*The Journal of Laryngology & Otology*
November 2002, Vol. **116,** pp. 937–941

# A cross-comparison of retrospective notes extraction and combined notes extraction and patient interview in the completion of a comorbidity index (ACE-27) in a cohort of United Kingdom patients with head and neck cancer

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**Abstract**

Co-existent comorbidity is a major determinant of treatment outcome in head and neck cancer. Most of the work pertaining to this topic has been done in the United States, where the standard practice is for trained cancer registrars to grade comorbidity using validated indexes by retrospective notes review. The adult comorbidity evaluation – 27 index (ACE-27) is a validated instrument that has been widely used in head and neck cancer. Although the required clinical data may be available in the notes, a significant amount of historical information is required to grade comorbidity. The aim of this study was to assess the accuracy and inter-rater reliability of the retrospective notes review process, in a typical setting in the United Kingdom (UK), by comparing the information obtained on notes review alone by a physician to that available after a structured patient interview. The study concludes that the retrospective notes review is an accurate and reliable technique for grading comorbidity whose completeness can be improved by the use of patient questionnaire as part of a structured interview.

**Key words: Head and Neck Neoplasms; Comorbidity; Questionnaires; Reproducibility of Results**

## Introduction

The term comorbidity stands for disease processes that coexist and are not related to the index disease being studied. Comorbidity has been found to have a significant impact on both survival and treatment selection in several types of cancer.[1–6] The greater the severity of the comorbid conditions, the greater their impact on survival. Comorbidity also has effects on the quality of life of patients with cancer. Patients with head and neck cancer (HNC) often have a history of tobacco and alcohol abuse, that increases the chances of comorbid ailments.

The adult comorbidity evaluation – 27 index (ACE-27) has been widely used in head and neck cancer in the United States. This is a modification of the original Kaplan-Fienstien index (KFI),[7] developed initially for adult onset diabetes mellitus to include items pertinent to cancer.[8]

No studies on the comorbidity burden in patients with head and neck cancer have been done in the UK so far. The technique in the United States has been to formally train cancer registrars in retrospective notes extraction. Piccirillo *et al.*[9] have shown that retrospective notes review by cancer registrars in the United States gives sufficiently valid information for comorbidity scoring using the ACE-27 index.

We have previously reported a pilot study[10] where we assessed the applicability of the ACE-27 index to retrospective notes review in a UK setting and identified the various sources of information in the notes. The laboratory values in the ACE-27 index were modified to reflect the SI figures widely in use in the UK. We have shown that retrospective data collection and completion of a comorbidity index in a UK setting is feasible from notes recorded over a number of different calendar years.[10] The ACE-27, however, has a few limitations for use in the UK, especially in relation to the item on human immunodeficiency virus (HIV) status as this confirmation typically remains confidential and may not be present in routine medical records. Some information required to complete grading refers to historical details and patient symptomatology that may not be routinely recorded in the notes. Newschaffer *et al.*[11] showed that multiple comorbidity data sources add valuable prognostic information and the use of single sources alone may result in some misclassification of comorbidity. A solution for enhancing 'notes extracted' data is to use a structured patient interview. This prospective study was therefore undertaken to assess the accuracy of the information available on retrospective notes

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Accepted for publication: 6 June 2002.

review by comparing this to the data obtained by patient interview and to study the inter-rater reliability of retrospective notes review in estimating the comorbidity burden.

## Materials and methods

Ethics committee approval for the study was sought and obtained. The demographic details of 20 patients were obtained from the prospective head and neck cancer database at the North Riding Infirmary, Middlesbrough, diagnosed with an index primary tumour within the last six months. Patients refusing treatment were excluded. The period of six months was chosen to ensure that the comorbidity informatoin obtained was temporally close to the time of diagnosis of the index tumour. The case notes available for study contained details of otolaryngological and ophthalmological clerking only, referral details from the general practitioner and treatment the patients have had. Notes folders may have been requested from other units related to general medical or speciality management during the course of the patients' assessment. Psychiatric notes were not usually available.

