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Sorting Things Out Classification and Its Consequences

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The MIT Press
Cambridge, Massachusetts
London, England

set of rules for interpretation + set of rules for change or the system
 + set of rules for interpretation + set of rules for change + set of rules
 for presentation).

Conclusion

At the start of this chapter we looked at two basic kinds of classification system: Aristotelian and prototypical. We have seen in the course of our analysis that medical classification systems are “naturally” prototypical, and that they nevertheless have to appear Aristotelian to bear the bureaucratic burden that is put on them. This burden is to act as a gateway between the worlds 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 narratives provides the give through which the prototypical classification can be made to look and feel Aristotelian.

The ICD as Information Infrastructure

Science is a systematized and classified knowledge of facts. The proposed change in the definition of stillbirth does not appear to be based upon such an orderly classification of known facts. It seems to be based upon misty theory, contrary to established concepts. It is therefore unscientific.

(*C.H. lexpert stat/46, doc. 43806, doss. 22685, 22 December 1927, 11*)

Introduction: Histories of Classifications

Over the past 300 years (beginning perhaps with the ineffable Leibnitz) there have been a number of sweeping encyclopedic visions for storing all knowledge in a single form—be this through perfecting language (Slaughter 1982), classification systems (for example, Melvy/Dewey’s library and industry schemes), or modes of knowledge organization (for example, Olet (Rayward 1975)). These schemes have found their historians, but their shadow side appears to be discovered anew each generation. This side is the barrier to complete knowledge systems, notably in the following forms:

- *Data entry as work.* No matter how good the scheme, its scope is limited by the fact that data entry is never an easy task, and there are never enough resources or trained personnel to make it happen. Not only will there inevitably be mistakes with respect to the internal structure of whatever classification one is representing, there will also inevitably be cultural variations with respect to how it is interpreted as well as culturally biased omissions.

- *Convergence between the medium and the message.* Within any society there are a limited number of technologies for storing information (from ledger books to file cards to computer databases). The information that gets stored is at best what can be stored using the currently

available technology: the encyclopedia comes to mirror the affordances of its technological base. In this process, people naturalize the historically contingent structuring of information; they often begin to see it as inevitable.

• *Infrastructural routines as conceptual problems.* No knowledge system exists in a vacuum, it must be rendered compatible with other systems.¹⁸ The tricky, behind the scenes work of ensuring backward and sideways compatibility is not only technical work, it challenges the very integrity of any unifying scheme. Such work, however, is itself often classed as "mere" maintenance and deemed unworthy of public, historical pride of place.

To understand the architecture of such schemes, then, we need to look at the traces they leave of their own history and constitution (as we did through reading the ICD). This chapter examines the historical intertwining of medium, message, routine, and data entry in the ICD. One of the challenges here is to understand how the drive for universal languages and databases is reconciled with the pragmatics of practice and the constraints of the installed base. True universality is necessarily always out of reach. At the same time, the vision of global data gathering and sharing is enormously powerful, and it needs to be understood in its own terms. This is one important context for the development and deployment of such systems as the ICD as tools.

During this century the information sciences have grappled with new ways of configuring, storing, and retrieving information. The rise of networked computing, and the extravagant advances in processing capacity have increased the pace and pressure of this struggle. We are clearly at a point today where we are witnessing the birth of an information technology as fundamentally new as was the printing press in its day (see Eisenstein 1979 for the latter). We do not take this as an unproblematic information revolution. Rather, by looking at the more sober, less glamorous aspects of this infrastructural transformation, we hope to discomfit some of the revolutionary hype (Bowker 1998). This chapter examines the historical background of the development of the ICD as information infrastructure.

As noted in chapter 1, there are too few theoretical tools available to the historian for grasping the development of a new information infrastructure. Infrastructure does more than make work easier, faster or, more efficient; it changes the very nature of what is understood by work. Such changes always span multiple disciplines, industries, and

lines of work. Forms of automation, for instance, begin in one sphere and spread across lines of innovation and dependency. Scientists say that the natures of their disciplines are changing, in no small part due to these infrastructural shifts. Stephen Hawking in his inaugural lecture as Lucasian Professor at Cambridge (a post once held by Newton) expressed a belief that by the turn of the century, computers would essentially perform work in theoretical physics. Humans would not be able to understand the mathematics, but they could aspire to interpreting its consequences (Hawking 1980). Pure mathematicians have now adopted a method of existence proofs that would have been unmanageable before the development of the computer, such as the solution to the four-color problem. Not only the scientist and the mathematician are affected. Classical scholars had to learn a new set of techniques (dealing with complex searches on a computer) and indeed pose a new set of questions of their data when classical text became available on-line (Ruhleder 1995). The Thesaurus Linguae Graecae houses the complete canon of classical Greek literature in electronic form. Since its inception in the 1980s, classical scholars have changed their working practices, including the definition of text, the value of word searches, and the role of concordances. J. David Bolter, *inter alia*, has commented that genres of fiction, too, are undergoing radical change with the development of hypertext (Bolter 1991). And more generally, as Beniger (1986) amongst others reminds us, the structure of industry is changing such that "information work" has become the dominant mode of work in industrialized economies (Kling, Olin, and Poster 1991).

Among other things, these changes imply that the worlds of knowledge and of industry are not the same worlds after the development of this new information infrastructure as they were beforehand. To explain what has happened, the historian has to range freely between the "inside" (looking at knowledge within physics, mathematics, classics, and so forth) and the "outside" (looking at changes in work practice and information management that hold over many fields at once).

