PATIENTS WITH NO PREVIOUS CANCER TREATMENT

Treatment	T Stage					Total
	T1	T2	T3	T4	X*	
Radiotherapy	2	1	0	0	0	3
Radiotherapy and chemotherapy	0	0	1	0	0	1
Surgery	0	2	4	5	1	12
Surgery and radiotherapy	0	1	3	4	1	9
Surgery, radiotherapy and chemotherapy	0	0	3	0	0	3
Total	2	4	11	9	2	28

*X is unknown or not stated in records.

TABLE V
TREATMENTS FOR OTHER HEAD AND NECK CANCER: PATIENTS WITH NO PREVIOUS CANCER TREATMENT

Treatment	T Stage					Total
	T1	T2	T3	T4	X*	
Surgery	0	1	0	1	0	2
Surgery and radiotherapy	0	0	0	1	0	1
Total	0	1	0	2	0	3

*X is unknown or not stated in records.

patients were reported to have functional speech post-surgery (55 per cent functional post-surgery/radiotherapy), defined as 'speech may be distorted, but 100 per cent intelligible.' Twenty-two per cent post-surgery patients were reported as having a moderate speech disability (26 per cent post-surgery/radiotherapy). This was defined as 'being intelligible only when the context known, often needing repetition and/or being supplemented by writing.'

Twelve per cent of patients had poor speech post-surgery (19 per cent post-radio/chemotherapy), defined as 'only occasional, or no, communication. More than 50 per cent speech was un-intelligible' (Table VIII).

Post-laryngectomy speech restoration

Thirty-eight patients who underwent a total laryngectomy were registered on the database during the 12 months from April 1997. In terms of speech

restoration (Blom-Singer procedure) as their chosen mode of communication at three months post-operatively. Nineteen patients (50 per cent) used an artificial larynx and five (nine per cent) used mouthing or writing (see Figure 2).

Long-term data are currently being collected and analysed at six and 12 months post-treatment.

Discussion

The collection of new data from clinicians to the database continued until the end of April 1999 and patients were followed up until April 2000. A number of projects have developed from this database study:

- (1) A comparative study of speech and swallowing morbidity, objectively examining the impairments resulting from differing modality treatments when treating large (T₃, T₄) tumours of the oral cavity and pharynx.

TABLE VI
COMPARATIVE QUALITY OF LIFE RECORDED AT 3 MONTHS POST-TREATMENT INCLUDING PATIENTS WITH NEW OR RECURRENT CANCER

Treatment	Better		Same		Worse		Not recorded	Total
Surgery	6	9%	24	36%	32	48%	5	67
Surgery and radiotherapy	3	10%	6	19%	22	71%	0	31

rehabilitation, only nine patients (23 per cent) used

TABLE VII
SWALLOWING STATUS 3 MONTHS POST-TREATMENT INCLUDING PATIENTS WITH NEW OR RECURRENT CANCER

Treatment	Normal		Consistency changes		Requies tube feeding		Not recorded	Total
Surgery	8	12%	46	69%	11	16%	2	67
Surgery and radiotherapy	4	13%	22	71%	5	16%	0	31

tracheo-esophageal puncture (TEP) or surgical voice

TABLE VIII
INTELLIGIBILITY 3 MONTHS POST-TREATMENT INCLUDING PATIENTS WITH NEW OR RECURRENT CANCER

Treatment	100% intelligible		80% intelligible with known context		50% intelligible or less		Not recorded	Total
Surgery	42	63%	15	22%	8	12%	2	67
Surgery and radiotherapy	17	55%	8	26%	6	19%	0	31

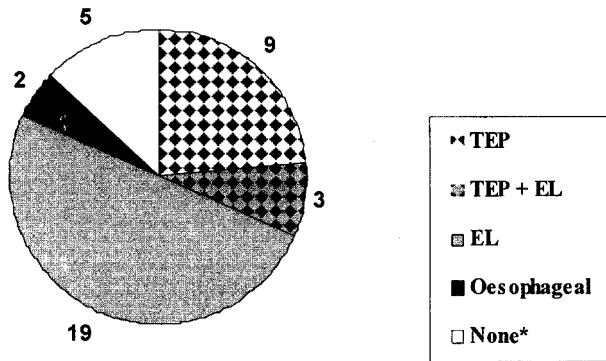


FIG. 2

Mode of voice for laryngectomy patients at three months post-treatment (n=38) using short phrases and/or good fluent speech.

*None consists of two patients using alternative communication systems; two patients using electrolarynx at single word level; one patient using oesophageal speech single word level.

- (2) The reasons for the low success rate for post-laryngectomy surgical speech restoration, using a qualitative research design, interviewing patients, carers, surgeons and speech pathologists. The interviews are recorded and transcribed with the recurring themes, attitudes and emergent issues being mapped and collated from each person and carer (where relevant). The data are assessed, using ethnographic methodology, which is well-researched by staff in Human Communication Sciences at La Trobe University and has been proven to be sensitive to change.

