

# Inclusion of Comorbidity into Oncology Data Registries

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**Abstract:** In order to train certified tumor registrars to code comorbidity information, an educational program was administered to five Certified Tumor Registrars at Barnes-Jewish Hospital in the fall of 1994. The program consisted of an introduction to comorbidity coding, the comorbidity instrument and documentation book, and clinical examples. Seventy-seven medical records coded by each CTR were assessed by sensitivity, specificity, and weighted kappa statistic for validity. A structured interview was also administered to determine the difficulty and time required for this task. Quantitative assessment of the coders ranged from 88-100% for sensitivity, 71-100% for specificity, and .79 to .95 for kappa. The interview responses indicated that coding comorbidity was relatively straightforward and not time consuming. It was concluded that cancer registrars can code comorbidity efficiently and effectively. The authors believe that comorbidity information can be included in hospital-based and national cancer registries.

**Key Words:** comorbidity, severity of illness index, prognosis, tumor registries, oncology

## Introduction

Patients with cancer often have other diseases, illnesses, or conditions in addition to their index cancer. These other conditions are generally referred to as comorbidities. Although not a feature of the cancer itself, comorbidity is an important attribute of the patient. Comorbidity has direct impact on the care of patients, selection of initial treatment, and evaluation of treatment effectiveness.

In many cancers, comorbidity is prognostically more important than tumor size or Tumor, Node, Metastasis (TNM) stage. Comorbidity is particularly important for slow growing cancers that affect older people. Cancers which fit this description or where comorbidity has already been shown to be an important factor are: breast; prostate;<sup>1</sup> oral cavity, pharynx, and larynx;<sup>2, 3</sup> bladder; ovary; uterus;<sup>4</sup> and non-Hodgkin's lymphoma. Based on recent cancer incidence rates,<sup>5</sup> these cancers represent approximately two-thirds of all adult cancers. While the importance of comorbidity to cancer statistics is obvious, surprisingly the American Joint Committee (AJC) TNM

staging system<sup>6</sup> and cancer registries do not include this important information.

The present TNM system of cancer classification is based primarily on tumor morphology and does not consider important patient-based prognostic factors, such as symptom type and severity, severity of comorbidity, and functional capacity. Previous research<sup>7-16</sup> describes multiple reasons for the exclusion of these important patient-based variables: 1) belief in the exclusive importance of morphology, 2) desire to avoid soft data, 3) previous lack of a taxonomy for patient-based variables, 4) desire to avoid multiple variables and components, and 5) desire to keep the system simple for clinical practice. However, the continued exclusion of comorbidity measures cannot be justified since several valid comorbidity instruments now exist.<sup>17-19</sup> None of the instruments were specifically designed to study comorbidity in cancer patients. Nevertheless, these instruments have been used successfully to classify comorbidity in several different cancers.

The objective of this research project was to demonstrate that Certified Tumor Registrars (CTR) could code

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#### "Inclusion of Comorbidity into Oncology Data Registries"

Research partially supported through grant from NCI grant # R25 CA68304.

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Submitted 11/04/98. Accepted 12/14/98.

comorbidity efficiently and effectively. A modification of Kaplan-Feinstein Index, a valid comorbidity index, was used to classify different comorbid diseases and to quantify the severity of the overall comorbid condition. If CTRs can code comorbidity accurately, then comorbidity can be added to oncology data registries.

## Methods

### Comorbidity Education Program

The educational program was administered to three Certified Tumor Registrars, and two individuals with tumor registry training who are working toward certification at Barnes-Jewish Hospital in St. Louis, Missouri. The research assistant (RA) who administered the program had a medical degree and three years experience coding medical records of cancer patients. The education program consisted of an introduction to the importance of comorbidity, the use of the comorbidity instrument and documentation book, and many clinical examples. The registrars coded comorbidity in the presence of the research personnel and immediate evaluation of their performance was adminis-

tered. The entire education session lasted approximately 10 hours and was completed in October 1994. Less time was required than planned because the CTRs quickly learned how to code comorbidity correctly. Comments and observations from the CTRs who participated in the training session were incorporated into the educational program.

