



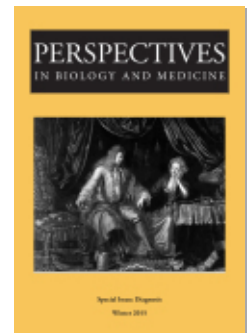
PROJECT MUSE®

Diagnostic Categories in Autobiographical Accounts of Illness

Michael P. Kelly

Perspectives in Biology and Medicine, Volume 58, Number 1, Winter 2015, pp. 89-104 (Article)

Published by Johns Hopkins University Press



➔ For additional information about this article

<http://muse.jhu.edu/journals/pbm/summary/v058/58.1.kelly.html>

DIAGNOSTIC CATEGORIES IN AUTOBIOGRAPHICAL ACCOUNTS OF ILLNESS

MICHAEL P. KELLY

ABSTRACT Working within frameworks drawn from the writings of Immanuel Kant, Alfred Schutz, and Kenneth Burke, this article examines the role that diagnostic categories play in autobiographical accounts of illness, with a special focus on chronic disease. Four lay diagnostic categories, each with different connections to formal medical diagnostic categories, serve as typifications to make sense of the way the lifeworld changes over the course of chronic illness. These diagnostic categories are used in conjunction with another set of typifications: lay epidemiologies, lay etiologies, lay prognostics, and lay therapeutics. Together these serve to construct and reconstruct the self at the center of the lifeworld. Embedded within the lay diagnostic categories are narratives of progression, regression, or stability, forms of typification derived from literary and storytelling genres. These narratives are developed by the self in autobiographical accounts of illness.

THIS ARTICLE TAKES A PHENOMENOLOGICAL APPROACH to the consideration of how diagnostic categories are used in lay accounts of the experience of chronic illness. The diagnostic categories of particular interest are those used by nonprofessionals to make sense of their own illnesses and those of others. These diagnostic categories are used by laypeople to explain why things are the way they are—that they feel unwell, and *why* they do—but they also provide an account of what might

Primary Care Unit, Department of Public Health and Primary Care, Institute of Public Health, Forvie Site, University of Cambridge, Cambridge CB2 0SR, United Kingdom.
E-mail: mk744@medschl.cam.ac.uk.

Perspectives in Biology and Medicine, volume 58, number 1 (winter 2015): 89–104.
© 2015 by Johns Hopkins University Press

be expected in the future—crudely, will they feel better, or will they not. They provide, in Alfred Schutz's (1967) terms, "because motives," or explanations of past experiences, and "in order to" motives, which are oriented to future events (87). Formal medical diagnostic categories also provide explanations of why things are the way they are (etiology) and what might be expected (prognostics), but these differ from the lay versions.

Lay diagnostic categories have been extensively described in the medical sociological literature down the years (e.g., Cobb 1954; Cobb et al. 1954; Fabrega 1974; Frenkel, Davison, and Davey Smith 1991; Herzlich 1973; Kosa and Robertson 1969; Pratt, Seligmann, and Reader 1958; Williams and Calnan 1996). First, there are very general diagnostic categories (called here type 1) that define the difference between feeling well and unwell. These describe general malaise or dis-ease: "I feel ill," "I feel poorly," "I don't feel too good," "I know there is something wrong," "I am in pain and discomfort." These constructs give expression to subjective feelings of unwellness and provide a language to describe those feelings within a broader human familiarity with pain, discomfort, and disease. The categories are general, nonspecific, and articulate feelings about self, and they are used intersubjectively to describe the ways others might feel. Illness is an intersubjective experience because we assume that our feelings of pain, discomfort, and suffering are readily understood by others (Schutz 1953). Type 1 constructs are among the most basic of intersubjective categories used more or less universally across the species.

Second, there are diagnostic categories that use labels like "flu," "cold," "fever," "bad chest," "cough," "ache," "pain," "diarrhea," and "sore throat." These type 2 categories are usually symptom- or body-site-focused, and while still general, they tend to be more specific than type 1. Associated with type 2 are lay etiologies, epidemiologies, prognostics, and therapeutics. These type 2 categories not only describe how people feel, but they also offer either a tentative hypothesis or a fuller explanation as to why they feel the way they do, what the likely outcome will be, and what if anything they need to do. These lay evaluations of seriousness, personal vulnerability, and so on have been much studied, originally in the literature about why people took actions to protect their health (Becker et al. 1977; Kirscht et al. 1966; Rosenstock 1960). Diagnostic categories involve naming, which helps maintain control, and they acknowledge the bodily changes that signify something is wrong (Millward and Kelly 2003); the lay diagnostic category explains what and why. Diagnostic labels also help to reestablish social practices and repair relationships, because they help make sense of the disruptions caused by malfunctioning bodies (Bury 1982). The use of type 1 and 2 diagnostic categories are commonplace, and as the literature on medical help-seeking has shown, it is generally only when people's symptom experiences move beyond these commonplaces that they may go to see a doctor.

The third lay diagnostic category (type 3) reflects formal medical categories. These categories may be familiar because they are common in the communities

in which the person lives, or they may be derived from various forms of cultural transmission—media, books, the internet, conversation, and so on. Many disease labels like “cancer,” “TB,” “diabetes,” “stroke,” “heart attack,” or “rheumatism” have entered lay discourse. People may have direct experience of some of these conditions, or they may have read or heard about them.