The date of diagnostic biopsy for the primary tumour was considered to be the date of diagnosis. All sources of relevant data for each system in the ACE-27 comorbidity grading scale were scrutinized. The medical preassessment was used as the primary source and other sources used for supplemental information. All data was extracted by two investigators independently and entered in a database. When conflicting data pertaining to a system was available from two sources, the best functional status was used to score. When a grade 3 score was obtained early in the grading for a given patient, data extraction was terminated as per the instructions for grading the ACE-27. After independent grading, the grades were compared and discrepancies between the raters resolved by discussion and used as the final notes review grade.

Patients were subsequently interviewed at the time of the routine follow-up appointment and the questionnaire (Appendix I) that was designed to obtain all historical information was administered. The nature and need for the questionnaire was explained to the patient and the patient's written consent obtained. The time taken for each patient to complete the questionnaire was noted to the nearest minute.

### *Analysis*

The accuracy of the technique of comorbidity grading from notes review was evaluated by using the grade obtained from information in the patient questionnaire and the notes as gold standard. The final retrospective notes grade was used as the test. All statistical calculations were done using StatXact 3.0 for Windows™ (Cytel software corporation, Cambridge, MA). Weighted Kappa ($\kappa$) statistic was calculated to assess the inter-rater reliability of the notes review process between the two investigators. The same test was used to examine the agreement between the final grades as rated by both investigators and the composite grade obtained from the patient questionnaire and the notes.

TABLE I
COMORBIDITY GRADES FOR THE COHORT

| Patient | Pre-questionnaire grade | Post-questionnaire grade |
|---|---|---|
| A | 0 | 0 |
| B | 2 | 1 |
| C | 0 | 0 |
| D | 3 | 3 |
| E | 3 | 3 |
| F | 2 | 2 |
| G | 1 | 1 |
| H | 2 | 1 |
| I | 2 | 2 |
| J | 1 | 1 |
| K | 1 | 1 |
| L | 1 | 1 |
| M | 1 | 1 |
| N | 0 | 0 |
| O | 0 | 0 |
| P | 0 | 0 |
| Q | 0 | 0 |
| R | 0 | 0 |
| S | 1 | 1 |
| T | 2 | 1 |

## Results

No change in grade occurred in 17 out of 20 patients when the information obtained from the questionnaire was compared to the final two-investigator grade obtained by notes review. Three patients with grade 1 comorbidity were upgraded to grade 2 (Table I). One had had uncomplicated pancreatitis 12 years ago, which had not been picked up during preassessment; the other two patients who were upgraded had chronic obstructive pulmonary disease that had not responded completely to treatment, a fact that had not been mentioned in the notes. New information identified by the questionnaire included two patients who had had a stroke 12 years ago and pulmonary embolus 10 years ago respectively, information that did not change the comorbidity grade owing to other coexistent diseases. The best performance score is usually selected when controversial information regarding an item exists, but no patient provided information that necessitated downgrading the comorbidity grade. Four patients had no comorbidity on notes review alone, with no change in grade following the questionnaire. The accuracy rate of retrospective notes review for comorbidity grading using the ACE-27 index is thus 85 per cent. Kappa-weighted statistics comparing agreement between the final notes review grade and the composite notes review/questionnaire grade was 0.92 (95 per cent CI = 0.82 to 1.0), indicating excellent agreement between the two techniques of comorbidity grading.

Kappa-weighted statistics also revealed excellent agreement between both investigators (0.87; 95 per cent CI: 0.74 to 0.99) when their grading of comorbidity was compared. The inter-rater disagreement occurred in four patients: good versus poor control diabetic control with oral hypoglycaemics in one patient, good versus poor response to therapy for chronic obstructive airway disease in three patients.

https://doi.org/10.1258/0022215060369499 Published online by Cambridge University Press

The average time taken to answer the questionnaire was 8.3 minutes, that was easily done prior to, or after the appointment, in the multi-disciplinary tumour clinic. When the information is being obtained prospectively, it is very rare that the number of patients needing to answer the questionnaire will be more than five, that corresponds to the number of new patients seen at the clinic. No inordinate delay in clinic times was noted over the period that this study was conducted. No patient needed help with interpretation of the questionnaire; one blind patient needed the questions to be read out to her. The questionnaire has a Flesch reading ease of 76.3 and Flesch-Kincaid grade of 4.6 using the grammar check tool in Microsoft Word 2000™ (Microsoft Corporation, Washington).

