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DEFINING CLINICAL SIMILARITY AMONG ICD-9-CM DIAGNOSIS CODES: DIAGNOSIS CLUSTER SCHEMES

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ABSTRACT

Detailed information about patients' medical diagnoses is recorded for virtually every encounter with the hospital emergency department (ED). Despite the wide availability of such information and the standardized reporting of diagnosis data with the *International Classification for Diseases, Ninth Edition, Clinical Modification* (ICD-9-CM), the fine-grained raw data have not proven useful in describing the primary reasons why patients visit the ED. A solution to this problem is to use a scheme of diagnosis clusters to group similar ICD-9-CM codes. The purpose of this paper is to address several important questions about diagnosis clusters in the context of emergency medicine. First, we examine the relationship between diagnosis cluster schemes and other means of organizing medical knowledge. Next, we explore the principles by which clusters should be defined, focusing on the concept of *clinical similarity*. We then examine three existing diagnosis clusters systems designed for other medical specialties, using 2 months of ED diagnosis data to evaluate their utility in describing the diagnoses patterns of the ED patient population.

1. INTRODUCTION

Every time a patient visits a health care provider in the U.S., the diagnosis made by the provider is translated into one or more codes drawn from ICD-9-CM, the *International Classification for Diseases, Ninth Edition, Clinical Modification* (USDHHS, 1999). ICD-9-CM was designed for the classification of morbidity and mortality; it is used today for reimbursement and reporting diagnosis and disease information to a variety of federal agencies, as well as quality assurance and institutional accounting for patient care. There are over 24,000 code-rubric (descriptor) pairs in the ICD-9-CM system. For example, 786.50 is the code for the diagnosis of CHEST PAIN, UNSPECIFIED, which was a frequently assigned diagnosis in a national sample of Emergency Department (ED) visits (MacLean et al., 1999). In a pilot study of patients visiting the University of North Carolina Hospitals ED, in one month there were over 1,600 different ICD-9-CM codes used for the 5,000 patients treated. These fine-grained raw data were not useful for describing the primary reasons why patients visit the UNC Hospitals ED, since any individual code was used in relatively few instances. The vast majority of the diagnosis codes were used in

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less than 5% of the records. From the individual codes, it is difficult to gain a broader view of what "families" of medical problems are seen. This situation is faced by clinicians, researchers, administrators, and others interested in ED patient visit data: how can ICD-9-CM codes be aggregated to facilitate analysis of diagnosis data? One answer is to use a scheme of diagnosis clusters which groups "similar" ICD-9-CM codes together.

In this paper, we will address the following questions about diagnosis clusters.

- Where do diagnosis cluster schemes fit among the myriad representations used for medical information, which include terminologies, classifications, ontologies, and other means of organizing medical knowledge?
- What are the principles by which clusters should be defined?
- Does a diagnosis cluster scheme designed for one use work for other uses? In other words, does a mismatch between the purpose of the scheme and the purpose for its application have a significant operational impact on the results of applying the scheme to diagnosis codes?

We explore these questions in the context of Emergency Medicine (EM). There is a growing interest in patient visit data from EDs on the local, regional, and national scale. Public health leaders have expressed the need for health data that can be analyzed in aggregate (Rice, et al., 1989, U.S. Public Health Service, 1990). ED clinicians and other associated with emergency care have also called for comprehensive, aggregated data regarding the nature and management of injury and illness in the hospital ED (Cordell, 1994, Garrison et al., 1994, NCIPC, 1997, Wears, 1992). There are several characteristics by which EM differs from other medical specialties. Definitive, detailed diagnoses are not often made in the ED setting, since the final results of laboratory tests and other diagnostic data are often not available during the ED visit. ED patients' diagnoses are often given at a more general level than those in primary care and inpatient settings. For example, a patient with a runny nose, productive cough and wheezing might be diagnosed with code 465.9, VIRAL UPPER RESPIRATORY INFECTION in the ED, whereas the same patient could receive the more definitive diagnosis of code 487.1, INFLUENZA after confirmatory laboratory tests. The modern ED sees patients with a vast range of problems, ranging from the stereotypical life-threatening trauma to more routine care such as a urinary tract infection. For many people, the ED is their only choice even for routine medical care. It is said that EM practice is driven by symptoms and treatments; the quest for a definitive diagnosis or cure is more frequently found in other stages of medical care.

2. DIAGNOSIS CLUSTERS AND CLINICAL SIMILARITY

Several medical informatics researchers have discussed the distinctions between nomenclature, terminology, classification systems, grouping schemes, ontologies, and related knowledge representations (see, e.g., Ingenerf, 1995, Cimino, 1996, Henry et al., 1998). For our purposes here, the important distinctions concern where and why they are used in the patient care cycle. Read et al. (1995, p. 57) identify "three distinct processes in information handling, terming for recording patient care, encoding for statistics and management, and grouping for costing and other analysis". In this model, standardized

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medical terms are used in recording a variety of observations about the patient in the patient record. The terms should be precise and unambiguous, and are intended for communication among health care professionals. Pedan (2000), along with Read et al. (1995) point out the expressive needs of a standardized terminology, to enable a clinician to describe whatever factors are important in understanding and treating the patient's condition.