The last lay diagnostic category (type 4) includes terms that are more precise and are used by nonprofessionals in a way that aligns with, but is not the same as, formal medical usage. The alignment occurs by virtue of familiarity, usually through direct experience of the disease in one’s own body or in that of a partner, child, parent, or other close intimate. “I have got type 2 diabetes” or “My friend has advanced small cell cancer of the lung” are examples of type 4 usage. The person using these terms does so both to make sense of things (as with all the categories) and also to communicate with medical care providers and others. However, the lay usage is not the same as the medical practitioner’s. Generally speaking, type 4 categories are not used by laypeople as a scientific description of the pathology or as a means of differentiating it from other clusters of symptoms; instead, they are used as a reference point or label, and as a catch-all explanation with assumed intersubjective shared meanings with medical professionals and with knowledgeable others. The formal medical category is not more objective or more real than the lay category: rather, there is an interchange between the two discourses. The typifications are used in different ways by the actors involved.

The use of these four types of diagnostic categories helps individuals with various conditions find explanations of their lived experience and plan future conduct (Schutz 1967). Lay epidemiology, etiology, prognosis, and therapeutics are part of our stocks of knowledge (Schutz 1970). We understand that people get ill and that some diseases are fatal and others much less serious. We have a sense of what is likely to arise in our own community of intimates and contemporaries (Frenkel, Davison, and Davey Smith 1991). We also have some sense of diseases that affect social actors in more distant places, and that affected our ancestors. We carry lay notions of how common or how serious particular conditions are, and of the kinds of things that medicine may be able to do to help.

The four types of diagnostic categories, along with lay epidemiology, etiology, prognostics, and therapeutics, are what Schutz called “typifications.” They are constructs used by social actors to operate in the world, and they are essential to the way people’s lifeworlds are formed. Diagnostic disease categories are among the most common typifications used in everyday life because of the ubiquitousness of illness, but they assume a particularly important role when individuals themselves are ill.

The diagnostic categories on which types 2, 3, and 4 are based are relatively modern. During the 19th and 20th centuries, there was a growing sophistication in the presentation of disease taxonomies. Although some diseases had been recognized and described in a way that aligns with current diagnoses many centuries before

(Porman 2012), it was in the 19th century that many maladies were separated into something approaching what one might recognize in a contemporary textbook. Better differential diagnosis was critical to improved therapeutics, and the various discoveries of distinct etiologies for different pathologies were fundamental to establishing medicine on a scientific footing (Carter 2003). Even so, if we consulted a textbook from the nineteenth century and compared it to a contemporary one, we would see marked differences in the taxonomies and the diagnostic categories then and now. This is because formal disease taxonomies are highly plastic, evolving and changing continuously; lay usage tends to lag behind the formal taxonomies.

Prior to the 19th century, developments in classification and treatment were made difficult by the convention of systematizing medicine around simple fundamental principles—to some extent echoed in the contemporary lay type 1 category. For example, monistic pathology was the idea that there was one cause of all morbidity. Monistic pathology was succeeded by the practice of naming disorders by classifying symptoms, much like lay type 2 categories. This produced highly confusing diagnostic categories of little practical medical use (Holloway 1964).

It was the shift to empirical observation, initially encouraged in the post-revolutionary Paris hospitals, that led to the formulation of recognizably modern disease categories (Holloway 1964). Underpinned by the use of scientific instruments like the stethoscope and microscope and the use of classification systems based on etiology, the new diagnostic categories were gradually appropriated into the lay world. Basic ideas about cause and effect, contagion and transmission, were common to both. Indeed, as public health efforts to protect the population from communicable and noncommunicable disease gathered pace, with educational campaigns about such matters as cholera, venereal disease, TB, immunization, and smoking, a general set of cultural categories was increasingly available to and used by the public. And of course individuals who got ill would be given some knowledge of their condition by their physician and would acquire very detailed understanding of the lived experience of it.

LIFEWORLDS AND ILLNESS

Sociological evidence collected over many years reveals that the self and the lifeworld it inhabits are fundamentally challenged by chronic illness (Anderson and Bury 1988; Bury 1982, 1988, 1991; Charmaz 1983, 1987, 1994, 1999; Fagerhaugh 1973; Kelly 1985, 1991, 1992a, 1992b; Kelly and Field 1996; Locker 1983; Pinder 1990, 1995; Robinson 1990; Scambler and Hopkins 1986, 1988, 1990; Strauss et al. 1984; Wiener 1975; Williams 1984; Zola 1982). A lifeworld is a person's subjective sense of the here and now (Schutz 1970), and thus lifeworlds are where we have a sense of existing and of what our existence means to us and to others. Individual lifeworlds also are the repository of our store of previous experiences and of the ways in which we have made sense of our own lives and the lives of others. Illness—our own or others'—constitutes an important ingredient in these experiences.

Schutz (1970) has argued that we interpret things in our lifeworlds on the basis of typifications, which allow us to organize the multiplicity of stimuli we encounter. Diagnostic categories are one such group of typifications. Many of these typifications consist of taken-for-granted assumptions about how the world is and how it works, including our bodies. These kinds of assumptions are the background to our everyday life: they are familiar, routine, and we seldom need to expend much cognitive energy on them. However, from time to time things we normally take for granted are thrown into stark relief, and then we have to give them close scrutiny and appraisal. For example, when we notice things going awry in our bodies, this captures our attention, and we use typification to guide our scrutiny of what is happening in our bodies. Type 1 categories are the background to almost the whole of everyday life, but as chronic illness becomes established, type 2, 3, and 4 categories become increasingly central organizing concepts around which the lifeworld is reconstructed. The categories become gradually more central to an ill person's autobiography.

In the classic description of the sick role, in which sick persons are exempted from normal social role responsibilities, not held responsible for their conditions, and obliged to cooperate with their medical advisors in the pursuit of getting well again (Parsons 1951), the diagnostic category becomes the core organizing concept for both doctor and patient. The power of the category on the person's self may be considerable as people become resigned to the illness. Chronic illness changes the classic formulation of the sick role and the doctor-patient relationship. As people learn to cope with chronic illness, whether by distancing themselves from their disease, by denying it, or by minimizing its impact on their lives, the diagnostic category becomes more attenuated. The self-definition "I am a diabetic" gives way to "I am a person with diabetes," which in turn gives way to "I am a person; there are many interesting things about me, one of which is that I have diabetes" (Kelly 1992a). In many instances, the diagnostic category shrinks in importance as the coping strategies kick in. In chronic diseases with unpredictable symptoms or with periods of exacerbation and remission, a person's experience will often entail a series of transitions in which the diagnostic category assumes varying degrees of salience (Bury 1982; Kelleher 1988; Kelly 1992a).

The use of diagnostic categories changes during the initial transition into illness. When someone first experiences symptoms they have not had before, or symptoms in some combination that is unfamiliar to them, it may be cause for alarm. Similarly, when they experience symptoms that are not commonplace, or that do not follow the lay expectations of getting better on their own accord, the search for meaning and the more detailed use of diagnostic categories begins (Mechanic 1962, 1972; Mechanic and Volkart 1960). Medical sociology has long been interested in this movement into unfamiliar symptom territory (e.g., Apple 1960; Croog, Lipson, and Levine 1972; Dingwall 1976; Kasl and Cobb 1966; Stoeckle, Zola, and Davidson 1963, 1964). The person begins an exploration of more-or-less focused diagnostic

categories, and this is a critical point in the decision to seek out medical help. At the same time, the person may seek out information or just hope it will all go away (Kelly 1985, 1992b).

When individuals do seek out medical assistance, the provision of a diagnosis by the doctor may form an important turning point in the experience. The diagnostic category provided by the doctor is a potentially very deep well of information. It may initiate a process of transition to a new sense of self as a sick person—as a chronically sick person—in a new and unfamiliar lifeworld. The diagnostic category provided by the doctor may correspond very broadly with the lay assessment of things, or it may provide an altogether different explanation to the one the person expected or perhaps wanted. This period of consultation is often experienced as a contested process. People presenting symptoms sometimes find it difficult to get the physician to acknowledge the seriousness of what is worrying them. Sometimes, because the symptoms are common or vague and nonspecific, the physician may be unable to provide a diagnosis; in other instances, the claims of people presenting may not be taken seriously by the physician or by the medical establishment more generally.

If a new typification is offered by the physician, it will have to be incorporated into the existing stock of knowledge by the person who has embarked on medical treatment. The acceptance, partial acceptance, or rejection of the diagnostic category commonly happens beyond medical encounters, in subsequent interactions with intimates and other professionals. At this point, the typifications being used by the person who is ill will often be a mix of types 2, 3, and 4. In the early stages of the illness, none of the categories provide once-and-for-all answers; they are part of a process whereby the self adjusts in the new and changing lifeworld of illness. The formal medical diagnosis may help to make sense of what has happened already and what the appearance of the early symptoms meant, and it may also help to organize the future. Inherent in a diagnostic category, whether type 2, 3, or 4, is the basis of a narrative that is progressive, regressive, or stable (Kelly and Dickinson 1997). In very broad terms, this a narrative about the future, a future in which a return to the pre-morbid condition can be expected, where a life with chronic illness might be anticipated, or where a trajectory to a decline in health or death might be the endpoint.

Since the 19th century, when microbes were discovered and particular diseases were linked to exposures to these microbes, and then in the mid-20th century, with the discovery of the lethal consequences of exposure to cigarette smoke, notions of specific causes of particular diseases have become firmly embedded in the culture of Western societies—a pathogenic paradigm (Antonovsky 1985, 1987; Carter 2003; Doll and Bradford Hill 1964). This paradigm, in which bad outcomes are the consequence of bad or toxic precursors, has joined other quasi-causal cultural categories, like disease as divine punishment, as a cultural motif. Not surprisingly, therefore, the use of diagnostic categories involves a lay etiology that invokes a

general understanding of cause and effect, usually involving relatively simple linear pathways. The medical elaborations of the complexities and uncertainties of etiology, prognosis, and therapeutics that inform clinical judgment tend to be absent from lay typifications. When we are sick, we want definitive answers—not ranges of uncertainty. The sick person will tend to use the diagnostic category as a heuristic, an aid to finding simple, quick answers and to avoiding complex, difficult, and uncertain problems (Kahneman 2011). This tends to work well with type 1 and type 2 categories, but in the case of types 3 and 4, there is a disjunction between the simple answer and what are actually very complex questions: “Will I recover?” “Will I die?” “When will I die?” “Will I be in pain?”

Uncertainty is intrinsic to medical practice. The difference between the patient’s hope for readily understandable answers and medical caution because of uncertainty is a major source of the often contested nature of the doctor-patient encounter. The classic formulation of the sick role, with its implied shared understanding of the diagnostic category, did not acknowledge this. Medical diagnoses and treatments are often far from straightforward (Wing, Bebbington, and Robins 1981). Patients tend not to present with symptoms corresponding neatly to the classifications in textbooks; indeed, the defining characteristic of clinical judgment is the ability to deal with what is not in the textbook. So although the patient may want simple and straightforward answers, that is not always possible. Watchful waiting might be the most appropriate initial response, as signs, symptoms, and test results may well be equivocal. But frightened people in severe discomfort will not necessarily welcome dwelling on and in uncertainty.

For the doctor, the diagnostic category is a helpful organizing principle or ideal type around which to conceptually organize the empirical evidence that is the totality of the patient’s signs, symptoms, and test results. An ideal type is a construction of elements abstracted from the concrete and put together to form a unified conceptual pattern. It involves an exaggeration of the concrete reality, but it is not necessarily to be found in it. An ideal type is not a hypothesis, a description of reality, an average, nor a formulation of the concrete traits common to a class of concrete things (Parsons 1937). It is merely a way of organizing complexity.

On the other hand, for the patient the diagnosis is a much less complex typification used to make sense of things, and patients therefore tend to want something definitive, not an interesting conceptual ideal type. Not surprisingly, patients in the initial stages of many chronic diseases may reject or deny the disease label. From the perspective of the person with illness, resisting the diagnostic category may be a highly adaptive strategy, because it allows the person time to muster resources and assistance and to do the cognitive work that is required to cope with a new, unanticipated, and unwelcome future (Lazarus 1985).

However, the obdurate nature of the sheer physicality of the disease will be critical (Kelly and Field 1996). When our experience of our own bodily or mental functioning changes, our lifeworlds change. Symptoms continually or unpredictably

disrupt usual social and physical routines. The body that we usually take for granted is no longer just background; when it malfunctions, the body intrudes into everyday life and imposes itself on our lifeworld. The functioning body becomes a focus of self-scrutiny, a scrutiny guided by the diagnostic categories. While an ordinarily functioning body requires little thinking about how it works, how to move, or how to eat and drink, in chronic disease, bits of the body that used to work don't, sometimes in highly unpredictable ways. Pain may intrude into our consciousness, and in severe incapacity our ability to feed ourselves or to drink may be lost or seriously impaired. Physical mobility may be compromised. In chronic illness, our bodies can intermittently or continuously interrupt our normal stream of consciousness. We seek explanations, using our understanding of diagnostic categories. As we do so, this changes our sense of self (Kelly 1991, 1992b).

Time is vitally important in this process. The experience has to be made sense of, and planned actions in the short, medium, and long term have to take account of the physical or mental limitations that the illness produces (Bury 1982). Schutz (1970) argued that in our lifeworlds we are aware of things as they happen, but we only make sense of them after they have happened. This is particularly the case when we are trying to understand changes in bodily functioning, which may make sense only after the terms of the diagnostic category have been applied (Williams 1984). And sense-making is not just about making sense of past symptoms or present predicaments, it is also about anticipating future actions and conduct.

SELF

The self is at the heart of the lifeworld, thinking, feeling, and observing. The idea of self used here is one in which the self is conceptualized as emergent in social interaction, in which language is the critical bearer of a person's ideas about his or her selfhood, and in which categories and typifications are used by the thinking subject to structure that person's sense of self. Self is neither a psychological thing nor a trait, although the cognitive processes involved during interaction clearly have a neurological basis (Cacioppo and Cacioppo 2013). This conception of the self derives from the work of Immanuel Kant (1781) and his influence on George H. Mead (1934, 1936). The focus on self has proved to be a rich seam for the investigation of the lived experience of chronic disease (Gerhardt 1989), and the particular interest here is in the way diagnostic categories can impinge on the self in the process of making judgments.

According to Kant, the self is a conscious, acting, thinking subject directly experiencing the world and ruminating on it. This notion of the self presupposes a preexisting social and physical world and an observational and judgmental/interpretive process that brings that external world into consciousness. Experience and rumination and the dialectical relation between them are the essence of self. This means that when bodily changes occur, such as pain, discomfort, unusual bleeding,

or breathlessness, the self both observes and thinks about these things in the context of previous knowledge and experience, using type 1 or 2 diagnostic categories. Preexisting knowledge forms the basis of the typifications used in conjunction with the empirical experience of the bodily changes: the knowledge is a priori, while the experience is a posteriori. The processes of reflection which the self engages in are interpretive and judgmental.

Reflection begins with experience of both external stimuli and internal feeling states like pain, anxiety, and nausea. However, Kant points out that we also have knowledge that is independent of experience or not derived from direct experience; within that body of knowledge are, significantly, general and specific diagnostic categories and understandings of lay epidemiology, etiology, prognostics, and therapeutics. These are important because without some a priori knowledge we would be unable to make sense of what we observe and feel: the experiences would be nothing more than an incoherent jumble (Weldon 1958). The bridge between experience and knowledge is the interpreting self, where the subjective feelings and observations about the body are fused with a priori diagnostic categories.

This interpretive process involves three different kinds of judgments. The first kind of judgment is an a priori analytic judgment, based on preexisting knowledge and ideas rather than on experience. Aspects of type 2 and 3 diagnostic categories are a priori analytic judgments. The second kind of judgment is an a posteriori synthetic judgment, based on observation and experience in the here and now (Ward 2006). The type 1 diagnostic category is an a posteriori judgment. The third kind of judgment is the a priori synthetic judgment, which is a fusion of a priori knowledge and a posteriori experience along with current experience. A priori synthetic judgments are the most complex we make (Guyer 2006; Ward 2006), because they involve induction and deduction. This third kind of judgment helps us make sense of novel experience. And this is the point at which the types of diagnostic categories are brought together with lay etiologies, epidemiologies, prognostics, and therapeutics.

Over the course of an experience of chronic illness, persons with the illness will develop increasingly refined understandings using synthetic a priori judgments, reaching a point at which they will know much more about their disease and its impact on their bodies than their medical practitioners do. At this point, the individual becomes the expert patient, and the classic sick role formulation falls away. In most cases of chronic illness, there will not be a cure. Life becomes a matter of the routine use of coping strategies of one sort or another, and the degree of cooperation with the medical advisor becomes, from the patient's point of view, much more contingent.

The self is not just a reactive or reflective entity, simply responding to or mirroring external stimuli. The thinking subject has a unified sense of itself doing that interpretation: it can observe its own subjectivity. Many thousands of successive sequences of interpretation of experiences occur every day, and the experience of

time as a unified experience continuing from moment to moment constitutes an autobiography. Chronic illnesses disrupt that sense of continuous autobiography (Bury 1982; Williams 1984), and judgments using diagnostic categories help to make sense of that altered autobiography.

As well as time, Kant observed that the idea of self also involves space. Our perceptions of the external world are determined by the ability to understand that our perceptions and interpretations are located in a spatial universe. Being chronically ill fundamentally alters the self's sense of being located in space, whether because of inability or restrictions imposed on mobility in physical space, or because of particular spatial locations, like being confined to bed, admitted to hospital, isolated, or quarantined.

NARRATIVES OF SELF

According to Kant, the continuous "I think" forms the platform for all our mental images and perceptions, which in turn become part of the self and are thought of as belonging to us. If this were not so, we would have as many diverse selves as we have images and experiences, and we would simply respond to each and every different external stimulus with no connections between succeeding perceptions and experiences. Our autobiographies provide us with the sense of continuity.

Autobiographical narratives are oriented to the past, present, and future, and diagnostic categories are critical in these formulations. Narratives are the carriers of meaning, as they are applied retrospectively to events, whether a mere moment ago or further distant in the past (Walsh 1967). Schutz (1967) distinguished between action in progress and action completed, and between the stream of experience and living in the world of space and time. The stream of consciousness is not caught up in reflection, because reflection belongs to the world of space and time and everyday life. Narrative is the way we make sense of the "now" of the stream of consciousness that has now passed. Our autobiographical narratives draw upon our vast store of reflected-upon past experiences. These narratives tend to be orderly, and Schutz notes that it is only when we have to solve a special kind of problem, like being ill, that we ask questions about the way the previously orderly worlds were constituted.

Rendering lived experience meaningful both distorts it and gives it a unity (Schutz 1970). The first step in autobiographical narrative construction is the immediate step of reflective sense-making after the experience of the now in the stream of consciousness. These immediate reflections make use of various typifications, including previous or extant biography, and they become part of an immanent and emerging revision to autobiography as the narrative evolves and develops (Williams 1984).

Narrative autobiographies evolve and change over the life course for all humans, but the entry of disease into the very center of the lifeworld can create a temporary or permanent disjunction between the previous lived experiences of the person

and the expected future life plans (Bury 1982). Autobiographical narratives are not just—and indeed are very seldom—simple chronologies of events. Narratives have structures; they draw upon cultural forms. The narratives of chronic illness use regressive, stable, or progressive elements drawn from the diagnostic categories, and they also draw upon typifications that are present in narratives and stories more generally.

Kenneth Burke (1937) described a catalogue of narrative forms found in stories, and both lay prognostics and types 3 and 4 lay diagnostic categories tap heavily into these narrative forms. *Epic* is about the acceptance of difficulties, and in this narrative form the role of the hero (in autobiographical accounts, the narrator) is amplified. Germs, viruses, contagion, or accidents or other external forces are the etiological mechanisms or fundamental causes of conflict in the epic; the person with the disease is not at fault. The epic stresses courage and sacrifice as well as the flaws in our nature, which are revealed as we face up to a test of some sort, like illness. Epic tends towards being progressive. Where people draw upon epic as the touchstone of their autobiographical accounts of illness, it tends to be in terms of triumph over the slings and arrows of the outrageous bodily misfortunes that afflicted them. The flaws and strengths revealed in their character become important points of self-knowledge, and people often recount that they learned things as a consequence of their predicament; they acquired wisdom about themselves (Kelly 1992a).

This links to a narrative style Burke called *elegy*, which emphasizes the disproportion between the self and the magnitude of the situation. Elegy often involves people making their misfortunes the basis of new insights, allowing them to transcend their situations. Patient support groups often make much of these aspects of dealing with illness, and they develop accompanying narratives of struggle and survival as mechanisms of social support for the patient and their loved ones.

Tragedy emphasizes hubris and nemesis; it is a narrative of pride preceding a fall. Sometimes the diagnostic category explicitly acknowledges this, in that some diagnostic categories contain etiological elements in which the illnesses are defined as a consequence of people's own actions. The victims have put themselves in harm's way, by smoking, by excessive alcohol consumptions, by having unprotected sex, and so on. An industry of public health behavior change that is premised on the idea of victim blaming feeds this kind of thinking (Crawford 1977, 1980). Tragedy takes its inevitable course to the bitter end. It is a downward or regressive narrative, in which with the onset of symptoms the die was cast, and the individual's life was changed forever for the worse.

Comedy, *humor*, and *ode* are the opposite of the heroic epic. Thus, rather than the individual being magnified so that the hero's character is as great as the situation demands, Burke observes that humor emphasizes the feebleness of the individual. Comedy entails loss of control, or events being out of the hands of the narrator, but it also entails a sardonic distancing from events and the shifting of blame to the events or to the disease and away from the person. This links with a narrative form

that Burke called *burlesque*, a disembodied, dehumanized form that is narrated as if the events are not happening to the narrator.

The accounts offered by the autobiographical narratives of illness don't so much fall into these styles or forms as draw upon them thematically (Kelly 1992a, 1992b). As ways of accounting for illness, they provide a set of pegs, or ready typifications to help organize stories and narratives. When people talk about their illnesses, they tend to switch from epic to comedy to tragedy depending on which version of self they are seeking to present, and at what point in the experience of the illness they find themselves. All the accounts are subject to a kind of Whiggish interpretation, in the sense that the further away in time the events are that are being described, the more triumphant the narrative tends to become (Butterfield 1931). The accounts offered are intrinsic to the coping process because they help to organize performance. They help furnish vocabularies of "because" motives as part of generalized symbol systems to make sense of the lifeworld.

What makes a story convincing both to others and self is not its content, nor in some sense its ultimate truth, but rather the way in which it draws upon these common literary categories that are repeated in popular culture, folkways, and norms and makes them intersubjectively communicable. One of the strange things about communications is that from the sender's point of view the message often has to be carefully built up, whereas from the receiver's point of view the meaning is graspable in an instant. As the listener grasps the intent of the speaker, two streams of consciousness become synchronous (Schutz 1970). We connect these streams of consciousness via the typifications we use: that is what makes them acceptable and convincing.

CONCLUSION

Although the everyday language people use to describe to themselves and to others how they feel, what they think is wrong with them, and what they think the future holds may be thought of as unscientific when compared to the language of the medical textbook or the peer-reviewed journal, these lay discourses and the typifications within them play a profoundly important role in the way that people make sense of what is happening to them and in their subsequent behavior. The four types of lay diagnostic category are pressed into service at various times in the illness experience, and when used in conjunction with lay epidemiologies, etiologies, prognostics, and therapeutics, they help individuals make sense of their changing lifeworlds as the illness takes hold. The categories are also important because the sense of self at the very heart of the lifeworld—connecting current experience, past experience, and knowledge derived vicariously—uses them when making judgments and interpretations. In the course of making these judgments or interpretations, the self also draws on another set of typifications, those derived from common narrative forms. These forms are also embedded in the diagnostic categories themselves, as conceptions of progression, stability, or regression.

As every medical practitioner is taught, it is important to listen to the lay diagnostic category, as well as the narratives in them and the way in which they are produced in the consultation. These various components often hold the key to the things that are really worrying the presenting patient, and they may contain important clues to help the physician reach a speedy diagnosis. They are interesting sociologically, given both their ubiquity and their illustration of the process of sense-making in illness, but they are also important springs to action, coping, or being overwhelmed by illness for the patient. But they are above all fundamental communication devices. The practitioner's task is to listen and to make, in Schutz's words, "the streams of consciousness synchronous." The physician must hear what the patient has to say and note that the diagnostic categories the patient is using inform the way the patient is thinking and feeling and will act subsequent to the medical encounter. From the physician's point of view, it is also important to remember that even when the lay categories sound like formal medical ones, they may have very different content, especially with respect to uncertainty. However, for all their differences in content, the lay categories are both real and important.

REFERENCES

- Anderson, Robert, and Michael Bury. 1988. *Living With Chronic Illness: The Experience of Patients and Their Families*. London: Unwin Hyman.
- Antonovsky, Aaron. 1985. *Health Stress and Coping*. San Francisco: Jossey Bass.
- Antonovsky, Aaron. 1987. *Unraveling the Mystery of Health: How People Manage Stress and Stay Well*. San Francisco: Jossey Bass.
- Apple, Dorrian. 1960. "How Laymen Define Illness." *J Health Hum Behav* 1 (3): 219–25.
- Becker, Marshall H., et al. 1977. "Selected Psychosocial Models and Correlates of Individual Health Related Behaviors." *Med Care* 15 (5 suppl.): 27–46.
- Burke, Kenneth. 1937. *Attitudes Towards History*. 3rd ed. Berkeley; University of California Press, 1984.
- Bury, Michael. 1982. "Chronic Illness as Biographical Disruption." *Sociol Health Illn* 4 (2): 167–82.
- Bury, Michael. 1988. "Meanings at Risk: The Experience of Arthritis." In *Living with Chronic Illness: The Experience of Patients and Their Families*, ed. Robert Anderson and Michael Bury, 89–116. London: Unwin Hyman.
- Bury, Michael. 1991. "The Sociology of Chronic Illness: A Review of Research and Prospects." *Sociol Health Illn* 13 (4): 451–68.
- Butterfield, Herbert. 1931. *The Whig Interpretation of History*. London: Bell.
- Cacioppo, John T., and Stephanie Cacioppo. 2013. "Social Neuroscience." *Perspect Psychol Sci* 8 (6): 667–69.
- Carter, K. Codell. 2003. *The Rise of Causal Concepts of Disease: Case Histories*. Aldershot: Ashgate.
- Charmaz, Kathy. 1983. "Loss of Self: A Fundamental Form of Suffering in the Chronically Ill." *Sociol Health Illn* 5 (2): 168–95.

- Charmaz, Kathy. 1987. "Struggling for a Self: Identity Levels of the Chronically Ill." In *The Experience and Management of Chronic Illness: Research in the Sociology of Health Care*, ed. Julius Roth and Peter Conrad. Greenwich: JAI Press.
- Charmaz, Kathy. 1994. "Identity Dilemmas of Chronically Ill Men." *Sociol Q* 35 (2): 269–88.
- Charmaz, Kathy. 1999. "From the 'Sick Role' to Stories of Self." In *Self, Social Identity and Physical Health*, ed. Richard J. Contrada and Richard D. Ashmore, 209–39. Oxford: Oxford University Press.
- Cobb, Beatrix. 1954. "Why Do People Detour to Quacks?" *Psychiatr Bull* 3: 66–69.
- Cobb, Beatrix, et al. 1954. "Patient-Responsible Delay of Treatment in Cancer: A Social Psychological Study." *Cancer* 7 (5): 920–26.
- Crawford, Robert. 1977. "You Are Dangerous to Your Health: Ideology and the Politics of Victim Blaming." *Int J Health Serv* 7 (4): 633–80.
- Crawford, Robert. 1980. "Healthism and the Medicalization of Everyday Life." *Int J Health Serv* 10 (3): 365–88.
- Croog, Sydney H., Alberta Lipson, and Sol Levine. 1972. "Help Patterns in Severe Illness: The Roles of Kin Network, Non-Family Resources and Institutions." *J Marriage Fam* 34: 32–41.
- Dingwall, Robert. 1976. *Aspects of Illness*. London: Martin Robertson.
- Doll, Richard, and Austin Bradford Hill. 1964. "Mortality in Relation to Smoking: Ten Years' Observations of British Doctors." *BMJ* 1: 1399–1410
- Fabrega, Horacio. 1974. *Disease and Social Behaviour: An Interdisciplinary Perspective*. Cambridge: MIT Press.
- Fagerhaugh, Shizuko Y. 1973. "Getting Around with Emphysema." *Am J Nurs* 73 (1): 94–99.
- Frenkel, Stephen, Charlie Davison, and George Davey Smith. 1991. "Lay Epidemiology and the Rationality of Responses to Health Education." *Br J Gen Pract* 41 (351): 428–30.
- Gerhardt, Uta. 1989. *Ideas About Illness: An Intellectual and Political History of Medical Sociology*. London: Macmillan.
- Guyer, Paul. 2006. *Kant*. London: Routledge.
- Herzlich, Claudine. 1973. *Health and Illness: A Social Psychological Analysis*. Trans. D. Graham. London: Academic Press and the European Association of Experimental Psychology.
- Holloway, Sidney W. F. 1964. "Medical Education in England 1830–1858: A Sociological Analysis." *History* 49 (167): 299–23.
- Kahneman, Daniel. 2011. *Thinking, Fast and Slow*. New York: Farrar, Strauss & Giroux.
- Kant, Immanuel. 1781. *The Critique of Pure Reason*. Trans. Norman Kemp Smith. Basingstoke: PalgraveMacmillan, 2007.
- Kasl, Stanislav V., and Stanley Cobb. 1966. "Health Behavior, Illness Behavior and Sick Role Behavior." *Arch Environ Health* 12 (2): 246–66.
- Kelleher, David. 1988. "Coming to Terms with Diabetes: Coping Strategies and Non-Compliance." In *Living with Chronic Illness: The Experience of Patients and their Families*, ed. Robert Anderson and Michael Bury, 137–55. London: Unwin Hyman.
- Kelly, Michael P. 1985. "The Subjective Experience of Chronic Disease: Implications for the Management of Ulcerative Colitis." *J Chronic Dis* 39 (8): 653–66
- Kelly, Michael P. 1991. "Coping with an Ileostomy." *Soc Sci Med* 33 (2): 115–25.
- Kelly, Michael P. 1992a. *Colitis*. London: Routledge.
- Kelly, Michael P. 1992b. "Self, Identity and Radical Surgery." *Sociol Health Illn* 14 (3): 390–415.

- Kelly, Michael P., and Hilary Dickinson. 1997. "The Narrative Self in Autobiographical Accounts of Illness." *Sociol Rev* 45 (2): 254–78.
- Kelly, Michael P., and David Field. 1996. "Medical Sociology, Chronic Illness and the Body." *Sociol Health Illn* 18 (2): 241–57.
- Kirscht, John P., et al. 1966. "A National Study of Health Beliefs." *J Health Hum Behav* 7 (4): 248–54.
- Kosa, John, and Leon S. Robertson. 1969. "The Social Aspects of Health and Illness." In *Poverty and Health: A Sociological Analysis*, ed. John Kosa, Aaron Antonovsky, and Irving K. Zola, 35–68. Cambridge: Harvard University Press.
- Lazarus, Richard S. 1985. "The Costs and Benefits of Denial." In *Stress and Coping: An Anthology*, 2nd ed., ed. Alan Monat and Richard S. Lazarus, 154–73. New York: Columbia University Press.
- Locker, David. 1983. *Disability and Disadvantage: The Consequences of Chronic Illness*. Tavistock: London.
- Mead, George H. 1934. *Mind, Self and Society: From the Standpoint of the Social Behaviorist*. Chicago: University of Chicago Press.
- Mead, George H. 1936. *Movements of Thought in the Nineteenth Century*. Chicago: University of Chicago Press.
- Mechanic, David. 1962. "The Concept of Illness Behavior." *J Chronic Dis* 15 (2): 189–94.
- Mechanic, David. 1972. "Response Factors in Illness: The Study of Illness Behaviour." In *Patients, Physicians and Illness: A Sourcebook in Behavioural Science and Health*, 2nd ed., ed. E. Gartly Jaco, 128–40. New York: Free Press.
- Mechanic, David, and Edmund H. Volkart. 1960. "Illness Behavior and Medical Diagnoses." *J Health Hum Behav* 1 (2): 86–94.
- Millward, Louise M., and Michael P. Kelly. 2003. "Incorporating the Biological: Chronic Illness, Bodies, Selves and the Material World." In *Debating Biology: Sociological Reflections on Health Medicine and Society*, ed. Simon J. Williams, Gillian A. Bendelow, and Lynda Birke, 157–68. London: Routledge.
- Parsons, Talcott. 1937. *The Structure of Social Action: A Study in Social Theory with Special Reference to a Group of Recent European Writers*. 2nd ed. New York: Free Press, 1949.
- Parsons, Talcott. 1951. *The Social System*. London: Routledge & Kegan Paul.
- Pinder, Ruth. 1990. *The Management of Chronic Illness: Patient and Doctor Perspectives on Parkinson's Disease*. Basingstoke: Macmillan.
- Pinder, Ruth. 1995. "Bringing the Body Back Without the Blame? The Experience of Ill and Disabled People at Work." *Sociol Health Illn* 17 (5): 605–31.
- Porman, Peter E. 2012. *Epidemics in Context: Greek Commentaries on Hippocrates and the Arabic Tradition*. Berlin: De Gruyter.
- Pratt, Lois, Arthur Seligmann, and George Reader. 1958. "Physicians' Views on the Level of Medical Information Among Patients." In *Patients, Physicians and Illness: A Sourcebook in Behavioral Science and Medicine*, ed. E. Gartly Jaco, 222–29. New York: Free Press.
- Robinson, Ian. 1990. "Personal Narratives, Social Careers and Medical Courses: Analysing Life Trajectories in Autobiographies of People with Multiple Sclerosis." *Soc Sci Med* 30 (11): 117–86.
- Rosenstock, Irwin M. 1960. "What Research in Motivation Suggests for Public Health." *Am J Public Health* 50 (3 pt. 1): 295–302.

- Scambler, Graham, and Anthony Hopkins. 1986. "Being Epileptic: Coming to Terms with Stigma." *Sociol Health Illn* 8: 26–43.
- Scambler, Graham, and Anthony Hopkins. 1988. "Accommodating Epilepsy in Families." In *Living with Chronic Illness: The Experience of Patients and their Families*, ed. Robert Anderson and Michael Bury, 156–76. London: Unwin Hyman.
- Scambler, Graham, and Anthony Hopkins. 1990. "Generating a Model of Epileptic Stigma: The Role of Qualitative Analysis." *Soc Sci Med* 30 (11): 1187–94.
- Schutz, Alfred. 1953. "Common-Sense and Scientific Interpretation of Human Action." *Philos Phenomenol Res* 14 (1): 1–37.
- Schutz, Alfred. 1967. *The Phenomenology of the Social World*. Trans G. Walsh and F. Lehnert. Evanston: Northwestern University Press.
- Schutz, Alfred. 1970. *On Phenomenology and Social Relations: Selected Writings*. Ed. H. R. Wagner. Chicago: University of Chicago Press.
- Stoeckle, John D., Irving K. Zola, and Gerald E. Davidson. 1963. "On Going to See the Doctor: The Contributions of the Patient to the Decision to Seek Medical Aid: A Selective Review." *J Chron Dis* 16: 975–89.
- Stoeckle, John D., Irving K. Zola, and Gerald E. Davidson. 1964. "The Quantity and Significance of Psychological Distress in Medical Patients: Some Preliminary Observations About the Decision to Seek Medical Aid." *J Chron Dis* 17 (10): 959–70.
- Strauss, Anselm, et al. 1984. *Chronic Illness and the Quality of Life*. 2nd ed. St Louis: Mosby.
- Walsh, George. 1967. Introduction to Alfred Walsh, *The Phenomenology of the Social World*. Trans G. Walsh and F. Lehnert. Evanston: Northwestern University Press.
- Ward, Andrew. 2006. *Kant: The Three Critiques*. Cambridge: Polity.
- Weldon, Thomas D. 1958. *Kant's Critique of Pure Reason*. 2nd ed. Oxford: Clarendon.
- Wiener, Carolyn L. 1975. "The Burden of Rheumatoid Arthritis: Tolerating the Uncertainty." *Soc Sci Med* 9 (2): 97–104.
- Williams, Gareth. 1984. "The Genesis of Chronic Illness: Narrative Reconstruction." *Sociol Health Illn* 6 (2): 97–104.
- Williams, Simon. J., and Michael Calnan. 1996. *Modern Medicine: Lay Perspectives and Experiences*. London: UCL Press.
- Wing, John K., Paul Bebbington, and Lee N. Robins. 1981. *What Is a Case? The Problem of Definition in Psychiatric Community Surveys*. London: Grant McIntyre.
- Zola, Irving. K. 1982. *Missing Pieces: A Chronicle of Living with a Disability*. Philadelphia: Temple University Press.