## Discussion

The impact of comorbidity on treatment outcome of head and neck cancer has been shown to be more significant than tumour stage. We have previously shown that review of different sources of relevant information in the notes appears to provide almost all significant information that is needed for completing the ACE-27 instrument on a retrospective basis throughout a wide range of years, over different clerking teams.[10] This study shows that retrospective evaluation of notes for comorbidity evaluation, from the sources we have identified in our previous work, is reliable and accurate. Large population-based studies have used the hospital discharge sheet, which details medical conditions as per the ICD-9 – CM codes, to assess comorbidity. However, it has been shown that coding from the medical records yielded more accurate assessments of overall health.[12,13]

It must be noted that the case notes available for study contained details of only otolaryngological and ophthalmological clerking, referral details from the general practitioner and treatment the patients have had; other medical notes were not available. It is possible that the episode of pancreatitis would have been picked up had the general medical notes been available, that would be the case in the majority of hospitals in the country. Significant information that could have potentially influenced treatment decision was unearthed in two patients after the questionnaire was applied, although the grade did not change because of other coexistent comorbidity. Given the high incidence of concurrent respiratory problems in the head and neck cancer population and the relatively imprecise historical information required for grading of comorbidity in the respiratory system, it is not surprising that interpretation has been subjectively different. This flaw of retrospective data collection can be effectively overcome by using the questionnaire. The presence of other medical notes would make it more likely that the results of lung function tests be available during grading, rendering the process more accurate. It must be noted that the grade did not change in any of the patients who were noted to have no comorbidity by notes evaluation alone, thus giving the technique a specificity of 100 per cent.

The results lend further credence to the finding of our previous study[10] that a comprehensive preassessment provides almost all the data required for assessment of the comorbidity burden. Although the accuracy of the technique is excellent, we believe that using the questionnaire on a routine basis will ensure that little information is missed out. Our study also shows an excellent agreement between both raters, which echoes the results of Piccirillo *et al*. (personal communication, presented at the annual meeting of National Cancer Registrars' Association, Albuquerque, New Mexico, May 2000). The latter study showed that ACE-27 comorbidity grading obtained by detailed examination of the medical record by cancer registrars is a very reliable process. When the grading of nine cancer registrars over a period of six months was compared to that of a trained research assistant, the weighted kappa score ranged from 0.81 to 1.0 (with one outlier at 0.68), indicating substantial to perfect agreement. The sensitivity of the grading process for the trainees ranges from 80 to 100 per cent and specificity from 86 to 100 per cent.

This study also supports the concept of the visit to the multi-disciplinary team being a focus for compilation of comorbidity grading, enables this information to be made available prior to deciding the management and fits with the patient's cancer journey. The extra time taken to answer the questionnaire in the setting of the multi-disciplinary clinic and to assess comorbidity by notes review may have a resource implication that is negated by the important role that comorbidity plays in management planning and outcome. We have shown that the mean time taken for doctors to obtain relevant data from the note is 16.8 minutes, in contrast to 35.9 minutes and 38.0 minutes for charts with, and without, comorbidity respectively for cancer registrars in the United States. This time difference can be attributed to the relatively concise notes maintained at our hospital as mentioned above and the medical background of the raters. The time taken to glean information from the questionnaire, include missing items and arrive at the final grade was never more than two minutes

The implications of this finding are significant: if comorbidity can be graded accurately by retrospective notes review in the UK setting, this should enable future studies on head and neck cancer outcome to be reported with the comorbidity information included. The process is quick and practical. Studies without comorbidity in the future in cross-comparing centres will have the weakness that comorbidity rightly or wrongly can be used as an excuse for poor performance.