### Comorbidity Measurement

The Kaplan-Feinstein Comorbidity Index<sup>18</sup> was developed from a study of the impact of comorbidity on outcomes for patients with diabetes mellitus. Specific diseases and conditions were classified according to their severity of organ decompensation: Mild, Moderate, or Severe. The Charlson Comorbidity Index<sup>17</sup> was created from studies of one-year mortality for patients admitted to a medical unit of a teaching hospital. It is a weighted index that takes into account the number and seriousness of comorbid diseases. The Index of Co-Existent Disease (ICED)<sup>19</sup> is another comorbidity instrument which relies on primary data. ICED attempts to predict length of stay and resource utilization after hospitalization. ICED assesses the patient's status in two separate components, physiological

and functional burden in order to calculate the overall burden of comorbidity.

The investigators modified the Kaplan-Feinstein Index for two important reasons. First, since the original was developed from the study of a cohort of patients with diabetes (index disease), this condition was not listed as a comorbid ailment. Second, the investigators felt that the original Kaplan-Feinstein Index did not include several important conditions (e.g., AIDS, dementia). The new index is referred to as the Modified Medical Comorbidity Instrument (MMCI). When developing the Modified Medical Comorbidity Instrument, the investigators sought advice from clinical experts and, when possible, the published literature to assign levels of comorbidity to the ailments not included in the original instrument.

The instrument grades specific diseases and conditions into one of four groups [Grade 0 is None; Grade 1 is Mild; Grade 2 is Moderate; and Grade 3 is Severe] according to the severity of organ decompensation and prognostic impact. Once the patient's individual diseases or comorbid conditions are classified, the individual is given an Overall Comorbid-

Table 1. — Examples From Modified Medical Comorbidity Instrument

Cogent Comorbid Ailment	Grade 3 Severe Decompensation	Grade 2 Moderate Decompensation	Grade 1 Mild Decompensation
<b>Cardiovascular System</b>			
Myocardial Infarct	M.I. w/in past 6 months	History of multiple M.I.s in past.	M.I. more than 6 months ago. ECG evidence of coronary disease.
Angina	Hosp. for angina pectoris. Unstable angina. Severe CAD as documented by cath.	Chronic exertional angina. Recent CABG for severe CAD (w/in past 6 months). Angina pectoris not requiring hospitalization.	Acute angina. Angina attack compensated with treatment. CABG for severe CAD (> 6 mo.)
Congestive Heart Failure	CHF w/in past 6 months. H/o Transplant w/in past 6 months or acute rejection. Ejection < 20%	CHF > 6 months. Transplant >6 months and/or no rejection	Exertional dyspnea. PND
Arrhythmias	Ventricular arrhythmia w/in past 6 months.	Ventricular arrhythmia more than 6 months. Sick Sinus Syndrome (SSS). Chronic atrial fibrillation or flutter. Pacemaker.	Atrial premature complexes
Hypertension	DBP ≥ 130 mm Hg. Severe malignant papilledema. Encephalopathy.	DBP b/w 115-129 mm Hg. 2° Cardiovascular symptoms: (i.e., headaches, vertigo, epistaxis)	DBP 90-114 mm Hg. Controlled HTN. No 2° Cardiovascular symptoms.
Peripheral Vascular Disease	Recent DVT. Use of venous filter for PE's.	Recent amputation or gangrene of extremity. DVT controlled with Coumadin. Chronic arterial insufficiency s/p fem-pop.	Old amputation. Intermittent claudication.
<b>Respiratory System</b>			
	Marked pulmonary insufficiency. Dyspneic at rest despite treatment. Narcosis. Pt. uses continuous O <sub>2</sub> . Recurrent status asthmaticus. Lung transplant.	Recurrent pneumonia. Dyspneic w/moderate activity despite treatment. Recurrent asthmatic attacks w/COPD.	Dyspneic w. moderate activity w/o treatment or only w/attacks. Pt. w/diagnosed COPD. Stable Asthma.