The process of encoding extracts salient pieces of information from the terms used in the patient record and fits them into a classification system such as ICD-9-CM or the Current Procedural Terminology (CPT), (AMA, 2000). Two clinicians seeing two different patients may use slightly different sets of terms to describe shortness of breath, wheezing, and a productive cough. Symptoms may be more severe in one patient than the other, or occur with different accompanying problems. But both diagnoses could be coded with 491.21, CHRONIC BRONCHITIS WITH ACUTE EXACERBATION, thus representing the fact that they suffer from the same disease. Information is lost in the encoding process, such as the individual characteristics of their conditions, whether they also have allergies to their pets, and so on. On the other hand, the assigned code can be used for administrative purposes such as billing and reimbursement, record retrieval, etc. There has been a great deal written about encoding stage along with the advantages and disadvantages of various classification systems (see, e.g., Feinstein, 1988, Cimino, 1996, Chute et al., 1996), but for the purposes of this paper, we will view the ICD-9-CM diagnosis codes as a given in the American healthcare system.

Read et al.'s (1995) third process, grouping, is our focus here. The overall purpose of grouping is to regard certain codes as being similar in some way, thus allowing the codes to be aggregated, or clustered, for a specific purpose. The clustering scheme lies on top of the coding system (e.g., ICD-9-CM), and provides a different view of the raw diagnosis data. For example, a well defined clustering scheme would allow hospital researchers and administrators to determine the most common medical problems seen in ED patients from a broader perspective than would be possible by just finding the most commonly assigned ICD-9-CM code.

Any collection of objects can be divided into clusters in many different ways. The context and purpose of the division, and therefore the idea of "what belongs together" drives the definition of the clusters. Definitions may be based on physical characteristics, context of action or use (Jonassen, 2000), or even the emotions objects evoke. For example, a bunch of children's toys could be grouped by color, by size, by material, by age-appropriateness, by type of play they encourage, or by how painful they are to step on barefoot in the dark. In each case, a "similarity rule" determines into which cluster an object should be placed. In the example, similarity could involve the number of small pieces a toy has that could be swallowed, or the number of pointy corners it has. Humans can view a single object from a number of perspectives, and therefore decide it is similar to almost any other object in some way (Barselou, 1983). As Rector (1999, p. 245) puts it, "A single fine-grained description may be classified in many different ways under many different coarse-grained abstractions for different purposes".

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The first step in defining a cluster scheme for diagnosis codes is therefore to define the purpose of the system. There are two main purposes for medical cluster schemes. Casemix groups, also known as Diagnostic Resource Groups (DRGs) (Health Systems International, 1988) or Healthcare Resource Groups (HRGs) (Read et al., 1995), are used to predict resource usage and costs, to create packages of insurance coverage, and to determine reimbursement amounts. DRGs may be defined by a combination of diagnosis, patient age, comorbidities, length of stay, average cost of treatment, and other factors. Diagnosis clusters, on the other hand are defined by *clinical similarity*, and group different diagnoses together to allow a variety of analyses, such as finding the types of diseases and disorders frequently seen in a certain population. This is the kind of cluster scheme in which we are interested.

What is clinical similarity? This is a crucial question in developing or using a diagnosis cluster scheme, but one which has not been definitively answered. Feinstein (1988) suggests that cluster rules based on clinical similarity may involve symptoms, causes of symptoms (etiology), expected course of disease, or prognosis. They might also include clinicians' decision rules, tests used to diagnose a disease, medications or tools used in its treatment, or the characteristics of people who are likely to contract it. Is clinical similarity defined the same way in all branches of healthcare?

From a distance, healthcare may be viewed as a single, uniform domain which is based on a fundamental body of knowledge. At this distance, healthcare appears quite different from other professions, such as construction or real estate. Taking a closer view, however, healthcare is seen as a collection of specialties and sub-specialties. A specialty can be focused on a particular patient age group (pediatrics, gerontology), a stage of care (emergency medicine, primary care, hospice care), a body system (gastroenterology, dermatology), or a disease (oncology, rheumatology). Although these specialties draw from a common knowledge base, they also have individual detailed areas of knowledge such as mechanisms of disease and disorders, diagnostic tests, and treatments. From a theoretical perspective, it is reasonable to hypothesize that the definitions of clinical similarity, and therefore the particular diagnosis clusters defined in a cluster scheme, also vary among specialties. From a more practical perspective, however, it has not been definitively shown that these differences are significant enough in nature or degree to affect the operational definitions of diagnosis clusters. In particular, the distinctive characteristics of EM described in the Introduction may not necessarily dictate a separate cluster scheme.

Specialization of knowledge can lead to other types of differences. A specialty may need more clusters that make finer distinctions in its own area of expertise, and fewer in peripheral areas. The resulting scheme would not necessarily be incompatible with other specialties' schemes, but would have a concentration of fine-grained clusters in the area of interest. For example, oncology may require more clusters that describe varieties of neoplasms than family practice. Supporting evidence for these differences is provided by the observations made on behalf of various specialties about the organization of ICD-9-CM. Many have commented that its hierarchy of codes does not support aggregation for their purposes. ICD-9-CM is organized along a variety of principles, including anatomic,

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pathologic or physiologic stratification and other operational themes, and is intended to provide wide coverage (Bowker and Star, 1999). Stausberg et al. (2001) explore the classification needs for surgery, and report that ICD-9 is generally ill-suited for surgery. Few codes represent surgical care, a handful of codes described a very large number of cases, and aggregating the data by truncating from 4 to 3 digits does not help. Wood et al. (1992) similarly maintain that ICD-9-CM is not well suited for family medicine.