## References

1 Feinstein AR, Schimpff CR, Andrews JF Jr, Wells CK. Cancer of the larynx: a new staging system and a reappraisal of prognosis and treatment. *J Chronic Dis* 1977;**30**:277–305

2 Piccirillo JF, Wells CK, Sasaki CT, Feinstein AR. New clinical severity staging system for cancer of the larynx. Five-year survival rates. *Ann Otol Rhinol Laryngol* 1994;**103**:83–92
3 Wells CK, Stoller JK, Feinstein AR, Horwitz RI. Comorbid and clinical determinants of prognosis in endometrial cancer. *Arch Intern Med* 1984;**144**:2004–9
4 Feinstein AR, Wells CK. A clinical-severity staging system for patients with lung cancer. *Medicine* (Baltimore) 1990;**69**:1–33
5 Clemens JD, Feinstein AR, Holabird N, Cartwright S. A new clinical-anatomic staging system for evaluating prognosis and treatment of prostatic cancer. *J Chronic Dis* 1986;**39**:913–28
6 Satariano WA, Ragland DR. The effect of comorbidity on 3-year survival of women with primary breast cancer. *Ann Intern Med* 1994;**120**:104–10
7 Kaplan MH, Feinstein AR. The importance of classifying initial co-morbidity in evaluating the outcome of diabetes mellitus. *J Chronic Dis* 1974;**27**:387–404
8 Piccirillo JF. Importance of comorbidity in head and neck cancer. *Laryngoscope* 2000;**110**:593–602
9 Piccirillo JF, Creech C, Zequeira R, Anderson S, Johnston AS. Inclusion of comorbidity into oncology data registries. *J Registry Management* 1999;**26**:66–70
10 Paleri V, Wight RG. Applicability of the Adult Comorbidity Evaluation – 27 and Charlson indexes to assess comorbidity by notes extraction in a cohort of United Kingdom patients with head and neck cancer: a retrospective study. *J Laryngol Otol* 2002;**116**:200–5
11 Newschaffer CJ, Bush TL, Penberthy LT. Comorbidity measurement in elderly female breast cancer patients with administrative and medical records data. *J Clin Epidemiol* 1997;**50**:725–33
12 Malenka DJ, McLerran D, Roos N, Fisher ES, Wennberg JE. Using administrative data to describe case mix: a comparison with the medical record. *J Clin Epidemiol* 1994;**47**:1027–32
13 Mefi C, Holleman E, Arthur D, Katz B. Selecting a patient characteristics index for the prediction of medical outcomes using administrative claims data. *J Clin Epidemiol* 1995;**48**:917–26

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Mr V. Paleri takes responsibility for the integrity of the content of the paper.
Competing interests: None declared

**Appendix 1**
Questionnaire for comorbidity evaluation

**Section 1 (heart and blood vessels)**

1 Have you had a heart attack in the past? YES/NO
If yes, please state the date. .....
2 Do you suffer from chest pain relating to your heart (angina)? YES/NO
*If NO, please go to question 6*
3 Is your angina (chest pain) present only on exertion or do you have it at rest? .....
4 If yes, have you been hospitalised for the same? YES/NO
5 Have you had any surgical procedures done for chest pain (angina)? YES/NO
If yes, please state the date. .....
6 Do you suffer from heart failure? YES/NO
*If NO, please go to question 11*
7 Do you feel breathless on exertion/or do you wake up at night out of breath? YES/NO
8 If you have breathlessness, does it limit your activites? YES/NO
9 Has your breathlessness due to heart failure responded well to treatment? YES/NO
10 Have you been hospitalised for your heart failure? YES/NO
If yes, please state the date. .....
11 Do you suffer from problems with irregular heartbeats? YES/NO
*If NO, please go to question 13*
12 Have you had a pacemaker inserted for this problem? YES/NO
13 Do you suffer from high blood pressure (hypertension)? YES/NO
*If NO, please go to question 18*
14 If yes, do you take medication for treatment of hypertension? YES/NO
15 Do you suffer from symptom of dizziness, nose bleeds or headaches caused by your high blood pressure? YES/NO
16 Have you had any eye or nervous problems due to the high blood pressure? YES/NO
17 Have you been admitted to the hospital for control of high blood pressure? YES/NO
18 Have you had blood clotting in your veins in the leg at any time in the past? YES/NO
*If NO, please go to question 21*
If yes, please state the date. .....
19 Are you on medication to thin your blood after the blood-clotting episode? YES/NO
20 Have you had any surgical procedure relating to the blood-clotting episode? YES/NO
If yes, please mention the procedure. .....
21 Have you had blood clots in the blood vessels to the lungs? YES/NO
If yes, please state the date. .....
22 Do you suffer from pain in your calf muscles when walking? YES/NO
*If NO, please go to question 25*
23 If yes, have you had surgical treatment for this? YES/NO
24 Have you had any limb amputation for blood vessel disease? YES/NO
If yes, please state the date. .....
25 Do you suffer from an aneurysm (enlarged blood vessels) in your chest or abdomen? YES/NO
*If NO, please go to question 27*
26 If yes, have you had treatment for the same? YES/NO