The story of information infrastructures is not, in this sense, the history of great people. Much of the work has been done offstage by communities of hackers, technicians, and engineers, and in maintenance, upgrades, and integration. Creating an infrastructure is as much social, political, and economic work as it is theoretical. Although in some sense knowledge is its *raison d'être*, it bursts the bounds of

traditional history of ideas: How then to write its history, avoiding both hype and getting lost in the details? As a one of the participants in the 1920s revision of the ICD declared in a frank letter to Dr. Norman White of the Health Section of the League of Nations:

You know, I am a great believer in taking things of this kind slowly. Statistics is a very unexciting field in which to work up a revolution. . . . I am offering you my personal opinion, of course, but it is this: that the Committee on joint causes of death propose, if it wishes, an ideal certificate and an ideal method of classifying joint causes of death, if it desires, in the next year or so, but that as a *beginning* it should propose some things which can be done and which the statisticians of the different countries feel that they *can* and *want* to do. If a few of these can be accomplished, then the Committee of experts and the Health Section can record some achievements which will pave the way for more fundamental reforms. (12B R842/ Doc. 51040, Doss. 22685, letter from Edgar Sydenstricker to Norman White, June 11 1925)

We will not attempt to give an overview of the whole range of infrastructural work. It is constitutive of, to use the unfortunate phrase, an “information age.” (Unfortunate because those who write about this as the information age tend to immediately retrospectively define all of human history as the history of information processing, and thus to effectively deny specificity to whatever age they are defining.) The phrase draws attention away from the material bases and work practices that are analyzed in this chapter. Information cannot analytically be released from these contexts.

The infrastructural work entailed in both design and use of this classification system is considerable. As we have seen, the ICD is used worldwide by states (on death certificates), by insurance companies, and within hospitals. The ICD fits perfectly into Star and Ruhleder’s (1996) definition of infrastructure (alluded to in the introduction and discussed in more detail in chapter 7 below). It is embedded in a myriad of databases. It is transparent as it invisibly supports medical work, and has wide spatial reach. (All countries in the world operate with a version of the ICD, though not always the same version!) It is learned as part of membership in the medical and medical actuarial professions, and it is linked with conventions of practice in all these domains.

The discipline and practice of statistics grew up during the nineteenth century (Porter 1986, Hacking 1990). As pioneering medical classifier Farr wrote: “statistics is eminently a science of classification” (1885, 252). As the word’s etymology indicates, it was a discipline intimately connected with the rise of statehood. Political and economic life in the industrializing countries of Europe was becoming ever more

complex. States experienced the need to gather and keep information about their citizenry. Medical statistics emerged as part of this burgeoning information-gathering activity.

Medical Classification and the State

During this century large modern states have found themselves forced into developing complex classification systems to promote their political and economic smooth functioning; people are travelling further and more frequently and living longer, more information-dense lives. Producing these classifications is tedious, long, committee work. It is nonheroic work, carried out by bureaucrats. For many, such work does not have a history. The archives of the WHO in Geneva preserve in black leather boxes stamped with gold on bright steel shelves the records of the struggle against smallpox. *Western medicine defeats ancient enemy!* The boxes stand proudly on the shelves, a battery of headlines awaiting a chronicler.

In searching for the archives of the construction and revision of the ICD, however, we were unable to find any such centralized and well-archived cache. Typically for an information infrastructure, the achievement of producing and maintaining a standard international list of causes of death—a massive bureaucratic, scientific, technical, statistical, epidemiological, human achievement—is considered beneath archival priority. Until recently, when every ten years a new edition was produced, records of the negotiations leading up to those editions were destroyed. Some earlier information remains as correspondence of individuals or committee associated with the League of Nations, or later the United Nations or WHO. For it usually appeared to the ICD’s designers, its record-keepers, and even those involved in implementing it, that what was interesting scientifically was the agreed-upon outcome, not the error-strewn path leading to it. That has for the most part been seen as too boring to bother with (with some notable exceptions that we shall discuss below).

The ICD’s lack of formal, boxed archives does not mean that it lacks history, as we have shown in the last chapter. Inscribed in the form and content of the list, as we saw, are a series of technical, social, political, and economic decisions taken at different moments. These decisions, taken at particular times for a given set of reasons, are paradoxically often more entrenched in the otherwise ahistorical ICD than they would be in some other form of historical object. This is due

to the inherently conservative nature of reform of large-scale data collection efforts. To maintain comparability of items in the classification from one revision to the next, and thence to carry out large-scale longitudinal public health and epidemiological surveys, changes must be minimized from one edition to the next. Thus the preface to the ICD's fifth revision (1938) notes:

The Conference endeavored to make no changes in the contents, number, and even the numbering itself of the various items, so that statistics based on the successive Lists should be as comparable as possible, and employees of the registration and statistical services of the different countries should have their habits of work changed as little as possible. Many possible improvements in matters of form and order were abandoned to achieve this practical object. (League of Nations 1938, 947)

As smallpox was eradicated from the face of the earth, its archives swelled. On the other hand, as the ICD grew larger, the archives disappeared. The list folded its history in on itself, however, becoming ever more ramified and complex, involving larger numbers of people in the processes of revision. The complexity of the artifact itself can be summarized as follows:

- Increased detail in data collection
- Increased cross-referencing by cause (occupational, disability-related, safety, morbidity as well as classical mortality)
- Conservatism in abandoning categories due to the need for historical comparability, leading to the preservation of anachronistic categories
- Links between the ICD and other state information systems, such as social security
- Preserving the ever more complex concerns of the governments involved in developing the ICD in category contents

The health of the citizen is central to the modern state, as François Ewald (1986) and others have shown:

In the earliest dawn of the nation the English inquired into the causes of death with a view to discovery and prevention. The protection of life was a fundamental principle of their laws. It was as much an object of their political organization as national defense or war. . . . The plagues of the sixteenth century proved that human life is exposed to invisible enemies more deadly than the mechanical forces of nature, the ferocity of animals, or the malignity of manlayers; and toward the end of Queen Elizabeth's reign the London Bills of Mortality were commenced. (Farr 1885, 218)

The equation can be brutal. One doctor responded in 1984 to a questionnaire on missed diagnoses (believed from autopsy analyses to be about 10 percent of all cases) that these "be quantitated on the basis of functional units, for example, number of productive work-years lost or number of symptom-free months lost" (Anderson 1984, 492). Or the equation can be martial: "By studying the causes which are injurious and fatal to men in our countries and in our cities, statistics will contribute to the removal of evils that shorten human life and to the improvement of the race of men, so that Citizens of a civilized State may be made to excel barbarians as much in strength as they do in the arts of peace and of war" (Farr 1885, 218). It can also be richly paternal, as shown here:

In 1974, New Zealand became the first country in the world to accept responsibility for the safety of its inhabitants for 24 hours every day, 365 days every year, from birth until death. At the same time, the Accident Compensation Corporation became the first organization in New Zealand, and possibly in the world, to become responsible for the prevention of accidents to all inhabitants as well as for compensating, and where necessary rehabilitating, those who suffered personal injury by accident. (Heidenstrom 1985, 69)

In each of these cases, the state pits itself against the passage of time and tries, in its own interest, to legislate immortality for its citizens. The benign side of this process is improved health, social justice, and quality of life. Its darker side, of great concern now in medical policy circles about genetic disease risks and conditions such as AIDS, is surveillance and medical discrimination.