**Table 2. — Description of Research Assistant and Certified Tumor Registrars**

Research Assistant	Educational Background	
1	MD	Three years coding experience
CTR	Certification	Educational Background at the Time of Evaluation
1	Certified CTR (1994)	Certified CTR (1994) 2 years College 20 years Medical Record Tech 2 years Tumor Registrar Tech
2	Certified CTR (1992)	3 years College ART Certified 5 years Medical Record Tech 2 years Tumor Registry Tech
3	ART Certified (1995)	ART Certified CTR Certification in progress
4	Certified CTR (1997)	2 years Nursing School ART Certified (1994)
5	None	2 years Tumor Registry Technician

**Table 3. — Difficulty and Collection Time for Coding Comorbidity**

CTR	How difficult is coding comorbidity?	How time consuming?	Average time to abstract chart (minutes)	Average time to code comorbidity (minutes)
1	Slightly	Slightly	30-60	2
2	Not at all	Slightly	90	15
3	Not at all	Not at all	30	1
4	Slightly	Not at all	45-60	3
5	Slightly	Not at all	90	2

**Table 4. — Quantitative Assessment of Certified Tumor Registrars' Performance**

CTR	Sensitivity	Specificity	Weighted Kappa
1	14/16 = 88%	3/3 = 100%	0.95
2	16/18 = 89%	1/1 = 100%	0.93
3	14/15 = 93%	3/3 = 100%	0.85
4	14/14 = 100%	3/4 = 75%	0.79
5	14/14 = 100%	5/7 = 71%	0.86

ity Score. This score is determined by the highest ranked single ailment. In the cases where two or more Moderate or Grade 2 ailments occur in different organ systems, the Overall Comorbidity Score should be designated as Severe or Grade 3. Severe or Grade 3 comorbidity is also referred to as "Prognostic" comorbidity since it is severe enough to impact on a patient's prognosis. A portion of the Modified Medical Comorbidity Instrument displaying comorbid ailments for the cardiovascular and respiratory systems is shown in Table 1.

**Population Under Study**

The study population consisted of three Certified Tumor Registrars and two individuals with tumor registry training

who are working towards certification from Barnes-Jewish Hospital. (Table 2) The expertise of the participants varied, with two senior cancer registrars and three individuals with tumor registry training and less cancer registrar experience. The registrars coded comorbidity severity from the medical records of cancer patients treated at Barnes-Jewish Hospital.

**Questionnaire**

A structured interview was administered to the five cancer registrars. The two main questions were "How difficult is it to code comorbidity?" and "How time consuming, on average, is coding comorbidity in relation to what is usually coded for a

chart?" The cancer registrars were also asked to estimate the amount of time, on average, to code comorbidity.

**Assessment of Performance**

The RA and co-investigators reviewed 77 charts evaluated by the participating CTRs. The medical records consisted of the analytic inpatient and outpatient cases of all adult cancer sites. The cases were classified according to the Registry Operations and Data Standards (ROADS) Manual<sup>20</sup> as Class of Case 0, 1, or 2. The sample was selected to ensure a broad representation of comorbidity. The goal of this review was to assess the validity and degree of agreement between the CTRs and the RA. The RA and co-investigators served as the "gold standard" for the assessment of the Overall Comorbidity Score.

To ease analysis, sensitivity and specificity were used to evaluate the ability of the CTR to accurately assess the presence and absence of prognostic comorbidity. Weighted kappa ( $\kappa$ ) statistic<sup>21</sup> was used to measure the degree of agreement beyond what would be expected by chance. Landis and Koch<sup>22</sup> established the following guidelines for the interpretation of  $\kappa$  values: 0.41-0.60 moderate agreement, 0.61-0.80 substantial agreement, and 0.81-1.00 almost perfect agreement as determined.

**Results**

**Difficulty and Collection Time for Coding Comorbidity**

Based on the responses from the interview, two CTRs responded that coding comorbidity was "Not At All Difficult," and the other three said that it was "Slightly Difficult." (Table 3) Two registrars said that coding comorbidity was "Slightly" time consuming and three said "Not at All." The time required to abstract an entire chart ranged from 30 to 90 minutes, while the time to abstract comorbidity information ranged from 1 to 15 minutes. On average, the time spent coding comorbidity was approximately 7.5% of the total chart abstraction time.