**Section 2 (lungs)**

27 Do you suffer from chronic bronchitis, emphysema or asthma? YES/NO
*If NO, please go to question 32*
28 If yes, has your breathlessness responded to treatment? YES/NO
29 Does your breathlessness limit your activities? YES/NO
30 Is your breathlessness present at rest? YES/NO

https://doi.org/10.1258/0022215026036949 Published online by Cambridge University Press

31 Do you need supplemental oxygen on a regular basis? YES/NO

**Section 3 (liver, stomach and pancreas)**

32 Do you suffer from chronic liver problems such as hepatitis or cirrhosis? YES/NO
*If NO, please go to question 35*

33 Have you been in hospital for bleeding problems in the gut? YES/NO

If yes, please state the date .....

34 Have you had a liver transplant? YES/NO

35 Have you been diagnosed to have ulcers in the stomach? YES/NO
*If NO, please go to question 38*

36 Do you need medication for the same? YES/NO

37 Have you had surgery for ulcers? YES/NO

38 Do you suffer from mild absorption or inflammatory bowel disease? YES/NO

39 Have you had problems with your pancreas and/or been in hospital for the same? YES/NO

**Section 4 (kidney)**

40 Do you suffer from any problem in your kidney? YES/NO
*If NO, please go to question 43*

41 Have you had a renal transplant? YES/NO

If yes, when? .....

42 Are you on dialysis? YES/NO

If yes, how long have you been on it? .....

**Section 5 (diabetes)**

43 Are you a diabetic? YES/NO
*If NO, please go to question 46*
If yes, is it well controlled? YES/NO

44 Is it controlled on oral medication or by insulin? .....

45 Have you been in hospital for diabetes associated complications? YES/NO

46 Do you have problems in other organs caused by diabetes YES/NO
i.e. for the eye, the nerves, the kidneys or the heart?

**Section 6 (brain and nerves)**

47 Have you had any stroke in the past? YES/NO
*If NO, please go to question 49*

If yes, please state when? .....

48 Has it left you with some disability YES/NO

49 Do you need full support for self care? YES/NO

50 Do you suffer from multiple sclerosis, Parkinson's disease or myasthenia gravis? YES/NO

51 Do you suffer from depression or other psychiatric disorders? YES/NO
*If NO, please go to question 53*

52 If yes, are you on medication for the same? YES/NO

**Section 7 (joints and muscles)**

53 Do you suffer from rheumatoid arthritis or other joint or muscle disorders? YES/NO
*If NO, please go to question 56*

54 If yes, please list the drugs that you currently take for this problem.

.....

.....

.....

55 Have you had kidney, lung or heart problems caused by the same diseases? YES/NO

**Section 8**

*(Please note the questions below exclude the current cancer for which you are being treated)*

56 Have you been diagnosed as having any other cancer, leukaemia or lymphoma in the past? YES/NO
*If NO, please go to question 59*

If yes, please state the date. .....

57 Are you currently on treatment for the same? YES/NO

58 Is it well controlled? YES/NO

**Section 9**

59 How much alcohol were you taking at the time you were diagnosed with the current cancer? .....
units per week

60 Do you suffer from any illnesses relating to excess alcohol consumption? YES/NO
*If NO, please END*

61 Was your social life affected by excess alcohol consumption YES/NO

62 Did stopping alcohol at that time cause any withdrawal symptoms? YES/NO

*Thank you for taking the time to answer this questionnaire*

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