A similar mismatch can be observed between ICD-9-CM structure and the needs of ED clinicians, and can be demonstrated by two types of problems. First, diagnoses that ED clinicians intuitively consider similar, and that should therefore be grouped together, do not have neighboring numeric codes. For example, 490 (a terminal code) represents BRONCHITIS, and 466.0 is ACUTE BRONCHITIS. The ED clinician would like these diagnoses to be grouped together because they represent related concepts from the standpoint of decision-making, diagnosis, and treatment. Second, concepts that ED clinicians view as distinct, and therefore belonging to different clusters, may have neighboring numeric codes. For example, 383.1 is CHRONIC MASTOIDITIS, while 383.3 is COMPLICATIONS FOLLOWING MASTOIDECTOMY. To the ED clinician, these codes represent different problems from an epidemiologic and etiologic perspective. Simple code truncation will not result in useful groups of codes.

Diagnosis clusters for EM can play an important role in allowing researchers, administrators, and others to leverage the rich information resource that lies in ED records. The next question to explore is whether any existing cluster schemes could be used for EM. Reuse would require that the operational definition of clinical similarity be the same. In other words, the clusters would have to group codes together in a way that "makes sense" to ED clinicians. Note that there are two parts involved in cluster definition. First, the cluster must include all codes that belong together, and exclude those that do not. For example, the EM experts on our team consider diabetes that occurs during pregnancy to be different from ordinary diabetes, which would indicate that it should not be included in a general "Diabetes" cluster. Second, the name of the cluster must accurately communicate to the EM clinician what is included and excluded from the cluster. We will discuss cluster naming in later sections.

3. THREE DIAGNOSIS CLUSTER SCHEMES

We have studied three existing ICD-9-CM cluster schemes systems, with the purpose of determining whether any of them can meet the needs of ED clinicians, researchers, and administrators, given that they were developed for other specialties. Although our ultimate goal in studying these three schemes is to determine their suitability for EM, we started with a comparative analysis of the schemes themselves, to determine their basic characteristics. We also examined how they handled a sample of diagnosis data from the UNC ED.

Schneeweiss et al. (1983, 1984, 1986, Rosenblatt et al., 1984) defined a set of diagnostic clusters for use in the outpatient family medicine setting. Users of the clusters have found that they reduce the large number of diagnoses assigned to patients in ambulatory family medicine practices to a manageable yet clinically meaningful set of clusters.

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These clusters have facilitated comparative analyses between family providers and practices. The scheme contains 120 groups. According to Schneeweiss et al. (1983), the developers used the following principle of similarity in defining the clusters.

> The clusters should identify groups of diagnostic rubrics that are clinically homogeneous. That is, each of the individual diagnostic rubrics within a cluster should ideally generate a similar clinical response from the physician in terms of the cognitive processes involved, the type of diagnostic tests ordered, the class of therapies employed, and the general services rendered. (pp. 107-8)

The original Schneeweiss et al. scheme was adapted for use in ambulatory internal medicine settings by Williams et al. (1991). B. C. Williams (personal communication, June 15, 2001), said that one purpose was to track the cases that residents had treated, to help ensure they had experienced a representative sample of internal medicine problems during their training. This scheme contains 100 clusters. According to Williams et al. (1991, p. 58), clusters were to be "clinically meaningful, each cluster containing diagnoses that have similar diagnostic and/or therapeutic implications".

The Agency for Healthcare Research and Quality (AHRQ, 1999) developed the Clinical Classification Software (CCS) clustering scheme for the purpose of aggregating data relating to hospital inpatient stays. (CCS is in two parts, one for diagnoses and one for procedures. We looked only at the diagnosis part.) CCS is defined in two versions, a single level, which contains 260 groups, and a multi-level, which combines the single level groups into 18 higher level groups. We worked with the single level version. Clusters were designed to be "clinically homogeneous", although the user guide does state that "[s]ome heterogeneous categories were necessary; these combine several less common individual conditions within a body system" (AHRQ, 1999).

All of these cluster schemes make possible a variety of statistical analyses that cannot be done with the original fine-grained ICD-9-CM codes. (For brevity, we will refer to these three cluster schemes as SCHN, WILL, and CCS, respectively, for the rest of this paper.) It is not clear, however, whether they are based on the same definition of clinical similarity. The guidelines given by Schneeweiss et al. are the most specific in defining what similarity meant in developing the clusters. Their definition is very context- and action-oriented, which fits the recommendations given by Jonassen (2000), and also our preliminary thoughts on the nature of clinical similarity in EM. Williams et al. talk about the "implications" of the diagnoses, while the CCS user guide mentions "clinical homogeneity". Clearly the variables that can (or should) contribute to "clinical similarity", and the specific values for any particular medical specialty, deserve further consideration.

One difficulty in working with these grouping schemes lies in the way they list the codes that are members of each cluster. ICD-9-CM diagnosis codes are in a 3.2 format, with 3 digits to the left of the decimal point, and 2 to the right. The 3 digits to the left are mandatory. For some codes, this is considered a terminal code, that is, one for which there is no further subdivision (Cimino, 1996). For example, 431, INTERCEREBRAL HEMORRHAGE, is a terminal code. Other 3-digit codes are non-terminal, and offer 4- and

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sometimes 5-digit subdivisions as terminal codes. For example, 432.2, SUBDURAL HEMORRHAGE is a terminal code, but 433.1, OCCLUSION AND STENOSIS OF PRECEREBRAL ARTERIES, CAROTID ARTERY, is not. The terminal codes under 433.1, which provide further detail, are 433.10, WITHOUT MENTION OF CEREBRAL INFARCTION, and 433.11 WITH CEREBRAL INFARCTION. CCS generally lists all the terminal codes in its cluster definitions, regardless of the number of digits. For some clusters, SCHN lists 3- or 4-digit non-terminal codes; for some, it lists both 3-digit nonterminals and the 4- or 5-digit expansions. WILL lists 3-digit non-terminal codes more often than either of the other two, but does occasionally list 4- or 5-digit expansions. In some clusters, the reason for the more detailed listing is obvious; if the group is intended to include all 4-digit codes under a single 3-digit code except one, then the included codes are given explicitly. Williams (personal communication, June 15, 2001) says that he believes it is appropriate to assume full expansion of non-terminal codes unless the sub-codes are listed explicitly in this way. For example, if a cluster lists 433, under this assumption it would also include 433.0, 433.00, 433.01, 433.1, 433.10 and so on. One result of this assumption is that WILL (and SCHN, if the same assumption is followed) cannot be used as published. Coders are generally instructed to assign the most specific code possible, based on the information given in the patient record. Therefore, prior to applying WILL or SCHN to a set of diagnosis codes, the non-terminal codes must be explicitly expanded to ensure the greatest level of matching. In comparing group membership and analyzing coverage of ED data, we used both strict matching (as published) and fully expanded versions. (We will refer to the fully expanded versions as SCHNF and WILLF, when it is important to differentiate.)

4. CLUSTER SCHEME COMPARISONS

We began our analysis with a comparison of cluster names and definitions from the CCS, SCHN, and WILL schemes. Then we examined how the schemes treated a sample of ED final diagnoses, analyzing their disposition of the most frequently used codes, and their overall coverage of the data. In this preliminary investigation, we focused on four types of clusters:

1. Clusters with exactly matching names.
2. Clusters with partially matching names.
3. Clusters that contained the most frequently occurring ICD-9-CM codes in a 2-month sample of diagnosis codes from the UNC ED.
4. "Miscellaneous" or "leftover" groups.

4.1 Cluster Name-Based Comparisons

Cluster names act as a representation of the cluster definition, and should be a succinct, summary description of their contents. A name should be meaningful to the people who will use it, in this case the clinicians in the specialty, as well as other healthcare professionals, because it will be the label attached to a variety of statistics. The name can almost be considered an intensional definition of the cluster, with the list of ICD-9-CM codes belonging to the cluster as the extensional definition.

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Table 1 (see Appendix) shows the clusters with exactly matching names, differing only in punctuation or number. 5.8% of CCS clusters, 18% of SCHN, and 25% of WILL were exact matches with a cluster from another scheme. (Recall that WILL was derived from SCHN.)

If one assumes that cluster names should be accurate reflections of their code membership, then it is reasonable to assume that clusters with the same name should have the same (or virtually the same) membership. Indeed, using full code expansion, there were no cases of entirely disjoint exact match clusters. There were several cases of intersection, however, where two clusters shared only a portion of their codes. In these cases, we can start to speculate about the principles underlying the similarity judgments used in defining the clusters. In some cases, for example, codes representing late effects of a disease or disorder were included in the same cluster as the disorder itself. CCS includes codes for late effects of burns in *Burns*, SCHN does not. Similarly, SCHN includes codes for late effects of cerebrovascular disease in its cluster, WILL does not. Subtler distinctions also occur. For example, CCS includes codes for abdominal tenderness in *Abdominal pain*, WILL does not. Any questions about the correctness or appropriateness of inclusions or exclusions must be answered in light of the purpose of the system, and its definition of clinical similarity. In our case, we are interested in appropriateness for EM, and would therefore rephrase the questions in this way:

- In EM practice, are the late effects of burns or cerebrovascular disease clinically similar to the initial burns and cerebrovascular disease themselves?
- Is there a significant difference that can be recognized in the ED between a patient presenting with abdominal pain and one with abdominal tenderness?

If EM experts' answers to these questions differ from experts in other healthcare specialties, the next question would be

- Are these differences significant enough to result in different cluster definitions?

Table 2 (see Appendix) lists a small sample of cluster names that were judged to be partial matches. (It also includes some exact matches, when a partial match occurs with the third cluster scheme.) A partial match occurred when the names included the same word or a related word, or started with a single modifier (e.g., "acute"), varied only slightly, and were judged to represent similar concepts by our team's EM experts. Because they were judged on the basis of word strings, this list does not include different but synonymous names. Frequently, the variation lies in an explicit statement of inclusion or exclusion. Of interest, therefore, is an examination to see if the name variation describes a real difference in the content of the clusters.

This list includes several examples where the difference in names accurately reflects a difference in cluster membership, but also several where this is not the case.

- SCHN and WILL both have a cluster named *Contraception*, while the corresponding cluster in CCS is named *Contraceptive and procreative management*. The contents of these clusters accurately reflect their names; CCS includes codes related to fertility, SCHN and WILL do not.

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- CCS and WILL both have a *Cataract* cluster, and SCHN has a cluster named *Cataract and aphakias*. CCS does not include the codes for aphakias in its cluster, SCHN does, thus reflecting its name. However, the *Cataract* cluster in WILL also includes aphakias. So two of the groups consider aphakias "clinically similar" to cataracts, but only one specifically mentions them in the cluster name. Without the explicit mention, would a clinician expect to find aphakias grouped with cataract? Would one obtain a different judgment if the clinician specialized in opthalmology?

- The gout clusters show a similar pattern. CCS includes all codes describing inflammation caused by crystals, as its cluster name indicates. SCHN includes only gout. WILL, however, also includes problems caused by dicalcium phosphate, although this is not reflected in the cluster name.

- The headache clusters show an interesting variant of this pattern. Despite the difference in names, all clusters contain codes for migraine. SCHN and WILL also contain the code for tension headache, which CCS omits.

- The sprain and strain clusters offer a final example. There are some small differences in coverage: SCHN and CCS include codes for sprain of back, while WILL clusters them with back disorders, and CCS includes a "late effect" code. The three clusters are otherwise the same, with an intersection of over 60 codes (assuming expansion of all non-terminal codes). So why does CCS call this cluster *Acute sprains and strains*? By definition (according to our EM experts), a sprain or strain is an acute event.

As with the exact match clusters, examination of the partial match clusters also raises some important issues in considering their suitability for EM diagnoses. In several cases a single cluster in one scheme intersects with more than one cluster in another. The diabetes and the fracture clusters are two areas where this occurs. These are two medical problems seen frequently in the ED, and however they are defined, will represent many patients' diagnoses.

CCS divides diabetes into two clusters, one *with complications*, and one *without complications*. The first group is the larger, including most of the ICD-9-CM diabetes codes. The second group includes 250.00, DIABETES MELLITUS WITHOUT MENTION OF COMPLICATION TYPE II NON-INSULIN DEPENDENT, and 250.01, TYPE I INSULIN DEPENDENT NOT STATED AS UNCONTROLLED. It also contains codes related to abnormal glucose test results. SCHN and WILL both have a single diabetes cluster, which are the same except that SCHN also includes diabetes in pregnancy. For EM, what does clinically similar mean in regard to diabetes? Are the symptoms and treatment of diabetes in the ED similar enough to require a single cluster? According to the initial judgments of the EM experts on our research team, diabetes in pregnancy is treated quite differently and should instead be grouped with other pregnancy-related conditions.

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SCHN and WILL both have a single cluster containing most codes relating to fractures, *All fractures and dislocations*, and *Fracture*, respectively. (They both place pathological fractures in *Osteoporosis*.) Despite the difference in cluster names, they contain the same codes. CCS, on the other hand, divides fractures by location of the body. There are separate clusters for pathological fractures and for dislocations. *Other fractures* contains fractures located in the neck, trunk, ribs, pelvis, etc. The first question is whether a single fracture cluster is specific enough for the purpose of aggregating final diagnoses for EM. If a finer division is needed, along what lines should it be drawn? Is location of fracture the best way, and if so, into which cluster should multiple fractures be placed? (CCS puts them in *Other fractures*.) Should it be based on the type of fracture (i.e., closed or open), or whether it is accompanied by lacerations or contusions? Or is there a concept of similarity based on treatment that would prove more useful?

A similar problem of division occurs with burns. All three systems place burn-related codes in a single cluster. CCS and SCHN each have a separate cluster for burns, while WILL includes them in *Skin – miscellaneous*, along with diseases of the nail, hair, sweat glands, and so on. If the needs of EM dictate more than one cluster for burns, what would be the appropriate dimension(s) of clinical similarity: site of burn, severity of burn (i.e., partial or full thickness), extent of body surface area involved, internal or external burn, cause of burn, or some combination of these?

4.2 Application of Cluster Schemes to ED Final Diagnosis Codes

In 2000-01, our research team conducted a pilot study to explore the feasibility of building a clustering scheme for ICD-9-CM diagnosis codes using the Unified Medical Language System (UMLS, NLM, 2000) as a support tool. Records containing the final diagnosis codes assigned to patient visits during July 1999 and January 2000 were extracted from the UNC-CH Hospitals ED administrative database. We chose to study one summer and one winter month to capture seasonal variations in diagnoses. The codes were stored in an MS Access database with all identifying information removed. Each record contained up to five final diagnosis codes. From these records, we pulled a list of all the codes that were assigned during the two months. Table 3 gives the numbers of codes and distinct codes for each month.

Table 3. Characteristics of pilot study data.

	July 1999	January 2000
# records (patient visits)	5,273	5,208
# codes	9,959	10,124
# distinct codes	1,800	1,644

With this data, we were then able to analyze the schemes' treatment of actual ED final diagnoses as an additional means of comparison and evaluation. Even if none of these schemes treated the ED data to the satisfaction of our EM experts, suggesting that there were differences in clinical similarity that affect the operational definition of clusters, the comparison will be helpful in developing an EM cluster scheme. Portions of one or more

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of them may serve as good starting points for defining the scheme. At the least, clusters that violate the EM experts' judgments of clinical similarity provoke discussion about how to improve them.

4.3 Placement of Common Seed Codes

From the pilot data we selected the 15 most common diagnoses as seed codes for our preliminary work. Table 4 (see Appendix) lists the ICD-9-CM codes, rubrics and frequency in the pilot data, and the clusters in which they were found in CCS, SCHNF, and WILLF.

The disposition of three of the seed codes exemplifies the types of decisions concerning clinical similarity we must make in creating our EM cluster scheme. The first is 276.5, VOLUME DEPLETION (also known AS HYPOVOLEMIA). None of the 276 codes or expansions (DISORDERS OF FLUID, ELECTROLYTE, AND ACID-BASE BALANCE) were included in the SCHN cluster scheme. WILL placed all of the 276 codes *except* 276.5 (VOLUME DEPLETION) and 276.6 (FLUID OVERLOAD) in a cluster called *Laboratory abnormality*. WILL did not include these two codes anywhere in the cluster scheme. (We will discuss this cluster more when we talk about miscellaneous code clusters.) If we were to adapt SCHN or WILL for EM, this is an example of the omissions of important concepts that we would need to address.

The next interesting situation concerns 305.1, TOBACCO USE DISORDER. To start with, there is some question as to the appropriateness and utility of this code as a final diagnosis in the ED. Nevertheless, since it is used in coding patient records, an EM cluster scheme must handle it in a reasonable manner. The way in which the different schemes treat alcohol, tobacco, and drugs is quite interesting (and confusing). There are at least two dimensions on which clusters could be defined: according to substance (i.e., tobacco, alcohol, drugs), or according to the nature of the problem (e.g., dependence, abuse, psychoses). CCS separates alcohol from tobacco and other substances, but combines all levels of problems in the two relevant clusters, *Alcohol-related mental disorders* and *Substance-related mental disorders*. SCHN defines a single cluster, *Alcohol and drug abuse,* which also includes related problems, such as CHRONIC LIVER DISEASE (571). WILL has one cluster that contains only 305.1, which was added because it represented an important and frequently-encountered problem in internal medicine. WILL also has a cluster named *Alcohol abuse* that is "limited to behavioral manifestations of alcoholism" (Williams et al., 1991, p. 58). A third cluster, *Substance abuse*, contains the remaining codes. These three schemes show evidence of different definitions of clinical similarity: what definition(s) would make sense for EM?

The situation surrounding respiratory infections is similar to that involving substances. CCS defines the clusters *Influenza*, *Other upper respiratory infections*, and *Pneumonia*. SCHN defines *Acute lower respiratory tract infection* and *Acute upper respiratory infection*, and *Sinusitis-acute and chronic*. WILL has *Acute respiratory infection*, *Lower respiratory infection* and *Sinusitis*. Again, the schemes have chosen different manifestations of clinical similarity.

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The final clusters we will discuss are three that have a "miscellaneous" feel from the EM perspective. CCS defines *Residual codes, unclassified* as containing codes representing general symptoms and abnormal laboratory findings from the 780's and 790's, as well as v-codes, which are related to personal and family history, condition, aftercare, and similar healthcare encounters. WILL has two such clusters: *Laboratory abnormality*, which contains codes related to a variety of codes in the 270's and 280's, and *Symptom or sign (excluding abdominal pain, atypical chest pain, constipation, headache, spine/back pain, blood in stool*), which contains many of the same symptom and findings codes found in CCS *Residual codes*. Is it possible to build a diagnosis cluster scheme without including one or more miscellaneous clusters? If not, how much will different schemes' miscellaneous clusters vary from one anther? We know, for example, that the codes in WILL's *Symptom or sign* cluster are very important in EM, and would probably not be viewed as clinically similar. In view of the fact that this cluster included the largest number of diagnosis codes in our pilot data, this is a significant observation.

4.4 Overall Coverage of Diagnosis Data

In this section we discuss the results of applying these three clustering schemes to our pilot ED final diagnosis data. The purpose of this experiment was twofold. First, we wanted to determine how extensively these schemes covered the data, and second, we wanted to determine the appropriateness of the resulting groupings. In the long run, we must decide whether any of these schemes would serve as a good base from which to start development of an EM cluster scheme, or whether it would be more efficient to design one from scratch. As we have shown, an important benefit of examining these schemes is that it prompts us to examine the needs of an EM clustering scheme more closely.

Three of our team members (BH, MC, PP) created a Java program called ClusterStats, which takes a file of cluster definitions and a file of diagnosis codes as input, and places the codes into the appropriate clusters. The program also calculates the number of diagnosis codes in each cluster, and the proportion of the entire set of codes placed in each cluster. We ran ClusterStats on the July 1999 and January 2000 pilot data for each of the three cluster schemes. Table 5 (see Appendix) describes the coverage each scheme provided. As expected, the full expansion versions of SCHN and WILL (SCHNF and WILLF) greatly increased coverage of the pilot data; results from both versions are shown in the table.

One of the desirable characteristics of a clustering scheme for EM is that each cluster capture a reasonable proportion of codes. We have not determined a precise value for "reasonable proportion", but it is clear that we want to avoid having many clusters that contain only a few diagnosis code instances. Unfortunately, that is exactly what happened when we applied these three schemes to our data. Table 6 shows the number of clusters in each coverage (C) range (less than 1%, between1% and 2%, and so on). The $C = 0\%$ row represents clusters into which no diagnoses fell. All schemes had a large number of clusters that contained less than 1% of the diagnosis codes each. On the other

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hand, a single cluster that captures too many of the diagnosis codes is also a potential problem, because it may be combining many disparate diagnoses, rather than truly representing many instances of the same medical problem. The *Symptom or sign* cluster in WILLF captured 8.8% of the July 1999 diagnoses, and 8.9% of the January 2000 ones. Given its miscellaneous nature, this is not a useful cluster for EM. Finding the best balance between a smaller number of large clusters and a large number of smaller clusters is likely to be difficult.

Table 6. Number of clusters for each coverage range.

	July 1999			January 2000		
	CCS	SCHNF	WILLF	CCS	SCHNF	WILLF
C = 0%	30	2	7	27	8	5
0.0 < C ≤ 1.0%	198	95	71	199	89	73
1.0 < C ≤ 2.0%	22	13	13	18	14	12
2.0 < C ≤ 3.0%	8	7	6	9	4	6
3.0 < C ≤ 4.0%	2	0	1	0	3	1
4.0 < C ≤ 5.0%	0	2	1	2	2	2
5.0% < C	0	1	1	0	0	1

Table 7 (see Appendix) shows the names of the ten largest clusters used for covering the pilot data. This table demonstrates how useful a diagnosis cluster system will be for understanding the medical problems seen in an ED, but also points out the importance of the cluster definition stage.

- It is easy to observe the difference between the summer and winter months by noting the appearance of a variety of respiratory infection clusters in January's top ten.
- Other problems show less seasonal variation, such as those represented by the hypertension, abdominal pain, diabetes, and urinary tract infection clusters.
- CCS and SCHNF both show a cluster for superficial injuries, contusions, and related diagnoses, but WILLF does not. Following up on this observation, it turns out that these codes are not included in the WILL scheme. (Recall that WILL was designed for internal medicine.) The frequency of these diagnoses indicates a need for inclusion in an EM cluster scheme.
- The largest clusters may be candidates for subdivision. As an example, we discussed this need for WILLF *Symptom or sign*, and the issues surrounding the alcohol, tobacco and drug codes.

5. CONCLUSION

Diagnosis cluster schemes play a unique role in the complex world of medical information and knowledge. They lie on top of existing coding systems such as ICD-9-CM, and allow clinicians, researchers, administrators, and others to gain a broader view of the medical problems seen in a particular practice, health-care institution, or patient population. However, the purpose of the scheme, as well as the definition of *clinical similarity* used, will influence its design, including the number of clusters, their names,

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and the diagnosis codes they contain. Our study of three existing cluster schemes illustrated many ways in which the difference in purpose and specialty affected their design.

Emergency medicine, like other specialties, has its own characteristics that will affect the design of its diagnosis cluster scheme. Studying the existing schemes has been very helpful in identifying many of the questions we must answer in the design process. Our results also indicate that none of them would be helpful for EM without some amount of modification. Validation of a scheme by experts with a variety of EM experience (e.g., in a variety of EDs) will also be a crucial step in development.

The idea of *clinical similarity* is one that deserves more attention.

- What are the factors that contribute to its formation?
- How complete is agreement among clinicians in the same specialty?
- Is clinical similarity defined differently (or similarly) in different specialties?
- Do clinicians acquire a sense of clinical similarity and if so, how?

Defining clinical similarity is one focus of our continuing research into the development of a diagnosis cluster scheme, which we call *ICEM: ICD-9-CM Clusters for Emergency Medicine*. But clinical similarity must be balanced with practical issues of determining a useful number and size of diagnosis clusters – not too many, not too few, not too big, not too small. The other focus of our research, therefore, is the definition and validation of the clusters in the scheme, along with a demonstration of its utility in describing final diagnoses in ED patient records.

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Appendix

Table 1: Exact Match Cluster Names.

CCS	SCHN	WILL
Abdominal pain		Abdominal pain
Asthma	Asthma	Asthma
Burns	Burns-all	
Cataract		Cataract
	Cerebrovascular disease	Cerebrovascular disease
	Chronic rhinitis	Chronic rhinitis
Chronic ulcer of skin	Chronic ulcer of skin	
	Congestive heart failure	Congestive heart failure
	Constipation	Constipation
	Contraception	Contraception
Glaucoma	Glaucoma	Glaucoma
	Gout	Gout
	Headaches	Headaches
	Hypertension	Hypertension
	Inflammatory bowel disease	Inflammatory bowel disease
	Irritable colon	Irritable colon
	Ischemic heart disease	Ischemic heart disease
	Lipid disorders	Lipid disorders
Malaise and fatigue	Malaise and fatigue	
Menstrual disorders	Menstrual disorders	
	Obesity	Obesity
Osteoarthritis		Osteoarthritis
Osteoporosis		Osteoporosis
	Seizure disorders	Seizure disorders
Sprains and strains		Sprain/strain
Syncope		Syncope
Tuberculosis		Tuberculosis
Urinary tract infections		Urinary tract infections
	Urticaria	Urticaria
Varicose veins of lower extremity	Varicose veins of lower extremities	

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Table 2. Sample of partial match cluster names.

CCS	SCHN	WILL
Cataract	Cataracts and aphakias	Cataract
Contraceptive and procreative management	Contraception	Contraception
Diabetes mellitus with complications	Diabetes mellitus	Diabetes
Diabetes mellitus without complications	Diabetes mellitus	Diabetes
Fracture of lower limb	All fractures and dislocations	Fracture
Fracture of neck of femur (hip)	All fractures and dislocations	Fracture
Fracture of upper limb	All fractures and dislocations	Fracture
Other fractures	All fractures and dislocations	Fracture
Pathological fracture	All fractures and dislocations	Fracture
Skull and face fractures	All fractures and dislocations	Fracture
Gout and other crystal arthropathies	Gout	Gout
Headache, including migraine	Headaches	Headache
Osteoporosis	Osteoporosis including collapse of vertebra NOS	Osteoporosis
Sprains and strains	Acute sprains and strains	Sprain/strain

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Table 4. Seed codes and corresponding cluster names.