Apart from this project offering innovative clinical research in the area of outcomes of speech and swallowing after head and neck cancer, this is an opportunity for developing and extending the partnerships between La Trobe University and hospitals in Victoria, Australia. This project represents innovative multi-centre clinical research in speech pathology. It is important to objectively map the morbidity of speech and swallowing outcomes from head and neck cancer and its treatment so that clinicians may have an evidence-base for advising future patients in terms of likely morbidity; timescales for improvement (if any). Clinicians need to closely define the impairment and develop possible treatments to reduce the morbidity (of speech, swallowing) and thus improve patients' QOL. There is potential to change clinical treatment and functional outcomes (speech, swallowing) for patients in this field of cancer rehabilitation.

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Professor A. Perry takes responsibility for the integrity of the content of the paper.

Competing interests: see acknowledgements

Appendix 1

Functional Outcomes / Head and Neck Cancer Database

Patient Status

Patient Initials: _____

Date of birth: (dd/mm/yy) __/__/__

Postcode: _____

Date: __/__/__

**This section of the form is to be completed by the
PATIENT with the assistance of the clinician**

Clinician's Initials: ____

Hospital:

 Assessment:

- 0 = Pre therapy
 1 = Post surgery (at discharge or 14 days post surgery)
 3 = Post DXT/chemotherapy
 4 = Three months post therapy
 5 = Six months post therapy
 6 = Twelve months post therapy

 Activity:

- 1 = I am usually in bed or chair and don't leave home
 2 = I don't go out because I don't have the strength
 3 = I am often tired and have slowed down my activities although I still get out
 4 = There are times when I can't keep up my old pace, but not often
 5 = I am as active as I have ever been
 6 = Not applicable

 Recreation:

- 1 = I can't do anything enjoyable
 2 = There are severe limitations to what I can do, mostly I sit at home and watch TV
 3 = There are many times when I wish I could get out more but I'm not up to it
 4 = There are a few things I can't do but I still get out and enjoy life
 5 = There are no limitations to recreation at home or away from home
 6 = Not applicable

 Employment:

- 1 = I am unemployed
 2 = I am retired, due to cancer treatment
 3 = I have only occasional employment due to cancer treatment
 4 = I have only occasional employment by choice
 5 = I am retired, not related to cancer treatment
 6 = I have a part time but permanent job
 7 = I work full time

 Appearance:

- 1 = I feel significantly disfigured and limit my activities due to my appearance
 2 = My appearance bothers me but I remain active
 3 = The change in my appearance is minor
 4 = There is no change in my appearance

 Health:

- 1 = Poor
 2 = Fair
 3 = Good
 4 = Very Good
 5 = Excellent

 Pain:

- 1 = I have severe pain not controlled by medication
 2 = I have severe pain controlled only by narcotics
 3 = I have moderate pain requiring regular medication (codeine or non-narcotic)
 4 = There is mild pain not needing medication
 5 = I have no pain

 Speech:

- 1 = I cannot be understood
 2 = Only my family and friends can understand me
 3 = I have difficulty saying some words, but most people can understand me
 4 = My speech is the same as always

 Taste:

- 1 = I cannot taste any foods
 2 = I can taste some foods
 3 = I can taste most foods normally
 4 = I can taste food normally

 Saliva:

- 1 = I have no saliva
 2 = I have too much saliva
 3 = I have too little saliva
 4 = I have a normal amount of saliva

Patient status form (cont'd)

Functional Outcomes / Head and Neck Cancer Database

Patient Status

Patient Initials: _____

Date of birth: (dd/mm/yy) ___/___/___

Postcode: _____

Date: ___/___/___

Saliva consistency:

Is the saliva of normal consistency (Y/N)?

Swallowing:

- 1 = Cannot swallow anything
- 2 = Can swallow liquids or vitamised foods
- 3 = Can swallow only soft food
- 4 = Normal swallow

Voice:

- 1 = No voice
- 2 = Husky or hoarse voice most of the time
- 3 = Husky or hoarse voice occasionally
- 4 = Normal voice

Respiration:

- 1 = Need oxygen supplement
- 2 = Always short of breath, even at rest
- 3 = Frequently short of breath after exertion
- 4 = Occasionally short of breath
- 5 = No difficulties

Is your current condition:

- 1 = Much worse than expected
- 2 = Worse than expected
- 3 = In line with your expectations
- 4 = Better than expected
- 5 = Much better than expected

Overall quality of life:

Including factors such as family, friends, spirituality and personal leisure activities

- 1 = Very poor
- 2 = Poor
- 3 = Fair
- 4 = Good
- 5 = Very Good
- 6 = Excellent

Comparative quality of life:

Compared to one year prior to diagnosis of your illness, how would you rate your quality of life in general now?