The registrars made several comments concerning coding of comorbidity. One registrar said, "You are weeding through the chart anyway, so it doesn't take much time." Another registrar said, "Once it's incorporated into the routine, it's relatively easy." Finally, a third registrar said, "Comorbidity is no harder than any other portion of the abstraction."

## Quantitative Assessment of Certified Tumor Registrars' Performance

Table 4 shows the results of the quantitative assessment of the CTRs' performance. The validity of the coding was rated by analyzing the sensitivity, specificity, and weighted kappa statistic. The values for sensitivity ranged from 88%-100% and values for specificity ranged from 71%-100%. The kappa values ranged from .79 to .95 (substantial to almost perfect agreement.) The two most experienced CTRs had kappa values of 0.93 and 0.95 — the highest values.

## Discussion

This paper describes the comorbidity coding education program completed by five certified tumor registrars. The program required approximately 10 hours and the CTRs' performance was assessed after completion of the program. The cancer registrars' verbal comments in the post-program interviews indicated that coding comorbidity is a simple procedure that can be performed in a time-efficient manner. The sensitivity, specificity, and kappa scores all demonstrated excellent performance and validation of the educational program. In this study with a relatively small sample size of actual medical records reviewed, it is impressive to note that 5 out of 5 participants achieved a kappa value above 0.75. This is impressive since kappa tends to underestimate the degree of agreement when small sample sizes are used.<sup>21</sup>

Comorbidity can be coded using a variety of instruments<sup>17-19</sup> and data sources. The sources can be considered as primary data sources (clinical) or secondary data sources (administrative databases). A clinical database utilizes primary data collected from physicians, nurses, or through chart reviews. Because cancer registrars primarily use the medical record as the source of information, the data they collect are referred to as primary data. Administrative databases are maintained by hospitals, insurance companies, and state and federal government. The information collected in these databases is generally referred to as secondary information. Clinical information is classified based on ICD-9-CM system (International Classification of Diseases, Ninth Revision, Clinical Modification). The ICD-9-CM system was created in an effort to trace the epidemiology of disease and mortality.<sup>23, 24</sup> The Ninth Revision of ICD took place in

Geneva in 1977, and went into effect in January 1979. Clinical modifiers (ICD-9-CM) were added to the ICD-9 code in an attempt to include more information relevant to clinical research along with the strict epidemiological taxonomy of ICD-9. Many researchers find that when using ICD-9-CM to code comorbidity they encounter ambiguity and inconsistency of coding diseases. Different medical record technicians can assign different codes to the same comorbid condition. In some cases, these inconsistencies have little impact on the patient's total comorbidity score. However, in other cases, these changes have an extreme impact on the patient's overall comorbidity.<sup>25, 26</sup>

Newschaffer, Bush, and Penberthy<sup>27</sup> looked at the degree of agreement and ability to predict all-cause mortality between different methods of comorbidity for a cohort of elderly breast cancer patients. Comorbidity was based on both medical records and Medicare claims data using indices from Charlson,<sup>18</sup> Satariano and Ragland,<sup>28</sup> and Kaplan and Feinstein.<sup>17</sup> Inter-rater agreement was good for all indices (kappas equal to or greater than 0.80). Agreement between comorbidity indices using medical record review and Medicare claims was considerably poorer (kappas between 0.30 and 0.40). However, claims-based and medical records-based comorbidity indices were similarly associated with mortality. The authors concluded that all indices were able to predict important outcomes, but that the Charlson index used as part of a medical record review probably performed the best.

The results of this study show that cancer registrars can code comorbidity efficiently and effectively. Through the efforts of the thousands of cancer registrars working in the nation's hospitals, comorbidity information could be included in hospital-based and national cancer registries. The authors believe that the addition of comorbidity information will improve the value of cancer statistics and the care of cancer patients.

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