Seeds			Clusters		
Code	**Rubric**	**Freq.**	**CCS**	**SCHNF**	**WILLF**
250.00	DIABETES WITHOUT MENTION OF COMPLICATION, TYPE II, CONTROLLED	298	Diabetes mellitus without complications	Diabetes mellitus	Diabetes
276.5	VOLUME DEPLETION	253	Fluid and electrolyte disorders	NOT FOUND	NOT FOUND
305.1	TOBACCO USE DISORDER	196	Substance-related mental disorders	Alcohol and drug abuse	Tobacco use
382.9	UNSPECIFIED OTITIS MEDIA	271	Otitis media and related conditions	Otitis media-acute and chronic	Ear-otitis/vertigo
401.9	ESSENTIAL HYPERTENSION, UNSPECIFIED	744	Essential hypertension	Hypertension	Hypertension
428.0	CONGESTIVE HEART FAILURE	227	Congestive heart failure, nonhypertensive	Congestive heart failure	Congestive heart failure
465.9	ACUTE UPPER RESPIRATORY INFECTION, UNSPECIFIED SITE	406	Other upper respiratory infections	Acute upper respiratory infections	Acute respiratory infection
486	PNEUMONIA, ORGANISM UNSPECIFIED	253	Pneumonia (except that caused by tuberculosis or sexually transmitted disease)	Acute lower respiratory tract infection	Lower respiratory infection
487.1	FLU WITH OTHER RESPIRATORY MANIFESTATIONS	62	Influenza	Acute upper respiratory infection	Acute respiratory infection
490	BRONCHITIS NOS	141	Chronic obstructive pulmonary disease and bronchiectasis	Acute lower respiratory tract infection	Lower respiratory infection
493.90	ASTHMA WITHOUT STATUS ASTHASTHMATICUS	265	Asthma	Asthma	Asthma
599.0	URINARY TRACT INFECTION, SITE NOT SPECIFIED	404	Urinary tract infections	Urinary tract infections (excluding urethritis)	Urinary tract infection
724.5	BACKACHE, UNSPECIFIED	190	Spondylosis, intervertebral disc disorders, other back problems	Low back pain and syndromes (excluding acute sprain)	Spine/back disorder
784.0	HEADACHE	233	Headache, including migraine	Headaches	Headache
786.59	CHEST PAIN, OTHER	179	Nonspecific chest pain	Chest pain	Atypical chest pain

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Table 5. Coverage of the pilot months' final diagnosis codes. First, the table lists the number and percentage of diagnosis codes covered. Then it lists the number of each scheme's clusters used, and the percentage of clusters in the schemes that represents.

	July 1999 (9,964 diagnosis codes)					January 2000 (10,124 diagnosis codes)				
	CCS	SCHN	SCHNF	WILL	WILLF	CCS	SCHN	SCHNF	WILL	WILLF
Diagnoses codes covered										
#	9.927	5,514	7,141	3,491	6,963	10,114	5,785	7,339	3,740	7,409
%	99.6%	55.3%	71.6%	35.0%	69.9%	99.9%	57.1%	72.5%	36.9%	73.2%
Clusters used										
#	230	114	118	61	93	228	109	112	60	95
%	90.1%	95.0%	98.3%	61.0%	93.0%	89.4%	90.1%	93.3%	60.0%	95%

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Table 7. Ten largest clusters used for pilot data.

	July 1999			*January 2000*		
Rank	**CCS**	**SCHNF**	**WILLF**	**CCS**	**SCHNF**	**WILLF**
1	Essential hypertension	Lacerations, contusions, and abrasions	Symptom or sign (excluding abdominal pain, atypical chest pain, constipation, headache, spine/back pain, blood in stool)	Other upper respiratory infections	Acute upper respiratory infection	Symptom or sign (excluding abdominal pain, atypical chest pain, constipation, headache, spine/back pain, blood in stool)
2	Substance-related mental disorders	Hypertension	Hypertension	Essential hypertension	Hypertension	Acute respiratory infection
3	Superficial injury, contusion	Alcohol and drug abuse	Substance abuse (excluding alcohol and tobacco)	Chronic obstructive pulmonary disease and bronchiectasis	Lacerations, contusions, and abrasions	Hypertension
4	Urinary tract infections	Diabetes mellitus	Diabetes	Viral infection	Acute lower respiratory tract infection	Lower respiratory infection
5	Abdominal pain	Urinary tract infections (excluding urethritis)	Spine/back disorder	Pneumonia (except that caused by tuberculosis or sexually transmitted disease)	Alcohol and drug abuse	Diabetes
6	Spondylosis, intervertebral disc disorders, other back problems	Abdominal pain (excluding pelvic)	Urinary tract infection	Sprains and strains	Diabetes mellitus	Spine/back disorder
7	Coronary atherosclerosis and other heart disease	All fractures and dislocations	Abdominal pain	Substance-related mental disorders	Acute sprains and strains	Ear-otitis/vertigo
8	Diabetes mellitus without complication	Depression, anxiety, and neuroses	Fracture	Fluid and electrolyte disorders	Fibrositis, myalgia, and arthralgia	Substance abuse (excluding alcohol and tobacco)
9	Other upper respiratory infections	Ischemic heart disease	Nonpsychotic mental disease (including "multiple stressors")	Abdominal pain	Abdominal pain (excluding pelvic)	Nonpsychotic mental disease (including "multiple stressors")
10	Sprains and strains	Acute sprains and strains	Ear-otitis/vertigo	Spondylosis, intervertebral disc disorders, other back problems	Depression, anxiety, and neuroses	Abdominal pain

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