- 1 = Much worse now
- 2 = Worse now
- 3 = About the same
- 4 = Better now
- 5 = Much better now

Current smoking status:

Average number of cigarettes etc. per day

Alcohol intake:

Average number of standard drinks per day
eg glass of wine, glass of beer

- 0 = None
- 1 = 1 – 2 standard drinks
- 2 = 3 – 4 standard drinks
- 3 = 5 – 6 standard drinks
- 4 = > 6 standard drinks

Usual type of alcoholic beverage consumed:

- 0 = None
- 1 = Spirits
- 2 = Beer
- 3 = Wine
- 4 = Combination

Additional comments:

Appendix 2

Functional Outcomes / Head and Neck Cancer Database	Clinician Status
Patient Initials: _____	Date of birth: (dd/mm/yy) __/__/__
Postcode: _____	Date: __/__/__

Speech pathology regime:

1 = Daily
 2 = Weekly
 3 = Monthly
 4 = Other, *specify*.....

Total number of speech pathology visits:
 (since last Status Form completed)

Disease status: (*circle numbers*)

1 = No evidence of disease
 2 = Residual disease, primary site
 3 = Residual disease, neck nodes
 4 = Recurrent disease, primary site
 5 = Recurrent disease, neck nodes
 6 = Distant metastasis

Does the patient have a severe late complication of treatment at this visit?

0 = No
 1 = Yes, *specify*.....

Has disease progressed since the last assessment?

0 = No
 1 = Yes

Has the patient received further treatment since the last assessment?

0 = No
 1 = Yes, *please complete the relevant treatment form*

Has the patient developed a new primary cancer since the last assessment?

0 = No
 1 = Yes, *please complete the diagnosis form*

Impairment:

Swallowing **Speech**

0 = Severe level of impairment
 1 = Severe/moderate level of impairment with some variability
 2 = Moderate impairment
 3 = Moderate/slight level of impairment
 4 = Slight level of impairment
 5 = No impairment

Disability:

0 = No functional communication
 1 = Occasional functional communication with a trained 'listener'
 2 = Occasional functional communication with others
 3 = Consistent level of functional communication with trained key persons
 4 = Functions well with occasional assistance
 5 = Functional communication

Handicap:

0 = Low self worth (esteem/value by others)
 1 = Low self worth
 2 = Mostly appropriate self worth and role with immediate family
 3 = No difficulties in familiar settings
 4 = Occasional restrictions/difficulties in some aspects of life
 5 = No difficulties with peer group, work, education or recreation

Distress:

0 = Severe consistent distress - overt and covert
 1 = Severe distress frequently experienced
 2 = Moderate and consistent distress
 3 = Moderate distress frequently experienced
 4 = Mild occasional distress
 5 = No inappropriate distress

Is the patient's condition:

1 = Much worse than expected
 2 = Worse than expected
 3 = In line with expectations
 4 = Better than expected
 5 = Much better than expected

Clinician status form (cont'd)

Functional Outcomes / Head and Neck Cancer Database	Clinician Status
Patient Initials: _____	Date of birth: (dd/mm/yy) __/__/__
Postcode: _____	Date: __/__/__

WHO performance status:

0 = Completely disabled, cannot carry out any self-care, totally confined to bed or chair
 1 = Capable of limited self care, confined to bed or chair more than 50% of waking hours
 2 = Ambulatory and capable of all self-care but unable to carry out any work, up and about more than 50% of waking hours
 3 = Restricted in physical activity but ambulatory and able to carry out light work
 4 = Able to carry out all normal activity without restriction

Intelligibility score:

1 = Unintelligible
 2 = Intelligible when the context is known (50%)
 3 = Intelligible when the context is known (80%)
 4 = Speech changed but 100% intelligible
 5 = Normal, no change to speech

Swallowing:

No oral feeding
 1 = Aspiration of secretions, patient rarely swallows
 2 = Secretions managed with suction and/or medication, patient swallows reflexively

Needs tube feeding
 3 = Tube feeding
 4 = Supplemental tube feeding

Dietary consistency changes
 5 = Liquefied diet
 6 = Vitamised diet
 7 = Soft diet

Early eating problems
 11 = Mild abnormality

Normal eating habits
 12 = Normal swallowing

Primary nutrition status:

1 = Parenteral /TPN
 2 = Percutaneous endoscopic gastromy
 3 = Nasogastric tube
 4 = Oral
 5 = Other

Laryngeal voice:

0 = Not applicable
 1 = Inaudible
 2 = Audible in quiet surroundings
 3 = Audible always

Oesophageal voice:

0 = Not applicable
 1 = No usable speech / involuntary sounds
 2 = Single words
 3 = Short phrases
 4 = Good fluent speech

Tracheo Oesophageal Puncture:

0 = Not applicable
 1 = No usable speech / involuntary sounds
 2 = Single words
 3 = Short phrases
 4 = Good fluent speech

Electrolarynx:

0 = Not applicable
 1 = No usable speech / involuntary sounds
 2 = Single words
 3 = Short phrases
 4 = Good fluent speech

Uses AAC system
 Such as gestures, computer etc. (Y/N)

Any other major illnesses/ complications:
 Give details.....

Comments: