The Kindness of Strangers: Kinds and Politics in Classification Systems

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ABSTRACT

THIS ARTICLE OFFERS A FORMAL READING of a classification scheme of international scope and long duration: the *International Classification of Diseases (ICD).* The argument is made that this classification scheme retains many traces of its own administrative and organizational past in its current form. Further, it is argued that such traces operate normatively to favor certain kinds of narrative of medical treatment while denying others. It is suggested that the *ICD,* like other large-scale classification systems, is able to do its work so effectively precisely because these traces permit a coupling of classification scheme and organizational form.

INTRODUCTION

> In so far as the coding scheme establishes an orientation toward the world, it constitutes a structure of intentionality whose proper locus is not the isolated, Cartesian mind, but a much larger organizational system, one that is characteristically mediated through mundane bureaucratic documents such as forms. (Goodwin, 1996, p. 65)

In the digital libraries that are being constructed today, a burgeoning number of formal classification systems are being inscribed deep into the infrastructure of the information system.

In this discussion, some medical classification systems with a long history will be examined—notably the *International Classification of Diseases (ICD-9-CM,* 1996; *ICD-10,* 1992), in operation since the 1890s—in order to discern the relationship between the use of the classification as an information storage and retrieval mechanism and its use to encode multiple political and ethical agendas.

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One classic division between kinds of classification system is that drawn by Taylor (1995), who distinguishes between Aristotelian classification and prototype classification. The prototype classification was defined by experimental psychologist Eleanor Rosch (1978). This distinction is going to be an important one throughout this discussion and will be explored in some detail. An Aristotelian classification works according to a set of binary characteristics, which the object being classified either presents or does not present. At each level of classification, enough binary features are adduced to place any member of a given population into one, and only one, class. So we might say that a *pen* is an object for writing within a population consisting of pens, balls, and bottles (Taylor, 1995). We would have to add in one more feature in order to adequately distinguish pens, for example, from pencils, balls, or bottles. A technical classification system operating by binary characteristics is called monothetic if a single set of necessary and sufficient conditions is adduced ("in the universe of polygons, the class of triangles consists of figures that have three sides"), polythetic if a number of shared characteristics are used (in our example, the pen could be described as thin, cylindrical, used for writing, has a ball point, and so forth) (Blois, 1984). Desrosiàres (1993) indicates a typical breakdown between monothetic and polythetic classifications in the work of statisticians. He associates the former with Linnaeus and the latter with Buffon (who engaged in local classification practices, just using the set of traits needed to make a determination in a specific instance) and writes: "These local practices are often carried out by those working in statistical centers, according to a division of labor whereby the chiefs are inspired by Linnaean precepts but the working statisticians apply, without realizing it, Buffon's method" (p. 296 [authors' translation]). Aristotelian models—monothetic or polythetic—have traditionally informed formal classification theory in a broad range of sciences, including biological systematics, geology, and physics.

Rosch's (1978) prototype theory argues that, in daily life, our classifications tend to be much fuzzier than we might at first think. We do not deal with a set of binary characteristics when we decide that this thing we are sitting on is a chair. Indeed, it is possible to name a population of objects that people would in general agree to call chairs that have *no* two binary features in common.

According to prototype theory, there is a broad picture in our minds of what a chair is, and this picture is extended by metaphor and analogy when trying to decide if any given thing that we are sitting on counts. We call up a best example and then see if there is a reasonable direct or metaphorical thread that takes us from the example to the object under consideration. Prototype theory has been powerfully developed within the field of sociolinguistics by George Lakoff (1987) and John Taylor (1995). One finding of the theory is that different social groups tend to have quite

different prototypes in mind when classifying something—e.g., a piece of furniture. Thus, when surveyed, a group of Germans came up consistently with a different set of best examples than a group of Americans (Taylor, 1995, pp. 44-57). For the Americans, chair and sofa are best fits for furniture, for the Germans, asked about möbel, it was bed and table.

An important implication of the theory is that there are levels at which we most easily and naturally distinguish between objects in the world, and that supervenient or subvenient levels tend to be more technically defined. Looking at a picture of a Manx coon cat, a nonexpert will say that this is a picture of a cat. An expert might call it either a Manx coon cat or a vertebrate.

This distinction between two main types of classification is a very useful one. However, there are a number of reasons for saying that it is not an absolute distinction—indeed, one could say that we all probably have a personal prototype of the ideal Aristotelian classification system, but that no one system in practice fully meets a single set of Aristotelian requirements. We stress "in practice" here, since it is practice that this discussion is largely about. Turning to an example from the workplace, it is possible to begin to see how practice and location mediates such divisions. In the medical arena, it emerged from a survey of physicians in 1979 in the United Kingdom that general practitioners "had a constant tendency to regard a wider range of phenomena as disease" than the hospital physicians, who in turn were more inclusive than the lay public—the perceived need for medical intervention being the determining axis (Prins, 1981, p. 176; Campbell, Scadding, & Roberts, 1979). An influential factor, Prins notes, seems to have been whether or not medical intervention was required. For the lay public, "measles" and "mumps" might be prototypical diseases, but "arthritis," a card-carrying *ICD-10* (1992) disease, might be seen rather as a condition.

So why do we seem in practice prototypical even if in principle Aristotelian? For two main reasons: (1) because each classification system is tied to a particular set of coding practices, and (2) because classification systems *in general* (we are not making this as an *ex cathedra* pronouncement) reflect the conflicting contradictory motives of the sociotechnical situations that gave rise to them.

Practices

Consider the *International Classification of Diseases* (*ICD-9-CM, 1996; ICD-10,* 1992). When originally drawn up, it had a maximum of 200 categories, not because this was the number of diseases in the world but because this had been the number of lines on Austrian census forms. If too many diseases got identified, then there would be no way of maintaining and analyzing registers of causes of death as the technology would not hold more information.

In addition to this inheritance, there is a practical Occam's razor. When doctors come to code causes of death, they are frequently faced with a set of difficult judgments (that may require an autopsy and further diagnostic work). They can simply go for the easiest solution—i.e., by using a generalized "other" category. They can then get back to dealing with their live patients (Fagot-Largeault, 1989). So the classical beauty of the Aristotelian classification gives way to a fuzzier classification system that shares *in practice* key features with commonsense prototype classifications—i.e., heterogeneous objects linked by metaphor or analogy.

The powerful habits of practice with respect to the humble tasks of filling out forms are often neglected in studies of classifying. Goodwin (1996) provides an elegant description of working student archaeologists matching patches of earth against a standard set of color patches—the Munsell color charts. He notes that earlier cognitive anthropological work on color assumed a universal genetic origin for color recognition but failed to examine the kinds of practices that informed the ways in which color tests were designed and carried out in the course of this research. Goodwin (1996) notes:

> Rather than standing alone as self-explicating textual objects, forms are embedded within webs of socially organized situated practices. In order to make an entry in the slot provided for color an archaeologist must make use of another tool, the set of standard color samples provided by a Munsell chart. This chart incorporates into a portable physical object the results of a long history of scientific investigation of the properties of color. The version of this chart that archaeologists bring into the field has been tailored to the distinctive requirements of their work situation. (p. 66)

The archaeologists constantly compare the pieces of earth against the chart, negotiate with each other, and transform their everyday terms for the earth into the formal numbered categories on the chart. The uncertainties they face along the way are removed once the numbers are selected and reported: "The definitiveness provided by a coding scheme typically erases from subsequent documentation the cognitive and perceptual uncertainties that these students are grappling with, as well as the work practices within which they are embedded" (Goodwin, 1996, p. 78).

Contradictory Requirements of Classification Systems in General

Classification systems in general inherit contradictory motives in the circumstances of their creation. This is very clearly illustrated by items in the *ICD* covering such charged ethical or religious issues as abortion or stillbirth. Over the years, defining the moment of birth differed radically from Protestant to Catholic countries and with technological changes. The final definitions given in the *ICD* directly reflect the charged political and

ethical atmosphere of the subject, distinguishing, for example, legal and illegal abortion as separate categories. In this sense, the *ICD* can also be read as a kind of treaty, a bloodless set of numbers obscuring the behind-the-scenes battles informing its creation. This dryness itself contains an implicit authority, seeming to rise above uncertainty, power struggles, and the impermanence of the compromises.

Indeed, one might observe that technical classification schemes are constructed in such a way as to fit our commonsense prototypical picture of what a technical classification is. Thus when the International Committee for the Nomenclature of Viruses, to which we shall return, floated the idea of using "siglas"—a series of code letters attached to the virus name to indicate its characteristics—Matthews (1983) describes the response as follows: "Leading virology journals were only lukewarm to try out cryptogram ideas. Among comments from this period: 'Why should they be given *funny names*? Are we not exposing ourselves to the laughter of the general public? Do we want to join the ranks of old-fashioned botanists and zoologists so soon?'" (pp. 13-14). A good technical classification should not only be correct in Aristotelian terms, it should, in good prototypical fashion, look and feel scientific. This is not an isolated case. The developers of the Nursing Interventions Classification (NIC) have made similar observations—e.g., they initially did not classify "leech therapy" not because it was not a scientific intervention but because it did not look and feel like one. With respect to the *ICD*, there has been a long debate within the patient community about naming chronic fatigue syndrome, for example (as there was for AIDS). Consider this discussion among patients suffering from chronic fatigue syndrome:

> Many patients feel that one of the greatest burdens of having chronic fatigue syndrome is the name of the illness. The word "fatigue" (which many patients refer to as the "F" word) indicates everyday tiredness. It reinforces negative perceptions that remain with the public and most medical doctors, despite a decade of steady, gradual research advances. (*Chronic Fatigue Syndrome Electronic Newsletter*, 20 February, 1997)

One option was to name it after Darwin, but it was felt that, although he had the scientific cachet, he did not necessarily have the disease. Inversely, Florence Nightingale's diagnosis is more certain but less prestigious:

> Nightingale's. (A general note: no historical figure has been definitively diagnosed with CFS/M.E. Purists may object to choosing any person in history, who may not have actually had the disease, as the basis for an eponym.) Florence Nightingale is a widely respected and world-renowned figure who founded the International Red Cross and the first formal school for nursing. For decades she had an undiagnosed, severely debilitating, illness with symptoms similar to CFS. Despite Nightingale's considerable talents and her personal character, many doubted that she had a physical illness. Her illness was

> quite controversial. A 1996 paper by D.A.B. Young that appeared in the *British Medical Journal* indicates that Nightingale's illness was likely to have been chronic brucellosis (a disease with symptoms similar but not identical to CFS). Patient groups have promoted Nightingale's birthday, May 12, as International CFIDS/M.E. Awareness Day, and Nightingale is a familiar symbol to those who know this disease. However, some argue that women's diseases often have difficulty in getting recognized and accepted. Choosing Nightingale's name as an eponym might add to, rather than offer relief from, current name-associated problems. (*Chronic Fatigue Syndrome Electronic Newsletter*, 20 February 1997)

More generally, Taylor, from a linguistic perspective, and Durkheim and Mauss (1968) (for whom primitive social classifications "seem to link, without any discontinuity, with the first scientific classifications" [p. 82]) from an anthropological one have observed that our technical classifications grow out of, and have to answer to, commonsense socially comfortable classifications. It just would not be socially feasible to call a donkey a fish no matter how good your scientific grounds.

There is no great divide between folk and scientific classifications. Below, we discuss one particular fault line between the two: a fracture that is constantly being redefined and changing its nature as the plate of lived experience is subducted under the crust of scientific knowledge. This fault line is the ways in which temporal experience—i.e., history, experience, development, memory, evolution—is registered in, and expressed by, two formal classification systems—the ICD and the INV. The crack comes when the messy flow of bodily and natural experience must be ordered against a formal neat set of categories. We will trace this particular faultline across the two classification schemes. It is the case that all complex classification schemes in fact have multiple sets of faults and fractures arising from similar tensions. On a meta level, the system of faults and tensions forms a kind of texture of any given organizational terrain; mapping this texture is a major research challenge for the field of social informatics.

The International Classification of Diseases is a Pragmatic Classification

In order to communicate information in the aggregate, it must first be classified. At any time over the past 100 years, one can find complaints about the Tower of Babel that afflicts the storage and communication of medical knowledge.[1] David Rothwell (1985) notes that:

> More than two hundred statistical systems are being used by the United States government to monitor health, occupational and environmental conditions through the country. Despite the incredible amount of information accumulated, there is no method of coordinating these data into a single coherent database, a national health information system. (p. 169)

Mark Musen (1992) complains:

> The medical-informatics community suffers from a failure to communicate. The terms that WMR uses to describe patient findings generally are not recognized by Medline. The manner in which Iliad stores descriptions of diseases is different from that of Dxplain. Therapy plans generated by ONCOCIN are meaningless to the HELP system. . . . Each time another developer describes yet another formalism for encoding medical knowledge, the number of incompatibilities among these different systems increases exponentially. (p. 435)

Musen indicates that there is no clear relationship between "the Unified Medical Language System [UMLS] advanced by the National Library of Medicine and the Arden syntax proposed by the American Society for Testing and Materials as a standard for representing medical knowledge" (p. 436). The *ICD,* he points out, originated as a means for describing causes of death; a trace of its heritage is its continued difficulty with describing chronic, as opposed to acute, forms of disease. This is one basis for the temporal faultlines that emerge in its usage. The UMLS originated as a means of information retrieval (the MeSH scheme) and is not as sensitive to clinical conditions as it might be (p. 440).

The two basic problems for any overarching classification scheme in a rapidly changing and complex field can be described as follows: first, any classificatory decision made now might, by its nature, block valuable future developments. If we decide that all instances of Sudden Infant Death Syndrome are to be placed into a single box (*ICD-10,* 1992, vol. 1, R 95, p. 890), then we are not recording information that might be used by future researchers to distinguish possible multiple social or environmental causes of the syndrome. We are not making it impossible to carry out such studies, but we are making it difficult to retrieve information. Second, inversely, if every possible relevant piece of information was stored in the scheme it would be entirely unwieldy.

The decision not to collect is the most difficult for any classification on these grounds, whether it be the acquisition department of a library, the curator of an art museum, or the collector of information for vital statistics. There are always practical budget and storage issues. These are balanced against two other factors: (1) the need for a well ordered and, in some sense, parsimonious repository that can be used, and (2) the side bets that are made about what material will be useful in the future. This latter is particularly difficult.

Collectors and curators of all sorts must become future forecasters and decide the boundaries of what will be useful for the future. There is no perfect answer, only a set of practical tradeoffs. This is a problem that has plagued museums of natural history, for example. Fossils found in the nineteenth century might come along with general information about

the depth at which they were discovered and the surrounding geological features (though they often did not). Even if this information was included, it was never as precisely noted as would be useful for geologists and paleontologists today since there was just no conception at that stage of the kinds of dating techniques that are used today. The museum is then faced with the choice between recording as much as possible now (which is very expensive and possibly not useful anyway) and having the collection perhaps last longer into the future or recording a judicious amount now (which will keep the administrative costs down) and having the collection possibly be not so useful in the future. The latter has generally been the de facto choice and is generally a reasonable one to have made since new criteria of relevance just cannot be predicted.

Different designers of the classification system have different needs—and the shifting ecology of relationships between the disciplines using the classification will necessarily be reflected in the scheme itself. As with the insurance company example above, these relationships must be resolved in order to make a usable form, often obscuring power relationships in the process. As Goodwin (1996) notes: "A quite different kind of multivocality, one organized by the craft requirements of a work task rather than the genres of the literary academy, can be found in mundane bureaucratic forms" (p. 66). But one must dig to find the voices. The process of filling out the forms may further obscure them. For example, the designers of the *ICD* recommend that its classification scheme be interpreted economically:

> The condition to be used for single-condition morbidity analysis is the main condition treated or investigated during the relevant episode of health care. The main condition is defined as the condition, diagnosed at the end of the episode of health care, primarily responsible for the patient's need for treatment or investigation. If there is more than one such condition, the one held most responsible for the greatest use of resources should be selected. . . .(*ICD-10,* 1992, vol. 2, p. 96)

This reflects a constant condition of the use of the ICD; it has been recommended throughout its history that priority should be given to coding diseases that represent a threat to public health. This goal is clearly a good one; equally clearly it can discriminate selectively against the reporting of rare noncontagious conditions.

Faced with these problems, the WHO has been consistently pragmatic in its aims and clear in its explanations of the ICD. From the time of the ninth revision on, it has been recognized explicitly that "the ICD alone could not cover all the information required and that only a 'family' of disease and health related classifications would meet the different requirements in public health" (*IDC-10,* 1992, vol. 2, p. 20). This "family" is pictured in ICD-10 (see Figure 1).

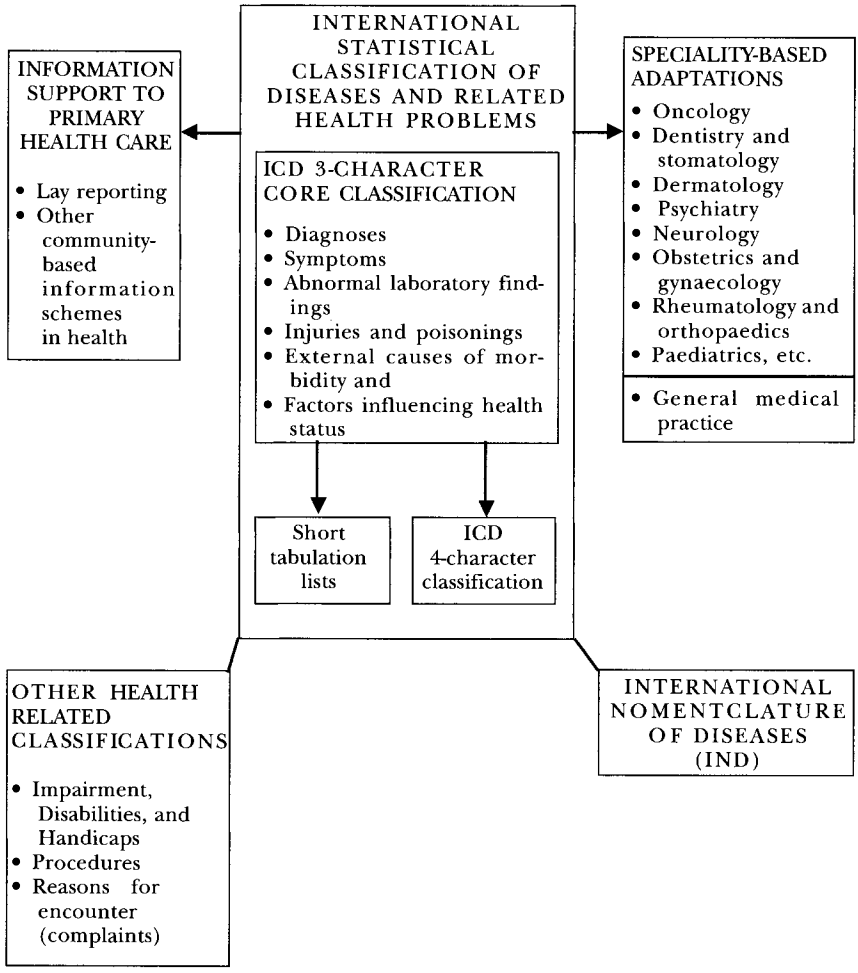

Figure 1. Diagram of Family of Disease and Health Related Classifications (Source: *ICD-10*, 1992, vol. 2, p. 4).

The family itself is a diverse one: there are various standard modifications of the *ICD*. The most significant is the *ICD-9-CM* (1996) where CM stands for "clinical modification." This has a complex history, originating in the development of modifications of the *ICD* for use in hospital information systems. It is now the classification of record in a wide variety of medical settings and is used for billing, insurance, and administration as well as in-patient medical records. This institutional entrenchment has made it very difficult for *ICD-10* (1992) to be fully adopted in the United States with the clinical modification necessarily lagging behind the production of the classification itself.

When we observe the ways in which culture and practice interweave in the text of the *ICD*, we are not unmasking a false pretender to the crown of science. We are drawing attention to an explicit positive feature of *ICD* design: "The ICD has developed as a practical, rather than a purely theoretical classification. . . . There have . . . been adjustments to meet the variety of statistical applications for which the ICD is designed, such as mortality, morbidity, social security and other types of health statistics and surveys" (*ICD-10*, 1992, vol. 2, p. 12). The preamble to the classification defines a classification of diseases as "a system of categories to which morbid entities are assigned according to established criteria" (*ICD-10*, 1992, vol. 1, p. 1). A *statistical* classification, such as the *ICD*, "must encompass the entire range of morbid conditions within a manageable number of categories" (*ICD-10*, vol. 2, p. 1). It is not meant to be a net to capture all knowledge but a workable epidemiological tool. This practical goal does not make it less scientific, of course; all classification systems are developed within a context of organizational practice. The goal of the *ICD*'s designers is to create what Latour (1988) has called immutable mobiles—inscriptions that may travel unchanged and be combinable and comparable. Indeed, the term "immutable mobile" might almost have been in the designers' minds when they wrote:

> The purpose of the *ICD* is to permit the systematic recording, analysis, interpretation, and comparison of mortality and morbidity data collected in different countries or areas and at different times. The *ICD* is used to translate diagnoses of diseases and other health problems from words into an alphanumeric code, which permits easy storage, retrieval, and analysis of the data. (*ICD-10*, 1992, vol. 2, p. 2)

The *ICD* has become the international tool for "standard diagnostic classification for all general epidemiological and many health management purposes" (p. 2).

The world has changed since the *ICD* was first introduced, and the classification scheme has evolved to try to encompass these changes. The *ICD* is thus both highly responsive and tightly constrained. A large-scale change in the way that people die (Israel, Rosenberg, & Curtin, 1986, p. 161) has led to an alteration in one line in the internationally recommended Death Certificate. This is, of course, one of the main bureaucratic uses of the *ICD*—i.e., the recording and compiling of causes of death from bureaus of vital statistics via coroners, hospitals, doctors, or priests:

> In considering the international form of medical certificate of cause of death, the Expert Committee had recognized that the situation of an aging population with a greater proportion of deaths involving multiple disease processes, and the effects of associated therapeutic interventions, tended to increase the number of possible statements between the underlying cause and the direct cause of death: this meant that an increasing number of conditions were being entered

> on death certificates in many countries. This led the committee to recommend the inclusion of an additional line (d) in Part 1 of the certificate. (*ICD-10*, 1996, vol. 1, p. 18)

Thus there is now one more blank line on the form to indicate multiple causation (see Figure 2).

Cause of Death		**Approximate interval between onset and death**
I		
Disease or condition directly leading to death*	(a).....	.....
	due to (or as a consequence of)	
Antecedent causes	(b).....	.....
Morbid conditions, if any, giving rise to the above cause, stating the underlying condition last	due to (or as a consequence of)	
	(c).....	.....
	(d).....	.....
II		
Other significant conditions Contributing to the death, but not related to the disease or condition causing it	.....	.....
	.....	.....

* This does not mean the mode of dying—e.g., heart failure, respiratory failure. It

(otherwise there would have been too many cases). The National Tuberculosis Association's (1955) edition of *Diagnostic Standards and Classification of Tuberculosis* notes that new laboratory tests had made it more difficult to decide whether a particular case of TB was active or inactive—activity could now be seen at sites previously considered inactive, and yet one would not necessarily want to call the "new" active sites cases of TB since they very well may not progress to the point of needing treatment. The committee cites the 1955 version of the book:

> The Committee, however, recognizes the fact that all classifications are ephemeral. They are useful only as long as they serve their purpose. The purpose of a clinical classification of tuberculosis is, however, a most important one. On it depend such matters as legal requirements for isolation, medico-legal considerations with respect to compensation for disability, standards for the return of patients to work, and similar matters. (p. 6)

For another example, the discovery of the lentiviruses led to the description of a new set of disease entities—i.e., slow acting viruses from which one could suffer asymptomatically for extended periods.

In the interests of creating a working infrastructure, Aristotelian principles are deliberately violated:

> *C15 Malignant neoplasms of oesophagus*
> *Note: Two alternative subclassifications are given:*
> *.0 - .2 by anatomical description*
> *.3 - .5 by thirds*

This departure from the principle that categories should be mutually exclusive is deliberate since both forms of terminology are in use, but the resulting anatomical divisions are not analogous (*ICD-10,* 1992, vol. 1, p. 190).

Where the state of the art is unclear, so is the scheme itself:

> Note: The terms used in categories C82-C85 for non-Hodgkin's lymphomas are those of the Working Formulation, which attempted to find common ground among several major classification schemes. The terms used in these schemes are not given in the Tabular List but appear in the Alphabetical Index; exact equivalence with the terms appearing in the Tabular List is not always possible.
> *Includes: morphology codes M959-M994 with behaviour code /3.*
> *Excludes: secondary and unspecified neoplasm of lymph nodes (C77.-).*
> (*ICD-10,* 1992, vol. 1, p. 215)

There are several specialty-based adaptations of the *ICD* originating in different national or international bodies (dermatology, stemming from the British Association of Dermatologists, and, under development, rheumatology and orthopaedics from the International League against Rheumatism) (*ICD-10,* 1992, vol. 2, pp. 5-6).

The *ICD* is also directly responsive to changes in the world. Diseases

themselves die (smallpox), are superseded (Gay-Related Immune Disorder becomes AIDS), are newly born (radiation sickness with the discovery of radium), or fall into disrepute (hysteria or neurasthenia). Since this is a statistical classification, a disease with no incidence is of no interest. Thus smallpox was still well defined within *ICD-9-CM* (1996):

050 Smallpox
Excludes: arthropod-borne viral diseases (060.0-066.9)
Boston exanthem (048)
50.1 Variola major
hemorrhagic (pustular) smallpox Malignant smallpox Purpura variolosa
50.1 Alastrim
Variola minor
50.2 Modified smallpox
Varioloid
050.9 Smallpox, unspecified (*ICD-9-CM*, 1996, vol. 1, p. 11).

By the time *ICD-10* was developed, this had collapsed into "BO3 Smallpox" with a footnote: "In 1980 the 33rd world Health Assembly declared that smallpox had been eradicated. The classification is maintained for surveillance purposes" (*ICD-10*, 1992, vol. 1, p. 150). Or again, malnutrition is defined in relativistic fashion—as the population changes so does the definition:

> The degree of malnutrition is usually measured in terms of weight, expressed in standard deviations from the mean of the relevant reference population. When one or more previous measurements are available, lack of weight gain in children, or evidence of weight loss in children or adults, is usually indicative of malnutrition. When only one measurement is available, the diagnosis is based on probabilities and is not definitive without other clinical or laboratory tests. In the exceptional circumstances that no measurement of weight is available, reliance should be placed on clinical evidence. (*ICD-10*, 1992, vol. 1, p. 290)

In these cases, then, the fact that the world is changing is reflected directly in the classification scheme. Another source for this recognition is of course the development of accident categories that also display in their explanations a historical cultural specificity. For example, this set of accident categories describes a series of tumbles more common in the industrial world than for a nomadic tribe:

E884	*Other fall from one level to another*
E884.0	*Fall from playground equipment*
	Excludes: recreational machinery (E919.8)
E884.1	*Fall from cliff*
E884.2	*Fall from chair*

E884.3	*Fall from wheelchair*	
E884.4	*Fall from bed*	
E884.5	*Fall from other furniture*	
E884.6	*Fall from commode*	
	Toilet	
E884.9	*Other fall from one level to another*	
	Fall from:	*Fall from:*
	embankment	*stationary vehicle*
	haystack	*tree* (*ICD-9-CM*, 1996, vol. 1, p. 289).

There is a relatively impoverished vocabulary for talking about natural accidents—the *ICD* is richest in its description of ways of dying in developed countries at this moment in history. It is not that other accidents and diseases cannot be described, but these cannot be described as well. Differentiating insect and snake bites, for example, is very important for those living in the rural tropics. However, while arthropods, centipedes, and chiggers are singled out under "bites" in the *ICD* index, snakes are only divided into venomous and nonvenomous, as are spiders.[1] Clearly this makes sense to some extent, given that this is a pragmatic classification. There is only a point in making fine distinctions between types of accident if those distinctions might make a difference in practice to some agency—medical or other. Simultaneously, those agencies have traditionally been more accountable to Western allopathic medicine and to the industrial world than to traditional systems.

So the *ICD* bears traces of its history as a tool used by public health officials in developed countries. It also reflects changes in the world at large—either the eradication of diseases or culturally charged changing understandings of certain conditions. Further, it is very much an entrenched scheme. There is a natural reluctance to make changes since each renders a previous set of statistics incomparable and hence less useful.

The first and last entries in the *ICD* describe a sociotechnical trajectory. The first disease in the *ICD* over the years has been cholera, unsurprising since cholera was the issue that, in the 1850s, brought participants to the table in an attempt to deal with this international threat. As we noted in the introduction, this threat was exacerbated by the development of steamship technology, which allowed cholera sufferers to carry the disease further before dying. The last condition given in the book takes us to the other end of the sociotechnical arc—i.e., the creation of cyborgs. The last condition listed in the *ICD* is Z99, "Dependence on enabling machines and devices, not elsewhere classified," with the very last entry, Z99.9, being "Dependence on unspecified enabling machine and device" (*ICD-10*, 1992, vol. 1, p. 1175). By some standard, we all now qualify for the Z99.9 condition.

The original sequence produced by William Farr (1885) is reproduced in the latest *ICD*:

> The ICD is a variable-axis classification. The structure has developed out of that proposed by William Farr in the early days of international discussions on classification structures. His scheme was that, for practical epidemiological purposes, statistical data on diseases should be grouped in the following way:
>
> epidemic diseases
> constitutional or general diseases
> local diseases arranged by site
> developmental diseases
> injuries. (p. 232)

This pattern can be identified in the chapters of *ICD-10* (1992). It has stood the test of time and, though in some ways arbitrary, is still regarded as a more useful structure for general epidemiological purposes than any of the alternatives tested (*ICD-10*, 1992, vol. 1, p. 13).

This classification scheme, then, makes no exaggerated claims to timeless truth. On the contrary, its designers have attempted to paint a fluid picture of the world of disease—one which is sensitive to changes in the world, to sociotechnical conditions, and to the work practices of statisticians.

There are Many Aids to Storytelling in the ICD

The classification system that is the *ICD* does more than provide a series of boxes in which to place diseases; it also encapsulates a series of stories, which are the preferred narratives of the *ICD*'s designers. Certain attributions of intentionality are easy to make, others are rather difficult. Some ways of life are clearly considered to be well led, others are called into question. Sometimes context is important, sometimes it can be ignored. Stories also come and go, narratives fade in importance (viz. the example of AIDS moving, in medical terms, from a specifically gay-linked disease to a more general one). If one should have doubts about how to encode a given story, one can turn to volume 2 (*ICD-10*, 1992) of the classification, which gives an extensive set of rules for the interpretation of causes of death. In this section, we will observe the various aids to storytelling to be found within the ICD.

The Setting

Frequently, when diseases were first named, they took on the name of their first scientific describer, of a famous victim, or of the place where they occur. Each of these kinds of naming strategy tells a simple story to accompany the classification. Throughout the history of classification systems over the past 200 years, such specifications have progressively been winnowed away to make way for new kinds of context and new kinds of description now considered more interesting and relevant.

What is known by many sufferers as Amyotrophic Lateral Sclerosis (Lou Gehrig's Disease) is coded by the *ICD-10* (1992) as G12.2: Motor Neuron disease (p. 398). (With the famous physicist Stephen Hawking now suffering from the disease, it may in future be more well known to the lay public as Hawking's Disease, as baseball player Lou Gehrig brought it to public awareness the first time.) In the index to the *ICD*, the Parisian neurologist Charcot can lay claim to an arthropathy (tabetic), a cirrhosis, a disease (tabetic arthropathy), and a syndrome. In the body of the text, Charcot's name tends to slip away—i.e., Charcot's syndrome becomes "I73.9 Peripheral vascular disease, unspecified"; there is no mention of Charcot (p. 504). The I73s (Other peripheral vascular diseases) are an interesting category. They show the various forms of modality (I73.0 is still proudly "Raynaud's syndrome," I73.1 is "thromboangiitis obliterans [Buerger]" (p. 503), I73.8 is "Other specified peripheral vascular diseases" and includes "Acroparaesthesia—i.e., simple (Schultze's type) or vasomotor (Nothnagel's type)" (p. 504). In general, as the modalities get deleted, the name of the person goes from being the name of the disease to a bracket after the name, to an entry in the index, until finally it slides gracefully out of the index onto the scrap heap of history. A similar process occurs with deletion of detail and the uncertainties of discovery in any scientific publication, as Latour and Woolgar (1979) noted in their classic *Laboratory Life.*

Places follow a similar path to abstraction and formal representation. The ideal *ICD* disease is not tied to a particular spot. It is rather identified with a particular causal agent. However, up to and including *ICD-9-CM* (1996), leishmaniasis was a classification that told a travelers' tale—i.e., not only do we know what you got sick of but where you got sick:

085 Leishmaniasis
085.0 Visceral [kalaazar]
Dumdum fever Leishmaniasis:
Infection by Leishmania:
donovani
infantum
dermal, post-kala-azar
Mediterranean
visceral (Indian)

085.1 Cutaneous, urban
Aleppo boil
Baghdad boil
Delhi boil
Infection by Leishmania tropica (minor)
Leishmaniasis, cutaneous:
dry form
late
recurrent
Ulcerating
Oriental sore

085.2 Cutaneous, Asian desert
Infection by Leishmania tropica major

Leishmaniasis, cutaneous:
Acute necrotizing
Rural
Wet form
Zoonotic form
085.3 Cutaneous, Ethiopian
Infection by Leishmania ethiopica
Leishmaniasis, cutaneous:
Diffuse
Lepromatous
085.4 Cutaneous, American
Chiclero ulcer
Infection by Leishmania mexicana
Leishmaniasis tegumentaria diffusa
085.5 Mucocutaneous (American)
Espundia
Infection by Leishmania braziliensis
Uta
Leishmaniasis, unspecified (*ICD-9-CM*, 1996, p. 16)

Similarly, for *ICD-10* (1992), we can still find Delhi boil in the index, but the main entry itself is a svelte:

B55 Leishmaniasis
B55.0 Visceral leishmaniasis
Kala-azar
Post-kala-azar dermal leishmaniasis
B55.1 Cutaneous leishmaniasis
B55.2 Mucocutaneous leishmaniasis
B55.9 Leishmaniasis, unspecified (*ICD-10*, 1992, vol. 1, p. 166)

So we go from primacy being given to a place (Baghdad boil) to primacy being given to a kind of place (urban cutaneous) to primacy given to a universal agent. Gradually the narrative of travel inscribed in the patient's code, present earlier, is deleted.

The loss of eponymy and place markers can, of course, be read as a story of the advance of science—the replacement of the local and specific with the general; the thing with the kind; the mutable immobile with the immutable mobile; and the concrete instance with the formal abstraction. However, another line of argument also deserves attention. As we have already seen, the *ICD* also reflects historical states of the world. The world has changed. With the huge increase in international travel over the past century and a half, it is more rare for a disease to be tied to a particular location—diseases themselves tend to spread to *kinds* of location. The malaria map of the world hanging on the wall at the WHO headquarters

in Geneva shows the expected tropical venues—and small red circles around major airports—as mosquitoes are transported from the tropics. We are, as a world, becoming more "abstract" in this way.

Similarly, research now is not attributed to single great figures who can claim sole responsibility for a discovery. Medical work was always done in teams, but these have become larger, involving complex social and institutional relationships of attribution as Gallo and Montaignier would be the first to remind us (in Grmek, 1990). A typical scientific article has so many authors that the death of the individual scientific author seems certain. In general, the *ICD* has gone from being the holder of a set of stories about places visited, heroic sufferers, and great doctors to holding another set of stories.

The Context of Disease

As people and places have moved out of eponymous and loconymous classification, they are replaced by a general set of categories—what we are calling the kindness of strangers. By this we mean that the classification system indicates a shift from our being individuals experiencing the world to our being kinds of people experiencing kinds of places. The constructions of social and natural science and of the legal world have moved in. Broken legs and ski resort locations co-evolve as do cancer rates and toxic waste dumps. The classification system, as we shall see in this section, has become a site which holds these constructions together and, through excluding other kinds of story, makes them more real. With the *ICD* providing the main legitimate means for describing illness, the social, economic, and political stories woven into its fabric become, by extension, the main legitimate narrative threads for the science of medicine.

Although particular places have moved out, two places have come to play a more significant role in the classification system—i.e., the laboratory and the "sociological home." The latter appears in the extra categories developed for *ICD-9* as supplemental codes, which in *ICD-10* (1992) have become fully integrated—what we might call the context codes. Thus housing is one of the conditions that can be broken down and described as part of the classification. In *ICD-9-CM* (1996) it is described as follows:

V60 *Housing, household and economic circumstances*
V60.0 *Lack of housing*
Hobos *Transients*
Social migrants *Vagabonds*
Tramps
V60.1 *Inadequate housing*
Lack of heating
Restriction of space
Technical defects in home preventing adequate care

V60.2 Inadequate material resources
Economic problem Poverty NOS
V60.3 Person living alone
V60.6 Person living in residential institution
Boarding school resident
V60.8 Other specified housing or economic circumstances
V60.9 Unspecified housing or economic circumstances. (vol. 1, p. 267).

The related code in *ICD-10* (1992) is expanded to include discord with neighbors and lack of adequate food (vol. 1, p. 1152). In both, the name of the city gives way to the name of the social category and social condition.

These context codes define what is considered to be medically relevant in one's material surroundings. They make it easy to structure studies in these terms (e.g., what effect does poor housing have on the incidence of tuberculosis). Simultaneously, they do make it much more difficult to deal with unrecognized contexts (what effect does conspicuous consumption have on cholesterol levels?). It is not impossible to do these latter studies, but the information is not "to hand" in the way that it is for medically sanctioned contexts. The reason for stressing this point is that it can be taken as a sign of the correctness of allopathic medicine that it has isolated the basic variables that must be taken into account in the development of public health policy or medical science. However, it is important to note that, although the *ICD* is a powerful tool, in this sense it also, as infrastructure, enforces a certain understanding of context, place, and time; it makes a certain set of discoveries (which validate its own framework) much more likely than an alternative set outside of the framework (since the economic cost of producing a study outside of the framework of normal data collection is necessarily much higher).

This sort of convergence is an important feature of large-scale networked information systems. Star, Bowker, and Neumann (In press) define convergence as:

> *Convergence.* . . is the double process by which information artifacts and social worlds are fitted to each other and come together. On the one hand, a given information artifact (a classification system, a database, an interface, and so forth) is partially constitutive of some social world. That is to say, the sharing of information resources and tools is a dimension of any coherent social world—be it the world of homeless people in Los Angeles sharing survival knowledge via street gossip, or the world of high-energy physicists sharing electronic preprints via the Los Alamos archive. On the other hand, any given social world itself generates many interlinked information artifacts. The social world creates through bricolage, a (loosely coupled but relatively coherent) set of information resources and tools. People without houses also log into the Internet, and physicists indulge in street gossip at conferences—as well as engage in a whole set of other information practices. Put briefly, information artifacts undergird

> social worlds, and social worlds undergird these same information resources. We will use the concept of convergence to describe this process of mutual constitution.

With these processes of convergence, the site of the medical work itself has gained in importance. The classification of tuberculosis, canonically difficult to diagnose accurately (compare Latour, In press), retains the story of what has been done in the laboratory as well as what has occurred in the body.

A15 Respiratory tuberculosis, bacteriologically and histologically confirmed
A15.0 Tuberculosis of lung, confirmed by sputum microscopy with or without culture
Tuberculous:
bronchiectasis }
fibrosis of lung }
pneumonia } *confirmed by sputum microscopy with or without culture*
pneumothorax }
A15.1 Tuberculosis of lung, confirmed by culture only
Conditions listed in A15.0, confirmed by culture only
A15.2 Tuberculosis of lung, confirmed histologically
Conditions listed in A15.0, confirmed histologically
A15.3 Tuberculosis of lung, confirmed by unspecified means
Conditions listed in A15.0, confirmed but unspecified whether bacteriologically or histologically. (*ICD-10*, 1992, vol. 1, p. 113)

In this case, the disease itself is always classified in terms of the work that has been done in the medical laboratory. Again, as new technologies are invented, historical shifts occur, as with the relationship between epilepsy and the EEG machine as diagnostic many decades ago.

The doctors themselves enter the story at the moment of classification, the patient rarely does. This comes out clearly if we compare migraine and epilepsy in *ICD-9-CM* (1996). Epilepsy is a condition that is defined by the doctor in the context of laboratory and so is a real condition:

345 Epilepsy
The following fifth-digit subclassification is for use with categories 3450,.1..4-.9:
0 without mention of intractable epilepsy
1 with intractable epilepsy (*ICD-9-CM*, 1996, vol. 1, p. 80)

So here the question is whether or not the patient objectively has intractable epilepsy in the opinion of the doctor. The determination of

intractable migraine relies on the voice of the patient and so is marked as a suspicious designation:

346 Migraine
The following fifth-digit subclassification is for use with category 346:
0 without mention of intractable migraine
1 with intractable migraine, ***so stated*** *(ICD-9-CM,* vol. 1, p. 80)

The laboratory context then is the "real" context of the disease; the classification serves to reinforce the separation of the patient from ownership of their condition. We should note at this point that we are not arguing that this makes the *ICD* a tool for evil and oppression. On the contrary, what we are trying to do is work out what kind of a tool it is—i.e., what work it does and whose voice appears in the unfolding narrative.

The legal context is often enfolded into the classification system. Thus the classification of blindness considers the American system of medical benefits:

369 Blindness and low vision
Note: visual impairment refers to a functional limitation of the eye (e.g., limited visual acuity or visual field). It should be distinguished from visual disability, indicating a limitation of the abilities of the individual (e.g., limited reading skills, vocational skills), and from visual handicap, indicating a limitation of personal and socioeconomic independence (e.g., limited ability, limited employment).
The levels of impairment defined in the table on page 92 are based on the recommendations of the WHO Study Group on Prevention of Blindness (Geneva, November 6-10, 1972: WHO Technical Report Series 518), and of the International Council of Ophthalmology (1976).
Note that definitions of blindness vary in different settings.
For international reporting WHO defines blindness as profound impairment. This definition can be applied to blindness of one eye (369.1, 369.6) and to blindness of the individual (369.0).
For determination of benefits in the USA, the definition of legal blindness as severe impairment is often used. This definition applies to blindness of the individual only.

369.0 Profound impairment, both eyes
369.00 Impairment level not further specified
Blindness:
NOS according to WHO definition
both eyes
369.3 Unqualified visual loss, both eyes
Excludes: blindness NOS:
legal [USA definition] (369.4)

WHO definition (369.00)

369.4 Legal blindness, as defined in USA
Blindness NOS according to USA definition
Excludes legal blindness with specification of impairment level 9369.01-369.08, 369.11-369.14, 369.21-369.22). (*ICD-9-CM*, 1996, vol. 1, p. 91)

Note in the above example that "blindness of the individual" might be psychogenic—i.e., due to brain damage or other organic cause outside the eye itself. The problem of localized versus "whole organism" conditions forms a serious source of coding problems. For example, depending on one's theory of cancer, it would be an immune disorder affecting the whole person or a localized phenomenon to be surgically removed with many gray areas in between for the different types of cancer.

In the example above, the legal definition can take precedence over the cultural and social. Thus cannabis dependence has its own category, while the culturally profoundly different absinthe and glue addictions are combined:

304.3 Cannabis dependence
Hashish Marihuana
Hemp
304.6 Other specified drug dependence
Absinthe addiction Glue sniffing
Excludes: tobacco dependence (305.1) (*ICD-9-CM*, 1996, vol. 1, pp. 69-70)

Few would argue that glue sniffing and absinthe addiction are similar phenomena. The former leads to more serious physical conditions than "cannabis dependence" (a category many would challenge) and yet does not rate its own category. Absinthe addiction is, one suspects, a hangover from earlier days. Because the origins of the *ICD* were French and absinthe abuse an important problem in Paris in the nineteenth century, it persists. These accidents of history, practice, and crime contain many clues to re-narrativizing the *ICD*. E970 to E979 in *ICD-9-CM* (1996) is an interesting set; it covers injuries *caused* by legal interventions:

Legal Intervention:
Includes: injuries inflicted by the police or other law-enforcing agents, including military on duty, in the course of arresting or attempting to arrest lawbreakers, suppressing disturbance, maintain order and other legal action
legal execution
Excludes: injuries caused by civil insurrections (E990.0-E999) (*ICD-9-CM*, vol. 1, p. 304)

This set includes state executions. Note that civil insurrections, where the definition of legal intervention is on the table, are classified together with

war. The definition of legal, of course, may be subject to its own retrospective reconstruction, as in the case of Rodney King.

Abortions, which may be to all intents and purposes the same medically, are marked differently in the *ICD* according to their legality:

635 Legally induced abortion
Includes: abortion or termination of pregnancy:
elective
legal
therapeutic
Excludes: menstrual extraction or regulation (V25.3)
636 Illegally induced abortion
Includes: abortion:
criminal
illegal
self-induced (*ICD-9-CM*, 1996, vol. 1, p. 154)

Each type of abortion (spontaneous or 634, legally induced, illegally induced, unspecified, failed attempted, or 638) has the same set of complications attached—i.e., nine difficulties, each accorded a digit (one of the most closely coded category sets in the *ICD*). When the issue arises, then, the *ICD* privileges the voice of the doctor and the laboratory over the voice of the patient and legal discourse over cultural and social discourse. One can read another order of social history from the nature of the silences in the story as well.

In general, the *ICD* carries with it its own context. This is a common feature of classification systems. One way of reading these is that they provide a stabilizing force between the natural and the social worlds. They hold in place sets of arrangements that allow one to read the natural as stable and objective and the social as tightly linked to it. For the *ICD*, this means describing disease in a way that folds the socially and legally contingent into the classification system itself and so naturalizes it. Inversely, the disease entity out there in the world is brought into the laboratory where the social and organizational work of its stabilization can best be guaranteed.

Cutting Up the World

In order to tell stories of the sort with which we are most familiar, one needs objects in the world that can be cut up spatially (compare Berg & Bowker, 1997) and temporally into recognizable units. Narrative structures are typically formed with a moving timeline, protagonists, and a dramatic structure unfolding over time. The *ICD* does in fact operate this kind of dissection, which we will discuss later. In the last section, we saw the constitution of a context within the *ICD*; in this section we will see the constitution of actants to populate that context and those stories.

Time Story 1: The Life Cycle

Temporally, the classification system provides a picture of acute (temporally bound) episodes within an otherwise well-ordered life. It is notoriously bad for describing chronic diseases; the interest is on the episode of treatment (Musen, 1992). Let us go through some temporal units presented by the *ICD.* Birth is extremely important and is very closely defined:

> Live birth is the complete expulsion or extraction from its mother of a product of conception, irrespective of the duration of the pregnancy, which, after such separation, breathes or shows any other evidence of life, such as beating of the heart, pulsation of the umbilical cord, or definite movement of voluntary muscles, whether or not the umbilical cord has been cut or the placenta is attached; each product of such a birth is considered liveborn. (*ICD-10,* 1992, vol. 2, p. 129).

Time flows very quickly for the newborn, and so temporal units vary accordingly: The neonatal period commences at birth and ends 28 completed days after birth. Neonatal deaths (deaths among live births during the first 28 completed days of life) may be subdivided into early neonatal deaths, occurring during the first seven days of life, and late neonatal deaths, occurring after the seventh day but before 28 completed days of life.

> Age at death during the first day of life (day zero) should be recorded in units of completed minutes or hours of life. For the second (day 1), third (day 2) and through 27 completed days of life, age at death should be recorded in days. (*ICD-10,* 1992, vol. 2, p. 131)

Given the bump in mortality that occurs around birth, this is not surprising.

When adult life begins, things start to slow down. Adults are defined in *ICD-9-CM* (1996, p. xiii) as people between 15 and 124 years old. If you make it to 125, you are "hors de categorie."

In the middle period, adulthood, there are some indications of what constitutes a good life. It should be well-ordered and rhythmic. Things should happen at the right time. Thus sexual development has its own timing:

> *259 Other Endocrine disorders*
> *259.0 Delay in sexual development and puberty, not elsewhere classified*
> *Delayed puberty*
> *259.1 Precocious sexual development and puberty, not elsewhere classified PED*
> *Sexual precocity:*
> *NOS*
> *constitutional*
> *cryptogenic*
> *idiopathic* (*ICD-9-CM,* 1996, vol. 1, p. 51)

Similarly, problems with temporal regulation of menstruation are well-

defined—i.e., too early, too late, too frequent, not frequent enough. Natural rhythms should not be upset.

A relatively recent temporal problem addition here is jet lag:

> *307.45 Phase-shift disruption of 24-hour sleep-wake cycle*
> *Irregular sleep-wake rhythm, nonorganic origin*
> *Jet lag syndrome*
> *Rapid time-zone change*
> *Shifting sleep-work schedule.* (*ICD-9-CM*, 1996, vol. 1, p. 71)

The reference to the "nonorganic origin" highlights that this is a situation-bound condition: the context (jet travel or night shift work) is directly folded into the disease.

To an outside observer, there is remarkably little reference to the process of aging. An adult is a timeless being who should be healthy; disease is not, in general, indexed by age. Further, the body is not present as something that gets used up and worn out; such stories have to be superadded (indeed the category of being "worn out" was in earlier additions of the *ICD* but has since been removed).

If you rent a house, your agreement with the landlord includes a "fair use" or "normal wear and tear" category; it is expected that the house depreciates over time and this is written into the legal code. There are only two references to normal wear and tear in the whole *ICD*. First, one can, as an adult, step out of the well-ordered life and suffer from premature or delayed senility, puberty, birth, and aging. Among the conditions under "delay" are delayed birth, development (including intellectual, learning, reading, sexual, speech, and spelling), menstruation, and puberty. In this case, the cycle structure is the same, but the patient is taking the steps too early or too late. Second—and there is only *one* example of this—you could use your body badly. The only specific instance of this, however, is that you can grind or otherwise mismanage your teeth:

> *521 Diseases of hard tissues of teeth*
> ...
> *521.1 Excessive attrition*
> *Approximal wear. Occlusal wear* (*ICD-9*, vol. 1, p. 125)

In *ICD-10*, abrasion of teeth carries with it an illuminating set of contexts: dentifrice, habitual, occupational, ritual, and traditional. Occupational abrasion in earlier times included the hazard "tailor's tooth," for example, where the teeth were abraded due to biting off the thread for hand sewing. In principle, the timeless adult could do many things excessively. There are categories for excessive thirst, secretion, salivation, sex drive, sweating, and binocular convergence among others. However, that superfluity is, only in this one case, indexed against an aging body. Note

that there are, of course, diseases associated more broadly and often implicitly with excessive wear and tear—e.g., cirrhosis of the liver associated with alcoholic excess. But here we are concerned directly with the representation in the classification system.

This curious invisibility of aging as wear and tear is one way in which the *ICD* stabilizes context and disease entity—the human body as the substrate of both is outside the flow of time. The human adult body becomes the unmarked category—i.e., the cipher against which laboratory, social, and natural time can be coordinated. Indeed we could go one step further and see the adult male body as the unmarked category—since there are many more diseases restricted to women than restricted to men; there are sixteen categories or clusters of categories that apply only to males and forty-two that apply only to females (*ICD-10*, 1992, vol. 2, p. 26). Feminist critics of medicine have long remarked on the relative pathologizing of the female body (Ehrenreich & English, 1973).

Nobody Dies of Old Age.[2] To finish with the life cycle before moving on to other temporal features, we should note that death itself is remarkably poorly defined in comparison to life. One can scarcely die of old age (Fagot-Largeault, 1989). The closest that one may get comes under a banner disclaimer:

> *ILL-DEFINED AND UNKNOWN CAUSE OF MORBIDITY AND MORTALITY (797-799)*
> 797 *Senility without mention of psychosis*
> *Old age*
> *Senile:*
> *Senescence debility*
> *Senile asthenia exhaustion*
> *Excludes: senile psychoses (290.0-290.9)* (*ICD-9*, 1996, vol. 1, p. 215)

The *ICD*'s life cycle for humans, then, is as follows: a spurt of intense activity at birth; timeless adulthood, when one is afflicted with a range of woes that carry their own temporalities (more on this anon); and an inglorious ill-defined end. The effect of this is, paradoxically, to make the individual an undefined tabula rasa onto which various diseases are inscribed. From this blank sheet, one can read various stories (with the aid of the *ICD*), restoring first context and then interpretation (which we shall deal with in the next section).

Time Story 2: The Virus

Diseases themselves change over time. HIV, for example, mutates rapidly in the individual so that no two people suffer from the "same" disease nor may the disease be the same even within a person. This extreme variability of the object world is a problem for any classification

system. The case of virus classification illuminates many features of categorizing difficulties and the strategies used to control them. We look here at some of the work of the International Committee on Taxonomy of Viruses (ICTV) (Murphy et al., 1995) so as to see how diseases that are present differently in every individual, and often vertiginously mutate, can be usefully classified.

Throughout the history of virology, there have been acerbic debates over just what are viruses. The great virologist Lwoff, echoing Gertrude Stein no doubt, declaimed in 1953 that "viruses should be considered as viruses because viruses are viruses" (Matthews, 1983, p. 7). Viruses themselves have moved from scientific category to scientific category. In the early twentieth century, the central definition of a virus was entirely negative. As Waterson and Wilkinson note, a virus was any disease organism which could be filtered through one of the "filter candles" developed for the purpose. This was a useful definition in that it excluded all other known disease agents; however, it did not guarantee the homogeneity of the category itself as Andrewes noted in 1930 when describing animal viruses:

> judgment must be suspended . . . in the case of the invisible viruses or so-called "filter-passing" organisms. Here our ignorance is almost complete; they are possibly a heterogeneous group but in the case of creatures which we cannot see and whose very existence is, in many cases, a matter of inference only, it is idle to talk of classification in the usual sense. (Matthews, 1983, p. 4)

So there was no one definition, or rather, the ultimate encompassing residual category. Here be dragons.

Equally, there was no one discipline studying the matter of virus classification. There was no study of virology per se until the 1980s. There was an *a priori* assumption, entrenched in disciplinary specialties, that animal and plant viruses were not the same. This was disproved in the 1940s when it was shown that some plant viruses could also affect insects (Matthews, 1983, p. 7). Groups that were not used to working together were forced to cooperate, and they did not necessarily like it. As with the numerous and passionate battles between cladistics and numerical taxonomy in biology (Duncan & Stuessy, 1984), there was a series of strong virological arguments that have left their traces in the literature. The arguments can be read in two ways. They are simultaneously about a struggle for professional authority on the part of the various disciplines involved and an attempt to find a single language with which to talk about the complex temporal and spatial properties of viruses.

The role of the classification systems in knitting together (or not) the specialties is clear in all accounts of virus taxonomy. Matthews (1983) notes, "in the period 1966 to 1970 there was considerable controversy regarding some of the rules, which developed into a serious rift between

most of the plant virologists, and some animal virologists" (p. 13). He comments on Fenner's presidency of the ICTV in the period 1970-1976:

> In retrospect perhaps the major contribution made by Fenner during his Presidency was to keep the plant virologists working within the ICTV organization. This really meant stopping the insistence of Lwoff's supporters on a hierarchical classification and Latinized binomials, and also, as noted earlier, deleting the rule regarding new sigla. In addition, Fenner exerted pressure to ensure that following two vertebrate virologists, a plant virologist should be the next President of the ICTV. (p. 20)

Murphy et al. (1995) note that even today: "Virus taxonomy is a polarizing subject when it comes up in hallway conversations." They go on to praise the ICTV for its work of

> true international consensus building, and true pragmatism—and it has been successful. The work of the Committee has been published in a series of reports, the *Reports of the International Committee on Taxonomy of Viruses, The Classification and Nomenclature of Viruses.* These Reports have become part of the history and infrastructure of modern virology. (p. v)

We see then that the development of the classification system is an occasion for the construction of the community for which that system will act as information infrastructure. The system is built as a political compromise between specialties. The kinds of truth and the kinds of stories that it can contain by their nature recognize this. As Murphy et al. (1995) state, the resulting classification system is in some sense arbitrary:

> Today, there is a sense that a significant fraction of all existing viruses of humans, domestic animals and economically important plants have already been isolated and entered into the taxonomic system. . . . [The] present universal system of virus taxonomy is useful and usable. It is set arbitrarily at hierarchical levels of order, family, subfamily, genus, and species. Lower hierarchical levels, such as subspecies, strain, variant, etc., are established by international specialty groups and by culture collections. (Murphy et al., 1995, p. 2)

The apposition of specialty groups (professionalization work) and culture collections (naturalization work) is unsurprising; Murphy et al. (1995) offer it in a different form later in the same work: "Unambiguous virus identification is a major virtue of the universal system of taxonomy . . . and of particular value when the editor of a journal requires precise naming of viruses cited in a publication" (p. 7).

Thus a first temporality associated with viruses is that the field itself has formed and changed rapidly, much like the organisms that it studies. This is an unsurprising echo, as the fact that the viruses transgress spatial boundaries and mutate enormously rapidly has contributed to the change.

So what is the problem with correlating virus time with laboratory time? The overwhelming difficulty has been that it is extremely difficult

for viruses to produce the kind of "genetic classification" whose genealogy Patrick Tort (1989) has so brilliantly traced across the social and natural sciences of the nineteenth century. A genetic classification is one that classifies things according to their origins—rocks might be metamorphic or sedimentary; languages might be Indo-European or Nilotic. Viruses have multiple possible origins—i.e., they look and feel the same since they pass the filter test and make you sick, but they got that way along multiple paths. This is an old problem in medical philosophy and diagnosis—a cure does not necessarily reflect a cause, and there may be many paths to a single symptom.

Ward (1993) gives four theories for viral origins. First, it is possible that some viruses "evolved from autonomous, self-replicating host cell molecules such as plasmids or transposons, by acquiring appropriate genes that code for packaging proteins" (p. 433). In this picture, they are simple chemical combinations that have acquired the replication habit of their material substrate. Second, "some viruses arose by degeneration from primitive cells in a manner similar to that proposed for the evolution of cellular organelles such as mitochondria and chloroplasts from bacteria" (p. 434). Here they are complex organisms that devolved. Third, "some RNA viruses are descendants of prebiotic RNA polymers" (p. 433). According to this theory, viruses might have co-evolved with life itself. Finally, there is the possibility that "some viruses evolved from viroids or virusoids, although it is equally possible that these small RNA, rather than being progenitors of viruses, are recent degenerative products of the more complex self-replicating systems" (p. 434). Where you do not have a single origin story, you cannot have a single biological classification system. Viruses have been classed into families and then into increasingly controversial supervenient categories (only one "order"—the Mononegavirales—has been approved to date by the ICTV). The supervenient categories frequently have the inconvenience of separating viruses that had been considered grouped together. With the lack of a single origin, the central class of virus "species" has been defined: "A virus species is a polythetic class of viruses constituting a replicating lineage and occupying a particular ecological niche" (Van Regenmortel, 1990, p. 49).

A "polythetic" class is a class that is defined by the congruence of multiple characteristics no one of which is essential. The attribution of occupation of a particular niche is essential for dealing with obligate parasites. This relatively loose definition opens up a space for the professionalization work that needs to be done in conjunction with the alignment of competing temporalities (of the virus and of the laboratory). There has, in recent years, developed a line of argument that with genome sequencing it will be possible to produce a coherent history of viruses that will make the species concept more historically accurate. This reflects a wider trend across many social and natural sciences to recover

the origin—in geology, the tide has turned against uniformitarianism (Allegre, 1992); in philosophy, Foucault's archeology has grown up in opposition to the postmodern denial of origins. However, even today a strictly genetic classification of viruses is possibly leading to category death:

> if mammalian viruses are descended from mammals, snake viruses from snakes, and honeybee viruses from honeybees, the group "virus" would cease to have any formal classificatory validity. It could be retained as a nonclassificatory group, analogous to the group of "animals with wings," but if it is not a monophyletic group, there is no doubt how cladism would deal with it; it presents no philosophical difficulty: the taxonomic category "virus" should be exploded. (Ridley, 1986, p. 51)

The demotion to a nonclassificatory group would again have professional consequences.

We see with the history of virus classification, then, that there has been a deliberate effort to create something that looks and feels like other biological classifications, even though the virus itself transgresses basic categories (it jumps across hosts of different kinds, steals from its host, mutates rapidly, and so forth). This has been somewhat of a deliberate political decision on the part of the international virus community: you need such classification systems in order to write scientific papers, provide keywords for indexing and abstracting, and compare results. Even in this most phenomenologically difficult of cases, the world must still be dissected into recognizable temporal and spatial units—partly because that is the way the world is and partly because that is the only way that science as we know it can work.

Stories of Carving Up the Body: The Vermilion Border of the Lip

In *Regions of the Mind,* Leigh Star (1989) examined the ways in which researchers, seeking to localize cerebral functions, cut up the brain into meaningful units. The process is a messy one since brains themselves come in many shapes and sizes. During the early days of research, a diagram of a "typical" monkey brain, with minutely localized and labeled regions, is transposed onto a representation of a human brain in an attempt to produce a standardized diagram. Human brains are of a much different size than monkey brains. Nevertheless, the need for standardized representations was so urgent that the physiologists overlooked this source of uncertainty, among others (Star, 1985). A similar problem occurs with the dissecting of bodies for medical purposes. Stefan Hirschauer (1991) has noted this for the practice of the surgeon's trade; Berg and Bowker (1997) have discussed the same phenomenon with respect to the development of medical records.

The *ICD* bears traces of this sort of uncertainty, most notably at liminal sites (those with borders that are unclear or are used in several different

categories), and with respect to roving categories like neoplasms (the cancer may overlap the *ICD* categories). We can use the vermilion border of the lip, also known as the "lipstick area," as a tracer for this. An early appearance in *ICD-9-CM* is as follows:

> *4. Malignant neoplasms overlapping site boundaries*
> *Categories 140-195 are for the classification of primary malignant neoplasms according to their point of origin. A malignant neoplasm that overlaps two or more subcategories within a three-digit rubric and whose point of origin cannot be determined should be classified to the subcategory .8 "Other." For example, "carcinoma involving tip and ventral surface of tongue" should be assigned to 141.8. On the other hand, "carcinoma of tip of tongue, extending to involve the ventral surface" should be coded to 141.2, as the point of origin, the tip, is known. Three subcategories (149.8, 159.8, 165.8) have been provided for malignant neoplasms that overlap the boundaries of three-digit rubrics within certain systems. Overlapping malignant neoplasms that cannot be classified as indicated above should be assigned to the appropriate subdivision of category 195 (Malignant neoplasm of other and ill-defined sites),*
> *140.0 Upper lip, vermilion border*
> *Upper lip:*
> *NOS*
> *external*
> *lipstick area. (ICD-9-CM,* 1996, vol. 1, p. 26)

The "NOS" in this classification stands for "not otherwise specified"—a protean modifier throughout the classification.

If we consider *ICD* as a prototype classification system, we can see the way of treating the vermilion border as part of a general strategy of distinguishing central members of certain categories from outliers. The vermilion border is *strictu sensu* part of the skin of the lip, but it is not a good member of that category:

> *173.0 Skin of lip*
> *Excludes: vermilion border of lip (140.0-140.1, 140.9) (ICD-9-CM,* 1996, vol. 1, p. 32)

Equally, it is definitely skin but is a special subcategory:

> *238.2 Skin*
> *Excludes: anus NOS (235.5)*
> *skin of genital organs (236.3, 236.6)*
> *vermilion border of lip (235.1) (ICD-9-CM,* 1996, vol. 1, p. 45)

Or again, it is definitely soft tissue but is an outlier:

> *239.2 Bone, soft tissue, and skin*
> *Excludes: . . .*
> *. . .*
> *vermilion border of lip (239.0). (ICD-9-CM,* 1996, vol. 1, pp. 45-46)

In *ICD-10*, its marginality is explicit:

> *D00.0 Lip, oral cavity and pharynx*
> *Aryepiglottic fold:*
> *NOS*
> *hypopharyngeal aspect*
> *Marginal zone*
> *Vermilion border of lip. (ICD-10,* 1992, vol. 1, p. 222)

This multiple reference to the vermilion border of the lip is a typical *ICD* naming strategy. If a region of the body might fall under several categories, its membership in a special category is explicitly marked.

In principle at least, the world itself—that messy, sprawling, sociotechnical system—should be divided into regions of relevant causal occurrence. The *ICD*'s work here is necessarily far from complete. Here, however, is one typically precise definition of a liminal zone in the outside world:

> *A* ***public highway (trafficway)*** *or* ***street*** *is the entire width between property lines (or other boundary lines) of every way or place, of which any part is open to the use of the public for purposes of vehicular traffic as a matter of right or custom. A roadway is that part of the public highway designed, improved, and ordinarily used, for vehicular travel. (ICD-9,* 1996, vol. 1, p. 274)

The *ICD* records accident statistics, including the place or mode. Such precision is needed for the compilation of, for example, effective safety statistics. This drive for precision is in principle unending—how much of the social and natural worlds would have to be described within the *ICD* in order to produce an exhaustive system?

The point here is not that these are bad definitions of lipstick areas and streets. It is that they are ineluctably arbitrary ways of cutting up the world. The goal with a classification system is to produce homogeneous causal regions. Homogeneous causal regions are zones without effective subdivision. For the vermilion border, there is no real distinction between upper and lower; for streets, there is no real distinction between tarred and gravel. There is no possiblity, in principal, that this can be other than a bootstrapping operation. All research work that explores medical causality has the *ICD* or a similar system as its base referent and so necessarily assumes the *ICD*'s set of homogeneous regions in order to design its tests, experiments, or projects. It is analytically always possible to act otherwise and carve the world up differently into other kinds of causal regions. Latour (1987) reminds us of this in *Science in Action.* He posits the thought experiment: How would someone challenge the basic premises of quantum mechanics? No one would deny that it is *possible* that these premises are wrong nor that an experiment *might* be designed to prove this. However, the economic and administrative cost of doing so would be huge. Who would fund the proposal? Who would referee the papers? How, in short,

would the inertia of the networks involved be overcome? In the same way, it is always possible (and somewhat more common than in the quantum mechanics case) to challenge basic *ICD* categories. However, it is in practice much easier to hypostatize and duplicate them for local usage. Exceptions occur when particular categories are linked with social movements and social problems; an outstanding example of this occurred with the de-medicalization of homosexuality in the *DSM-3* after challenges from the gay community (Kirk & Kutchins, 1992).

We have seen in this section that medical classifications split up the world into useful categories. They do not describe the world as it is in any simple sense. They necessarily model it. This modeling within classification systems of all sorts is where the real work gets done in terms of the enfolding of social, political, and organizational agendas into the scientific work of describing nature—in this case, in the form of disease entities.

Interpretation is also Enfolded into the *ICD*

We saw in the last section how the *ICD* divides the world into standard Aristotelian units of time and place and, in doing so, how it produces favored readings of the body and of the world at large. The WHO goes one step further. It not only provides, through the *ICD*, a set of possible stories, it also provides, bundled up in the classification system, explicit rules for the interpretation of those stories.

In order to follow this through, we need to look at the form of the standard international death certificate (see Figure 2 above). Ann Fagot-Largeault (1989) has done a wonderful philosophical analysis of this document; our own description will not attempt to be as complete. It is the death certificate that constitutes the archetypical use of the *ICD*—indeed, until *ICD-5*, the classification only covered causes of mortality and did not seek to represent morbidity. The death certificate itself has as a major heading, "Cause of Death." It is split into sections, "Cause of Death," "Approximate interval between onset and death," and other contributing factors or significant conditions.

It is a difficult task to summarize a complex series of conditions to a single cause of death, and the work of interpretation begins on the form itself. A single cause is favored for very practical reasons. In the first place, it is hard enough to compile statistics at all, and the task could get overwhelming if multiple causes were allowed. Further, a single cause of death provides the lowest common denominator over multiple collection systems—from medical examiners in a large hospital to medical paraprofessionals in the underdeveloped rural areas. Finally, as the *ICD*'s developers point out, the goal of the classification system is not to describe complex phenomenologies but to prevent death:

> From the standpoint of prevention of death, it is necessary to break the chain of events or to effect a cure at some point. The most effective

> public health objective is to prevent the precipitating cause from operating. For the purpose, the underlying cause has been defined as "(a) the disease or injury which initiated the train of morbid events leading directly to death, or (b) the circumstances of the accident or violence which produced the fatal injury." (*ICD-10*, 1992, vol. 2, p. 31)

This statement revealingly indicates a recognition by the system's developers that reality is indeed more complex than their registration system can describe. All the analytic points made to date in this discussion can be read into this one statement: the *ICD* is a pragmatic classification ("the most effective public health objective" [p. 31]), and it divides the world spatially and temporally into causal zones that underwrite preferred stories ("it is necessary to break the chain of events. . .at some point" [p. 31]).

The cause of death as given on the death certificate by the attending physician is frequently not, as Fagot-Largeault (1989) points out, the cause of death that is entered into the statistical record. The classifications entered on the certificate are themselves systematically re-coded so as to constrain the kinds of story that the statistics tell.

One standard algorithm is that precision always beats no precision (this is an echo of John King's [personal communication] wonderful observation about technical arguments in the policy domain: "[N]umbers beat no numbers every time"). On a deeper epistemological level, the substitution of precision for validity is often a needed expedient in getting work done (Star, 1989; Kirk & Kutchins, 1992). It may also become a kind of gatekeeping tool in theoretically defining a ground of knowledge. It functions as follows in the *ICD*:

> Where the selected cause describes a condition in general terms and a term that provides more precise information about the site or nature of this condition is reported on the certificate, prefer the more informative term. This rule will often apply when the general term becomes an adjective, qualifying the more precise term.
>
> "Example 57: I (a) Meningitis
> Tuberculosis
>
> Code to tuberculous meningitis (A17.0). The conditions are stated in the correct causal relationship." (*ICD-10*, 1992, vol. 2, p. 48)

This is doubtless a very reasonable rule. However, it is significant that it sets in motion a process that begins placing mediating layers between what the doctor says and what gets reported.

In general, these mediating layers refashion the story that the act of classification permits. The records clerk is given the license to change the doctor's classification in such a way that it will reflect the best current medical theories:

> ***Rule 3.*** If the condition selected by the General Principle[3] or by Rule 1 or Rule 2 is obviously a direct consequence of another reported condition, whether in Part I or Part II, select this primary condition. (*ICD-10*, 1992, vol. 2, p. 34)

Thus, for example,

> [w]here the selected cause is a trivial condition unlikely to cause death and a more serious condition is reported, reselect the underlying cause as if the trivial condition had not been reported. If the death was the result of an adverse reaction to treatment of the trivial condition, select the adverse reaction. (*ICD-10*, 1992, vol. 2, p. 45)

Derrida (1980) reminds us that it is through what is excluded as trivial that we can frequently understand systems of thought by pointing directly at what is important. Similarly, this opening of the door to an undetermined attribution of triviality is one significant moment, hidden in the third volume of a massive classification system, where the work of reifying current categories is done. Only certain causal chains will be permitted at the moment of classification. This in turn naturally impacts the interpretation at the other end of "raw data" in the form of epidemiological statistics:

> The expression "highly improbable" has been used since the Sixth Revision of the *ICD* to indicate an unacceptable causal relationship. As a guide to the acceptability of sequences in the application of the General Principle and the selection rules, the following relationships should be regarded as "highly improbable." (*ICD-10*, 1992, vol. 2, p. 67)

After this passage, there follows a series of unacceptable chains. For example, a malignant neoplasm cannot be reported as "due to" any other disease than HIV; haemophilia cannot be "due to" anything, and no accident can be reported as due to any other cause—except epilepsy (*ICD-10*, 1992, vol. 2, p. 68).

An acceptable string of classifications in a death certificate is one which fits into an internally consistent chain that reflects current medical knowledge. In the process of arriving at such a chain, all qualifiers should be removed: "Qualifying expressions indicating some doubt as to the accuracy of the diagnosis, such as 'apparently,' 'presumably,' 'possibly,' etc., should be ignored, since entries without such qualification differ only in the degree of certainty of the diagnosis" (*ICD-10*, 1992, vol. 2, p. 88).

In the process of achieving this certainty, multiple causality often has to be arbitrarily collapsed into unicausality—here by a principle of first come first served:

> If several conditions that cannot be coded together are recorded as the "main condition," and other details on the record point to one of them as the "main condition" for which the patient received care, select that condition. Otherwise select the condition first mentioned. (*ICD-10*, 1992, vol. 2, p. 106)

Any working classification system will have such standard rules attached. Such rules are theoretically interesting for several reasons. First, the *ICD* developers have explicitly recognized that it is not enough to control the classification (the name of the disease). They also have to attempt to exercise control over the language game in which the classification is

inserted—this indeed is the purpose of the rules contained in volume 2. This attention to both the base level and its meta-level is a bureaucratic necessity that simultaneously conjures the wild world of the patient's body into the ordered world of medical knowledge. Second, the rules themselves serve to systematically reduce ambiguity and uncertainty, even where these are integral to the attendant physician's depiction of the situation of the patient. Those who see the patients are aware of this uncertainty; those who apply the rules also know of it; those who read the final statistics are shielded from it. The patients live it. Finally, there is of course a potential infinite regress in the control of, first, the name of the disease, then on rules for using these names and so forth. The final level at which regress occurs is in the presentation of results. The WHO recognizes that, when dealing with small populations, you can get wild fluctuations of information on mortality or morbidity from year to year. In order to achieve stability and certainty at this level, one needs to sacrifice precision: to go up to broader *ICD* rubrics, aggregate data over a longer period, use the broadest of the recommended age groupings and aggregate areas (*ICD-10,* 1992, vol. 2, p. 137).[4] The regress itself to ever higher levels of control marks the fact that the world is always slightly out of reach—it cannot be contained in the classification system, or the system plus set of rules, or the system plus set of rules for interpretation plus set of rules for change, or the system plus set of rules for interpretation plus set of rules for change plus set of rules for presentation.

Conclusion

At the start of this discussion, we looked at two basic kinds of classification system—i.e., Aristotelian and prototype. We have seen in the course of our analysis that medical classification systems are "naturally" prototypical and that they nevertheless have to appear Aristotelian in order to bear the bureaucratic burden that is put on them. This burden is to act as a gateway between the world of the laboratory and the hospital (with precisely defined closed environments) and the workaday world. As we consider the stories embedded in the system, from the point of view of work and practice, we understand that both the "intuitive" and the "technical" are always present in systems such as the *ICD.*

The way in which this gateway function is provided is twofold. First, the Aristotelian classification embeds within itself a set of implicit narratives that align the artificial categories of the *ICD* with the real world. Second, the rules for interpretation and presentation sit on top of the *ICD* and nudge its categories along prepared legitimate pathways. This combination of embedded and supervenient narrative provides the "give" through which the prototypical classification can be made to look and feel Aristotelian.

Increasingly, we will see work classifications and formal library classifications merging in the digital library of the future—the UMLS, which includes both the *ICD* and classifications of nursing work, among others, is a good example. In this discussion, the argument has been made that, as this happens, we need to pay due attention to the political and ethical undergirding of classification systems before they become so deeply inscribed in our information infrastructure that they are lost to sight (while their consequences propagate).

NOTES

[1] One finds similar complaints today about the World Wide Web to the point where a special electronic journal has been founded: *Journal of Internet Cataloging: The International Quarterly of Digital Organization, Classification, and Access.* Retrieved September 25, 1998 from the World Wide Web: http://jic.libraries.psu.edu/. See also Marcia Bates's (In press) excellent article on incomparability between Web search engines.

[2] Ironically, the slogan, "nobody dies of old age" was an anti-ageist aphorism first popular in the 1980s and used by groups such as the Grey Panthers. It was meant to imply that the social invisibility of old people led to them being medically invisible or overlooked as well. It is an interesting example of the inversion of the prototypical and Aristotelian aspects of death.

[3] The general Principle is: "when more than one condition is entered on the certificate, the condition entered alone on the lowest used line of Part I should be selected only if it could have given rise to all the conditions entered above it." (p. 34)

[4] Recommended age groupings and regional groupings are:
<1, 1-4, 5 year groups from 5-84, 85+
<1, 1-4, 5-14, 15-24, 25-34, 35-44, 45-54, 55-64, 65-74, 75+
<1, 1-14, 15-44, 45-64, 65+ (128)
"Classification by area should, as appropriate, be in accordance with:
each major civil division;
each town or conurbation of 1,000,000 population and over, otherwise the largest town with a population of at least 100,000;
a national aggregate of urban areas of 100,000 population and over;
a national aggregate of urban areas of less than 100,000 population;a national aggregate of rural areas." (p. 128)

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