Much has been written about the state's role in classifying and monitoring mental health (Kutchins and Kirk 1997); much less about classifying and monitoring physical health. Yet this latter work has been just as politically fraught and just as imbricated in the rise of the modern state. As mentioned above, the ICD was developed following an international event in 1893 in Paris. This conference in turn followed a series of conferences to deal internationally with cholera.

Why cholera? There were a number of cholera epidemics in nineteenth-century Europe; one series in the latter part of the century being caused by pilgrims returning from a pilgrimage to Mecca infected with the cholera bacillus (see figure 3.1). In early years, returning on foot and by sailboat, infected pilgrims had died before they returned to France. As noted in the introduction, now they were returning by rail and steamboat, and they were able to bring the disease with them back into the metropolis before dying. So as



ABLUTION SACRÉE DE ZENZEM
(D'après le *British medical Journal*.)

Figure 3.1
Sacred ablutions in the zenzem, or fountain, at Mecca.
Source: Proust 1892.

the communication between the countries of the world increased at the apogee of the imperialist age in the 1890s, so did the need to monitor health and welfare on an international scale.

When the ICD classification was first drawn up, it was based on one of the few preexisting classifications: Bertillon's list of causes of death in Paris (see Bertillon 1900). The center of the French empire imposed its own classification scheme on its colonies and other imperial powers followed suit. This fact was remarked upon at the time by many. For example, a South African doctor noted that tropical diseases were underrepresented. This omission remains a sore point to this day.

Doctors in Africa, for example, have complained about the burden of providing AIDS statistics to first world countries. These statistics are of little use to them internally, in those (all too common) circumstances when they have no means to treat patients. The compilation, demanded by epidemiological agencies such as the WHO, takes up valuable medical and epidemiological resources. For them, AIDS is only one of a series of endemic causes of death. It is one that it will only be worth singling out for treatment once appropriate medical services are in place and general urban sanitary conditions are improved. Until then, the need that western doctors have to trace the detailed genesis and development of the disease is not felt so urgently. Thus the concern was raised in a conversation with the director of health statistics at the WHO in Geneva in 1989 that many of these statistics were being collected to further the careers of public health officials in the United States. (This is discussed further in the next chapter.)

A simple agonistic reading of the ICD is that the system was set up in an age of imperialism and helped impose an imperialist reading of disease from the West onto the rest of the world. There is truth in this, and many medical anthropologists and activists have ably told this story (Anderson 1996). Another, more subtle story can be told alongside this one. Management of the ICD played a part in the creation of the modern state, in many protocols for state-to-state negotiations, and in many international organizations. The degree to which it came to constitute medical knowledge is unknown, and that story is yet to be told.

This knowledge-creating role becomes clear when one looks at the highly complex bureaucratic work involved in developing and maintaining the ICD. Numerous groups use it for many different purposes. Medical insurance companies need a standard list of causes of death and of morbidity to work out standardized scales of payment for different treatments. They develop elaborate risk tables for different groups of subscribers (and thence modulate their premiums). Epidemiologists also use the ICD, to track down the causes of a given new disease, one needs a standard terminology and good records. Only with these in place can one determine that the disease only affects those who eat a certain kind of food, or have a certain genetic heritage or occupational history. Government health officials need good records to determine public health policy and services. For example, if tuberculosis is a major problem in a given area, then one might set up a clinic, or organize free x-rays there.

To maintain a good international system of medical classification, a huge amount of detailed information is needed about both the citizens of a particular state and about citizens of countries with whom they are in contact. No information is irrelevant. The state must have better information than the family itself. As noted in the case of New Zealand above, its need for information is effectively infinite. Below, for example, is a wish list from 1985 for a national medical information system in the United States:

The system must capture more data than just the names of lesions and diseases and the therapeutic procedures used to correct them to meet these needs. In a statistical model proposed by Kerr White, all factors affecting health are incorporated: genetic and biological; environmental, behavioral, psychological, and social conditions which precipitate health problems; complaints, symptoms, and diseases which prompt people to seek medical care; and evaluation of severity and functional capacity, including impairment and handicaps. To accomplish this, a series of interlinked classifications would be required, designed so that all of the information is stored in a common database. The entire spectrum of medical terminology would be included, from the layman's language used to describe ill health and terms used by professionals at the institutional level to molecular terms from each of the basic sciences and terms related to causes of death used at the international level. Feinstein, in a recent paper, proposed to capture even more data consisting of the observations and quantitation of such clinical phenomena as the type and severity of symptoms, the rate of progression of illness, the severity of co-morbidity, the functional capacity of the patient, the reasons for medical decision, problems in maintaining therapy, the impact of the ailment and its treatment on familial and interpersonal relationships, and other aspects of the physical activities and mental functions of daily life. (Kodhwel 1985, 169-170)

There is no foretelling what information will be relevant. This is what Lemke (1995) calls the dilemma of choosing between typological and topological. The construction of typologies or classes forecloses labeling options and presets the options about the range of possibilities. For scientific and ethical reasons, he argues for a topological approach in classifying persons, visualizing dimensions that may be added to in an expandable matrix (Lemke 1995). Those who gather information for the ICD and related systems face precisely this dilemma. Heidenstrom says, for example, "to classify a chisel, a hand drill, and a spanner [wrench] together as 'hand tools', or the first two as 'cutting and piercing instruments' may be obscurantist, or even misleading. Whereas to one accident researcher it is significant that a chisel is edged, a drill pointed, and a spanner neither, to another it may be more important that the chisel is pushed, the spanner turned and the

drill operated by rotary motion" (1985, 76). A topological approach would ideally preserve this multiplicity of meanings.

To record information properly about a given disease at a given time, everything about the social, economic, personal, and physical conditions of the patient can be relevant (some will recognize this as a version of Spinoza's problem). The encyclopedic vision so common in information sciences envisions a preemptive, or open-ended capture of the information attributes of any object. For epidemiology, this would ideally mean that patient information would be captured at the lowest descriptive level (atomic units). In future years, the data so collected could be re mined as advances in medical knowledge re-configure the attributes. For example, the discovery of a new disease could be read backwards into existing data, and entities unknown at the time of data collection could be read out of the data. In practice, as the above examples show, the infinite possible ontologies of objects is limited by the pragmatics of data collection and by the inescapable inertia of categories already in use.

The expanding wave of information gathering practices is a defining characteristic of the modern state, as Foucault (1991) observes. To produce and maintain standardized medical records, state bureaucrats needed to create a uniform set of data-gathering and encoding practices. Without these practices, standardization could not be achieved. These standards entailed a range of governmental activities, including accustoming citizens to the regular collection of information about ever more detailed aspects of their personal lives. Standards also meant enforcing a standardized set of procedures.

These practices, and the standardized information thus generated, meant that information could be rendered comparable across situations. In turn, the development of a professional class that could use the information garnered was fostered (see Abbott 1988 for the medical profession as archetypal modern profession). This process appeared indefinitely expansive.

As the general level of sanitation improved during the nineteenth century in industrializing countries, doctors needed ever finer classification systems to discriminate these infrastructural effects from other disease agents. At least in the western world, more people were living to an age when they died more complex deaths. Infant mortality, appendicitis, or malnutrition no longer killed them in such great numbers at earlier ages. This is the story from within the history of medicine. But by the same token, as the modern state developed its

view of legitimate government as the management of a large information system, states produced a proliferation of ever finer classification systems. Along with this, a bureaucracy developed to manage these systems across a wide set of domains of which the medical domain is a chief example. Building the ICD involved building the state as much as developing medical knowledge.

This double movement—building an information system and building the state—is an intricate one. Bootstrapping is always involved. To create something as basic as an information infrastructure or a scientific standard, much of the infrastructure or standard already needs to be in place. (How else does one organize the data?) Thus, from the early days of the modern state, the need for such a chicken-and-egg operation can be traced with the development of hospitals (e.g., in France after the revolution). Until there was a working classification of diseases—such that people with one disease would not be mixed in with those suffering from others—then patients died wholesale. The hospital served as a place in which to share diseases and on that basis was dreaded by most. But a classification could not be developed unless people suffering from a given disease could be isolated. The establishment of working classifications depended on being able to develop specialized information about particular diseases. This in turn could only be obtained through studying cases in a controlled situation where patients were not subject to a wide range of complicating illnesses and infections (Dagognet 1970).¹⁸ To solve this class of problems in establishing and maintaining the ICD, its designers quite explicitly acted as if ICD statistics were *already* accurate. By so doing, they hoped that the future data gathering would conform to this gamble. Thus when the League of Nations began working on morbidity statistics, it did not try to impose a perfect classification scheme with a functioning bureaucracy. Rather, it admitted:

It is fully realized that much of the information called for in this plan is now utterly lacking in international, or frequently even in interurban comparability. This is evidently the case, for example, in regards to the records of school medical examinations, which are frequently not comparable even between two different examiners in the same town. Experience shows, however, that comparability of statistics has rarely, if ever, been obtained before there was a definite demand for it. Rather than omit from the beginning all data which are not yet satisfactory, the authors have hoped, by including them and utilizing them for what they are worth, to create a demand for their improvement and for international definitions and standards which lead to the development of comparability. Wherever possible, checks have been devised to facilitate evaluation of the data. (Stouman and Falk 1936, 904)

There have been many minor methods for cobuilding the ICD and its bureaucracy in this fashion. Laws have been passed in individual countries demanding that all causes of death be reported by the relevant statistical service. A single standardized death certificate (developed in the 1920s) has been adopted worldwide.

Doctors frequently bemoan the (clinical) resources wasted on searching for the one true cause of death, and as discussed below, consider filling out the certificate virtually a waste of time. Many attempts have been made to educate them in the epidemiological value of a good death certificate. None of these measures alone has rendered the ICD a perfect tool, as Kerr White complained of the ICD up to the ninth edition: "There is no coherent conceptual or organizing theme, to say nothing of theory, and yet this classification and its modifications seek to meet the needs of policymakers, statisticians, third-party payers, managers, clinicians, and investigators of all persuasions and pre-occupations in a wide range of socioeconomic and cultural settings around the worlds" (Kerr White 1985, 17–18). Both the acceptance of the role of the state in garnering statistics, however, and its bureaucratic competence so to do, has increased drastically over the past 100 years.

Over the past several hundred years, there have been many critiques of the veracity of medical statistics. John Graunt in 1662 (using original spelling) noted:

17 . . . I found that all mentioned to die of the French-Pox were returned [sic] by the Clerks of Saint Giles's, and Saint Martin's in the Fields onely; in which place I understood that most of the viles, and most miserable houses of uncleanness were: from whence I concluded, that onely hated persons, and such, whose very Noses were eaten of, were reported by the Searchers to have died of this too frequent Maladie.

18 In the next place, it shall be examined under what name, or Casualtie, such as die of these diseases are brought in: I say, under the Consumption; forasmuch, as all dying thereof die so emaciated and lean (their Uters disappearing upon Death) that the Old-women Searchers after the mist of a Cup of Ale, and the bribe of a two-groat fee, instead of one, given them, cannot tell whether this emaciation, or leanness were from a Phthisis, or from an Hectick Fever, Atrophy, etc; or from an Infection of the Spermaick parts, which in length of time, and in various disguises hath at last vitiated the habit of the Body, and by disabling the part to digest their nourishment brought them to the condition of Leanness above-mentioned. (Graunt 1662, 37)

William Farr, almost two centuries later made a similar remark (constituting an example of the assertion that systems have progressive histories but their work-arounds do not):

The French explicitly reject women as informants and thus must in many cases forego the best possible testimony. Women are almost always, except on the field of battle, in attendance or present at death. The wife does not forsake the husband, the mother the child, in the last moments. In marriage and in birth, the two great acts of registration, the woman is indissolubly associated with the other sex, and from men in death they are not divided. On what ground then is the woman rejected peremptorily as a witness? The French principle is inapplicable to English women. But in England we may well avoid rushing to the other extreme. Why should a majority of the informants of some districts be ignorant women who sign the registers with marks and cannot read and check the entry to which their signature is attached in the national records? (Farr 1885, 226)

Farr went on to write that classification was "another name for generalization," which was basic to the natural sciences, and that good classification depended on the "form, character, and accuracy of the observations" (Farr 1885, 233). He recommended that the mode of observation should be recorded along with the cause of death. In the early 1900s in Russia, one priest would have the task of filling in the death certificates for a scattered population of 100,000 rural inhabitants (Fagot-Largeault 1989, 242). These results would in no way be comparable with the meticulous statistics collected in Paris. Such discrepancies, through a slow series of changes, have become less marked, although they have by no means disappeared (see Sorlie and Gold 1987). Comstock and Markush (1986, 180) remark that "most physicians have had no training in the purpose and process of death certification . . . medical information on death certificates is often incomplete . . . diagnoses on death certificates do not necessarily reflect information obtained after death . . . mortality statistics are not published promptly."

The original list of causes of death covered several million people. The ICD's fifth edition (1938) was estimated to cover a reasonable proportion of the world population at 630 million (League of Nations 1938, 946). The current tenth edition is not yet by any means universal; several countries have decided to stay with ICD-9.

With the rise of the state and of statistics playing such a role in the creation and maintenance of the ICD, it is no surprise that the list itself—to the casual glance a flat list of causes of death—has inscribed affairs of state onto its representation of the afflicted human body, as shown in the last chapter. From the beginning, the definition of the moment of life has been a key battleground. Catholic countries fought to recognize the embryo as a living being, statistically equivalent to an infant; Protestant countries were far less likely to accord the status of

life to embryonic citizens. There were in addition wide ranges of variation even within nations in how long gestation must last to encode a stillbirth. In Maryland, (historically a Roman Catholic U.S. state), life was defined as "all products of conception." In the state of Washington, it was only those advanced beyond the "seventh month of utero-gestation" (C.H./expert stat./46, doc. 43806, doss. 22685, 22 December 1927, 3). Even in discussing breathing as the sine qua non of life, the committee was forced to ask whether the baby breathed or only attempted to breathe.

A compromise position reached in 1930 was that a baby must have tried to breath three times to be ranked as an infant mortality rather than a stillbirth. Various editions of the ICD have had special sections devoted to this topic. Equally, the ultimate cause of death is also state defined. This was made explicit in 1932 when, if there were two equal underlying causes of death (e.g., cholera and leukemia), then the cause that would be most useful to the public health arm of the state (in this case cholera, which was a matter of public health concern) would be taken statistically as the underlying cause.

Categories of accidental death and death by suicide have similarly always inscribed a diverse series of government regulations and local bureaucratic contingencies. Consider this set of categories from the ICD's fifth revision (1938). In this edition there were many categories for suicide, with categories 163 (suicide by poisoning) and 164 (other forms of suicide) being devoted to it. Subcategories of the latter included:

- 164. f. Suicide by crushing.
 - fa. Suicide on railways.
 - fb. Other suicide by crushing.
- (ICD-5, 974)

Some chief forms of accident included:

- 187. Cataclysm (all deaths, whatever their cause).
 - 192. Lightning.
 - 193. Other accidents due to electric currents.
- (ICD-5, 976).

This latter is footnoted: "Except accidents from transport, accidents in mines and quarries, agricultural and forestry accidents, or accidents due to machinery, classed under nos. 169-176, and deaths from operations of war, classed under nos. 196 and 197" (ICD-5, 976).

The pattern is clear. The railway authorities needed to keep track of the number of bodies of suicides they had to recover and manage. The London underground introduced "suicide pits" between the rails (still in use today). They wanted to know the efficacy of these pits in capturing and saving the life of the attempted suicide. Equally, mines, quarries, and war were tracked and managed by different government departments. Thus, it was useful for them to keep these statistics separate, even though the lay observer might see no difference between electrocution on a battlefield and electrocution at home. Again, the typological-topological problem of encyclopedic knowledge reappears. Who will be able to recover which knowledge? Finally, categories about which nothing could be done (medical "fait divers" of all sorts) could not demand detailed treatment: "cataclysm" (as a residual category) would do for them all.

This government pressure on medical authorities to develop useful classifications has been a constant theme. To take but one example, in Norway in 1981 the Government Action Committee for the Prevention of Child Accidents and public servants dealing with the 1976 Act of Product Control on working with consumer products asked the health authorities for a registration scheme. In this fashion all consumer products could be brought under a standard classification scheme (Lund 1985, 84). Thus the health authorities got into the business of classifying not only diseases (natural kinds) but also manufactured articles (social kinds) that might become causal agents in morbidity and mortality. The horizon of detail expands again.

It is clear then that a history of the ICD is only in part a history of medical progress, strictly speaking. Indeed, it must inevitably lag behind the field of medicine. To maintain historical comparability of statistics, the ICD is necessarily conservative with respect to changes. Even at ten-year intervals, a new disease entity may take more than twenty years to be included since the pace of medical discovery and the uncertain process of consensus can be very slow. As shown in chapter 1, some diagnoses may only by achieved with advanced medical technology. In turn, this technology may be slow to spread around the world to become available and familiar to revision centers. In the advent of a new epidemic such as AIDS, diagnostic, nosological and epidemiological tangles have persisted for more than a decade, spanning the implementation of ICD-9 and ICD-10 among affected countries.

The history of the ICD is thus inextricably a history of the formation of the modern state—both at the small-scale level of the development of particular bureaucratic structures and at the large-scale level of the installing of and justification for methods to keep populations under surveillance. After World War II, this development increasingly involved multinational corporations and the computerized flow of epidemiological and medical information across all manner of organizations.

Medical Classification and Information Processing

The ICD is a complex information-processing tool. As such it is at any one time associated both with a theory of applied historical knowledge and a particular configuration of technology. It must have an historiographic aspect—a theory of historical knowledge—in the sense that it embodies an understanding of what information about the past can and should be retained.

The historical problem is particularly complex since there has been a secular change in the form that death takes. People no longer die the way that they used to at the turn of the century, as noted above. In 1900, the overriding causes of death were the single great epidemic diseases: tuberculosis, pneumonia, smallpox, and influenza. These tended to attack people indiscriminately, from their prime to old age. Nowadays, with antibiotics and other medicines, people tend to live longer and to break down more slowly. As noted in chapter 2, they tend to be carried off not by a single disease but by a complex of diseases (Israel et al. 1986, 161). Matching this trend, the emphasis in applications of the ICD has changed. It has gone from recording a single underlying cause of death to looking for a complex of causes.

Consider for example the standard International Form of Medical Certificate of Cause of Death adopted by the WHO in July 1948 (reproduced in Fagot-Largeault 1989, 72 and discussed in chapter 2). This was the canonical form that was used to apply the ICD so as to produce epidemiological statistics. It locates a single "disease or condition directly leading to death," with space for two antecedent causes ("morbid conditions, if any, giving rise to the above cause, stating the underlying condition last"). There is then free space for "other significant conditions contributing to the death but not related to the disease or condition causing it."

Designed and standardized in the 1930s, the death certificate echoed the positivist analytic philosophy of the time. Now the trend is toward fractured, postmodern, multiple causation. (Nordenfeldt 1983 has an excellent discussion of this philosophical history.) The history of philosophy, the history of ways of dying, and the history of death classification—are these three histories or one? This question makes no sense unless we look at the ways the ICD as an information infrastructure knits together temporal, philosophical and scientific concerns. Earlier in this century, historians in general effected closure on the past by bringing what we now see as problematic single historical actors (“great men”) before the tribunal of history. Similarly, the original ICD also tried to effect closure: to provide a single, centralized record of the great epidemic diseases. Modern historians constantly point to the openness of the past. The past, we are told, is recreated afresh at each instant in the present; one role of the historian is to honor this openness while telling the best story one can (Serres 1993, C. Becker 1967). Modern medical classification systems, most particularly the ICD rival SNOMED (Système de Nomenclature Médicale) strive in precisely the same way to keep the past open. Ideally, they would become topological, but with an ease of management, data entry, and controlled vocabulary preserved. Thus far, this goal has proved elusive.

To tell the story as one internal to the history of medicine, consider the problem of tracking AIDS through history. AIDS achieved recognition as a disease in a slow process. Gay and sexual politics, medical profit making, and medical research were embroiled together in both its definition and its control. From the public health side, researchers at the Centers for Disease Control began to notice increased requests for a drug used to treat Kaposi's sarcoma—a rare condition previously afflicting certain localized or well-defined population groups, such as elderly men of eastern European descent. Intensive epidemiological work revealed that sufferers were largely male homosexuals. Transmission to hemophiliacs indicated that it could be passed on in the blood. Then Luc Montagnier and others located a virus that is generally believed to cause the disease (although for some both causal and priority questions remain open).

Statistics compiled before the epidemic used ICD categories without reference to AIDS-related conditions. It is thus virtually impossible to search back through the historical record to find earlier instances of AIDS. The old statistics do not record what were believed to be con-

tributing causes of death. As a thought experiment, people with AIDS from the 1920s might have died of any of a number of opportunistic infections now associated with AIDS, such as pneumocystis carinii. Their deaths, by the then current ICD, would be widely distributed throughout the classification system, and some would be buried as simple pneumonia.

Further complicating the historical retrieval problem, “rare” contributing diseases are often deliberately excluded from the kept record. The ICD is after all primarily a statistical classification. Biostatisticians and epidemiologists are most interested in regular patterns of recurrent diseases. The standard death certificate has no room for clusters of diseases to be recorded; and even if two or three are mentioned, they often get reduced to one at the moment of the compilation of statistics. Grmek (1990) discusses at length the evidence for possible former cases of AIDS that remained in the historical record contingently. In some cases, they involved famous figures (for example, Erasmus) whose life was recorded in great detail. In others, they stood out as medical curiosities, such as the unexplained death of a Norwegian family in the 1950s. In that case, the husband had been a sailor who visited East Africa; his wife and subsequent children all died with a set of symptoms akin to those afflicting AIDS patients. Old blood samples have only been kept in aleatory fashion. Even where they have been preserved, they might give false positives to diagnostic tests. It is only through finding a pattern of immune system breakdown that there could be any hope of tracking such diseases through time. That would (would have) require(d) recording all contributing causes, even when it is, at the current state of knowledge, “obvious” what the patients died of. This is infeasible for both practical and epistemological reasons.

The reasons for wishing to maintain an “open past” as told from within the history of medicine are clear, however impossible to implement. But if one focuses through the history of medicine in such a fashion, one is likely to miss both the contemporary pragmatics of the period in question and to isolate medicine as a special case among disciplines.

In fact, medicine shares many commonalities with other disciplines and professions that have adopted new information infrastructures. To tell this story, we can turn to the history of information technology during this century and to the ways in which technological constraints and information processing developments have shaped the ICD.

The Technological Configuration: Another Way to Think of Epidemiological History

The ICD is at each historical point associated with a particular configuration of technology. Like much modern information technology it bears traces of its past, inheriting the inertia of the installed base upon which it was built (Hanseth, Monteiro, and Hatling 1996). Computer screens tend to be eighty characters wide, an echo of the eighty columns of the preceding punch-card technology (Norman 1988). Similarly the ICD bears traces of its technological ancestry: The 200 headings restriction inherited from the census forms is the most obvious physical example. Both the form and the implementation of the ICD have been influenced by development of information processing technology. For the former, Blois (1984, 124) remarks that the use of numeric codes in the ICD was directly attached to the development of punch-card technology. As an example of the latter, in the United States coding of more than the single underlying cause of death was a failure before 1968 despite repeated attempts. Such coding became standard when an automated computerized system was implemented for the selection of the underlying cause of death (Israel et al. 1986, 165).

Tracing the imbrication of the technological configuration and the form and use of the classification system, the history of the ICD attaches directly to the development of information processing technology this century. The story begins in the nineteenth century, with the rise of large-scale bureaucracies. This development is still underexplored by historians, but one consensus that appears to be emerging is that insurance companies, banks, railway companies, the post office, and the government were at the heart of this development (Chandler 1977, Yates 1994, Campbell-Kelly 1994, John 1994, Friedlander 1995, Bud-Frierman 1994). As companies began to operate over a very large space (railway companies simultaneously created that space and operated within it), a need arose to share information on a standardized form. A mechanical punched-card technology was developed for storing and sorting large quantities of tabulated information. A hole punched on a certain row of a certain column of a card could mean whatever one wanted it to mean: and cards could be mechanically sorted. Among the first applications of this technology was the use of the Hollerith tabulators for the American census in 1890. Without this aid the information gathered at this census would have taken longer than ten years (the period between censuses) to sort using the old methods.

Information stored on punch cards could be retrieved much more quickly than information stored in, say, ledger books. It was difficult to implement the punch card technology, however, which came into its own only for large-scale statistical and accounting applications. It was expensive and cumbersome to go through huge numbers of cards. The cards themselves had to be printed on the finest quality material, an additional expense (Campbell-Kelly 1989). In the case of the ICD, only certain centralized government bureaucracies could afford the necessary technology and personnel to successfully implement the new information processing possibilities. As a result some countries soon adopted this mode of information processing while others never did. For similar reasons, the problem of divergent information technology resources has dogged the ICD to the present day.

In the 1950s, electronic stored program computers began to appear. There was talk both in the popular press and in academic circles of creating an "electronic brain." The dream in medical circles became the integration of all the various kinds of trace that were kept of medical encounters (Blois 1984, 127). First there was the patient medical record: the hospital's central account of what had happened to the patient. Then there were the local versions of that record stored and maintained by the various hospital departments. Then there were the notes kept by the doctor, the reports to health insurance companies, and the reports to government statistical services. If a single standard language (drawing in part on the ICD) could be imposed on all these reports, then all the various services that needed information could draw it from a single central source. All relevant information would be preserved. The most famous resultant record system, still operating today, is COSTAR: the Computer-Stored Ambulatory Record. This was developed at the Massachusetts General Hospital, starting in 1969, where it was first applied to a population of some 37,000 Harvard Health Care Plan patients. The record was designed to be used by researchers, doctors, and government agencies. Its programming was written in a special interactive programming language called MUMPS (the Massachusetts General Hospital Utility Multi-Programming System) (Barnett 1975, 4).

The central challenge in the subsequent period up to about 1980 became integration of the data so collected. It was clear that the new information technology could provide data integration. At the same time, it was not clear just what sort of integration was needed.

The various ways the new information technology would interact with medical practice was hotly debated. One such project was that of

making automatic medical diagnostic tools. In some tests, the expert system MYCIN could outperform doctors in clinical tests, rather than in diagnosis. Paradoxically it was never actually adopted, since it tended to be very cumbersome and slow. Berg relates how this kind of expert system was pitted against the production of clinical-decision support systems, which could advise the doctor not so much on the diagnosis as on the course of treatment to follow (Berg 1997). (In a further complication, often the diagnosis itself is *ex post facto*. That is, the treatment worked, therefore the patient must have had such and such a disease.) A myriad of similar examples litter the history of the ICD and medical language and recordkeeping.

Whatever the form of integration and automation, more categories were needed to manage the range of uses to which the system would be applied. During the post-World War II period, the ICD has increased hugely in size. Sprawling sets of modifications were produced for specific clinical and administrative purposes. Thus ICD-8 was modified by the U.S. Public Health Service to provide greater detail in certain disease categories and was published for use in the United States as the International Classification of Diseases—Adapted (ICDA) 1967. This in turn underwent further revision by the Commission on Professional and Hospital Activities (CPHA) for use in American hospitals, which was published in 1968 as the Hospital Adaptation of ICDA (H-ICDA). Later versions included that of the Royal College of General Practitioners (1972); the International Classification of Health Problems in Primary Care (1975); and the OXNIS Code of the Oxford Community Health Project 1975. Huffman (1990, 346–364) gives a clear summary of all the modifications and modified modifications that were generated.

Again this is a classic story of information processing from 1950 to 1980. More than 100 standard computer languages were created during this time. Each of these standard languages spawned 100, often mutually incomprehensible, dialects (Metropolis, Howlett, and Rota 1980). The WHO attempted to control this process for the ICD by producing guidelines on how to modify the ICD for particular purposes. These guidelines were themselves modified locally, however, a classic problem in decentralized organizational control.

In the post-1980 period, the resultant steely skyscraper is not so different in kind from the Gothic brick construction of the 1890s. There are a thousand “controlled medical vocabularies” for a thousand purposes, many of them having embedded within them some version

or other of the ICD. As one article put it: “We are often reminded that medical knowledge has grown to the point where we require the assistance of computers to manage it. One response has been the construction of controlled vocabularies to facilitate this process. We are now at the point where the vocabularies themselves have reached unmanageable proportions and must again call on computers for help” (Cimono et al. 1989, 517). The call now is for a unified medical language system (UMLS) that will provide for automatic, flexible communication among all authorized controlled medical vocabularies. Embedded within the UMLS will be the ICD. Embedded in the ICD will be flexible classifications that will, in principle, allow a reconfiguration of past records. And surrounding all of it are secondary and tertiary analysis and fiduciary industries that audit, monitor, and collect revenues based on their expertise in analyzing the intertwined category schemes. Figure 3.2, for example, advertises a firm with precisely this mission. Readers will recognize herein a familiar chapter in the history of expert systems, with the emphasis moving from faith in a unitary vision of the world as modeled in symbolic artificial intelligence to the management of multiplicity and pragmatic circumstances. By concentrating on the ICD and information technology, we are able to see a new kind of “open past.” Rather than searching for disease precedents described before about the internal history of medicine, we may also find them in the history of information technology.

As such, this open past is shared by a number of different disciplines and professions. Note though, as David Levy (1994) points out more generally, that the move to computerization may lead in some senses to less flexibility and local variability than in the past. Jucovy (1982, 467) states that in the medical field, “computers will probably firm up lexical use in much the same way as printing served to fix the spelling of words a few centuries ago.” The reconfigurable past of the ideal database meets the installed inertia of the standardized bases—thus the old dialectic is transferred to a new medium.

Conclusion

A key outcome of the work of information scientists of all kinds is the design and implementation of information infrastructures. In looking at the case of the development of the ICD, a fundamental figure-ground problem emerges in the analysis of such infrastructures. In particular, the medical classification system that underlies a large part

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Figure 3.2
Monitoring the intertwined classifications: the recovery room. An advertisement for one of the many auditing service firms that track the integration of information.

Source: *Healthcare Financial Management*, December 1996. Courtesy of Leco and Associates, Pittsburgh. (Note: They no longer provide the DRG review service.)

of all medical bureaucracy is historically contingent both with respect to its political origins and technological underpinnings. However we may tell the story of the open past, the dream of an unconstrained encyclopedia is evanescent.

This is not of itself surprising. Towers of Babel are perhaps the rule, not the exception. To classify is human and all cultures at all times have produced classification systems. Modern Western culture has produced more than most, often without realizing it. It is often asserted that Eskimos have fifty terms to describe snow. On close examination, this is an urban legend—Eskimos have only a handful of such terms (Pullum 1991). On the other hand, however, Arctic explorers have hundreds, scientifically laid out in their expedition manuals (Pyne 1986).

A consistent finding of the history of science is that there is no such thing as a natural or universal classification system (see for example Lakoff 1987, Latour 1987). Classifications that appear natural, eloquent, and homogeneous within a given human context appear forced and heterogeneous outside of that context. Borgès gives a wonderful invented list created by the Chinese emperor: "animals are divided into: (a) belonging to the emperor, (b) embalmed, (c) lame, (d) sucking pigs, (e) sirens, (f) fabulous, (g) stray dogs, (h) included in the present classification, (i) frenzied, (j) innumerable, (k) drawn with a very fine camelhair brush, (l) *et cetera*, (m) having just broken the water pitcher, (n) that from a long way off look like flies" (cited in Foucault 1970, 15).

In a similar trope, Bertillon (1895, 263) pointed out the incongruity of Farr's "natural" (for the 1850s) grouping of gout, anemia, cancer, and senile gangrene as a single kind of disease. In like fashion, our own lists can appear strange to outsiders. Thus supporters of the rival schools in modern biological classifications—cladistics and numerical taxonomy—each make rapprochement between species or splits between them that jar common sense perceptions. The ICD as an information infrastructure is an invisible underpinning to medical practice. On close examination it constitutes a classification as strange in its way as Borgès'. But as with many strange things, it has become well adapted to modern bureaucracy. We can tell the story of this adaptation as the integral, costructuring rise of both the modern state and the new information technologies.

As for the ICD, we saw that one could foreground state interests and see the developing ICD as reflecting and partially determined by these

interests. In this picture, the ICD is a passive list, molded by outside forces. The ICD can, on the other hand, be brought into center stage as one of the mechanisms developed this century for producing and defining the modern state. According to this position, it is no happenstance that a series of universal classifications emerged in the late nineteenth century (classifications of work, industrial equipment, and criminal physiognomies, see Tort 1989). Rather, the development and maintenance of such classifications by increasingly ramified bureaucracies changed what it was to be a citizen of a given state. They provided fundamental tools for communication and control.

Finally, looking at the ICD and information processing, we saw that one could as well tell the history of medical classification internally from within the history of medicine as the story of the development of better and better classifications in tune with the development of medical knowledge. When we emphasize the infrastructure of classified medical knowledge associated with the ICD, we see a classic story of the development of computing infrastructure. Thus the ICD can be understood as one of many classification systems this century that have changed in tune with the development of computing technology: the storage and retrieval devices involved played a large part in shaping the nature and form of the classification system.

Given Star and Ruhleder's (1996) definition of infrastructures as being hybrid creations of work practice and information medium, such figure-ground switches are helpful historically. Working infrastructures like classification systems are deeply embedded both in practice and in technology. Their history cannot be told independently of the work practices that they constitute or the media in which they are inscribed. The work practices associated with the ICD link its history with of a set of classificatory practices defining the modern state and later the modern corporation. The media associated with the ICD link its history with a set of classificatory principles associated with a particular technological base developed for the management of distributed information.

The analysis of information infrastructures forces us to pay close attention to the unit of historical analysis. One might say that typically an historian seeks to examine the change in an historical entity over time—a person as she or he gets older, a state as it goes to war, an idea as it is born, developed, and superseded. In these standard cases one assumes—rightly or wrongly—that what it is to be a person, a state, or an idea does not change in the course of the historical treatment. It

is, in other words, the passive backdrop against which the historical drama is played out. Information infrastructures are constitutive of that backdrop; when they are foregrounded, and the historian's standard categories are rendered contingent, they become objects of historical examination.

To bring together this Janus face of infrastructure, we make a double kind of shift. This is the "infrastructural inversion," discussed in chapter 1 (Bowker 1994). The inversion helps provide a framework within which one can consider the filiation among information processing practices and technologies across a range of arenas. This also generalizes the history told here of the ICD. The problems faced by the ICD and its solutions have as much in common with the history of the Dewey classification system in libraries and industry as they do with the history of medicine before the ICD.

To do historical justice to the development of information infrastructures, one must move among stories that historians traditionally tell of people and places and things and those stories that are generally left untold: of the woof and warp of the canvas on which historical dramas are painted.²⁰