

RUNNING HEAD: Everyday Illness Understanding

Understanding Illness in Everyday Life

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Abstract

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### Introduction and Objectives

You awaken one morning feeling queasy and with a terrible headache. Although nausea and headache are unpleasant physical symptoms, they are not highly distinctive; they *could* indicate a variety of problems. Understanding what your symptoms signify requires you to sort through the possibilities. Let's list a few, keeping in mind that many others could be added to the list:

Did you have dinner last night with friends at the newest restaurant in town? Maybe your symptoms have been caused by a food-borne contaminant. If you learn that others in your dinner party have similar symptoms, then you'll feel more confident that contamination explains your feelings.

On the other hand, if you went to an off-campus party last night and overdid it a bit, you might conclude you're experiencing a hangover.

Another alternative is that you've contracted the flu virus that's been going around campus. You've had contact with fellow students who've had it, and the symptoms certainly fit the descriptions you've heard.

Yet another is that you have a chronic disease, such as diabetes, and your symptoms are the same ones you always have when there's a medication problem.

Yesterday a friend told you that your romantic companion has been seeing someone besides you, and you went to bed feeling confused and hurt.

The list illustrates that most of us begin the illness explanation process by trying to link our symptoms with *recent* events or activities. We rarely ask whether our symptoms might have been caused by something that happened months (or years) ago. It also illustrates our tendency to concentrate upon *physical* causes. We expect illness to be caused by things we've ingested or touched. This contrasts with many traditional cultures, in which symptoms and illness may be attributed to such supernatural causes as divine retribution for evil acts, tests of moral character, and malevolent curses. Third, our list shows that

illness explanations almost invariably involve *comparisons*; we compare our current feeling-state with past states, with information gathered from other people, and with abstract ideas gleaned from personal experience, family, and media about "typical" disease symptoms. Finally, we generally *normalize* our symptoms; we interpret them as relatively benign, rather than as life-threatening ("Oh my God! A brain tumor and stomach cancer!"). The larger point is that illness explanations are neither haphazard nor idiosyncratic, but rule-governed. In this chapter, I shall use the term **explanatory models** in referring to the informal assumptions, beliefs, and knowledge people use to make sense of illness in everyday life. This term was coined by Kleinman (1988), a medical anthropologist who is also a medical doctor. Near synonyms include *implicit* or *common-sense models* and *lay explanations*, but Kleinman's term is widely accepted by scholars in a variety of fields.

Explanatory models for illness resemble the formal diagnostic systems of medical scientists and practitioners, in that both help to identify health problems and facilitate decision making about treatment. Everyday explanations incorporate and are shaped by concepts from mainstream medical science; I say I've been "infected by a flu virus," not that I've "lost my soul" (Salmon, 2006; Shorter, 1992). Still, I've neither seen a flu virus nor understand how it works, so my self-diagnosis is at best an educated guess based on my faith in medical science and the resemblance of my symptoms to those that seem typical for flu. Our grasp of medical concepts is fragmentary, so explanatory models fill gaps in our formal knowledge and direct our attention selectively to certain categories of causes for illness. Our everyday explanations both overlap *and* conflict with the formal systems of medical science (Slaughter, Keselman, Kushniruk, & Patel, 2005).

Explanatory models are of interest in themselves, because of what they can reveal about people's thought processes. Most illnesses are unpleasant and some are genuinely frightening, so explaining them has an emotional urgency that differs from, say, understanding the causes of World War II. In the context of health studies, explanatory models are important because they link individual experience to health behaviors and social relationships. If you decide your headache and nausea are the predictable results of excessive partying, you'll treat the symptoms in very different ways than if you've made a flu attribution.

Moreover, social effects vary with the explanations we adopt: a hangover probably does not excuse you from a scheduled exam, but neither does it obligate you to warn friends that you may be infectious. On the other hand, attributing your symptoms to flu entitles you to an excused class absence and simultaneously requires you to avoid contact with other people.

### Chapter Objectives

One purpose of this chapter is to provide a historic overview of the explanatory models of illness of people from European and North American cultures. Explanatory models are not invented anew each generation but rather are passed along and gradually mutate; there are continuities between the ways people thought about illness in past times and contemporary thinking. Another objective is to describe a specific approach to studying explanatory models, *the common sense model of illness representations* (Leventhal, Brissette, & Leventhal, 2003).

Finally, we'll look at the influence of *mind/body dualism* in illness explanations: our tendency to distinguish mental/psychological causes from physical/ physiological causes for illness. Dualism affects how seriously we take people's illness reports and even our recommendations for medical treatment.

### Explanatory Models in Historic Context

Illness invites people to engage in explanatory speculation. They want to know why and how illness befalls them, and what to do about it. Thus, we find evidence of such speculation throughout recorded history. Reviewing this record, we should be on guard against seeing it as a story of the ignorant, superstitious beliefs of past times. It may be convenient to think of history as a series of "ages" or "eras," but of course there are no dividing lines that absolutely distinguish ancient from modern times. Seemingly ancient beliefs persist in contemporary explanatory models, albeit in updated forms that take current knowledge into account. Moreover, when we use *science* as the standard for assessing illness explanations of bygone times, we should remind ourselves that many scientific beliefs of 100 years ago – or even 20 years ago – have been replaced; for example, a bacterial infection has been implicated in the majority of stomach ulcer cases, but it has taken years for the role of *heliobacter pylori* to be accorded equal weight

to the more traditional view that ulcers are induced by stress (Thagard, 1999). The standards science provides us constantly change.

As noted earlier, educated Americans rarely invoke **supernatural explanations** for illness, but this has not always been true. Sinfulness has long been blamed for inviting divine wrath in the guise of individual illness and epidemic disease (Brandt & Rozin, 1997; Thomas, 1997), and divine will has often been the answer to questions about why specific persons are visited by illness or escape it. However, one characteristic of the Western tradition of thought is our belief that events are governed by natural laws – *naturalism*. Therefore, we tend to think that divine purposes are implemented through the processes of nature.

Still, contemporary Americans are neither universally nor absolutely reluctant to identify supernatural causes for illness; sometimes, it depends on how researchers ask the question. Landrine and Klonoff (1994) found that California college students rarely cite supernatural forces when asked to *list the causes* of illness spontaneously. The researchers then provided the same students a new list of illness causes and asked them to *rate the importance* of each one. The new list specifically included such items as "sinful acts," "punishment from God," and "lack of faith," in addition to "diet," "exhaustion," and "worry." The "how important" format elicited surprisingly strong endorsements for divine, mystical, and even sorcery-based explanations. Latino and African-American students were most likely to endorse such explanations, but 20 to 30% of students who self-identified as White also assigned an important role to some supernatural causes. This suggests that when people think it's socially acceptable, they're quite willing to attribute illness to the supernatural.

Based on its sheer longevity in the history of Western thinking about illness, the **humoral theory of disease** is the premier "natural" viewpoint. Humoralism dates at least to the 5th century B.C. in Greece, and versions persisted as formal medical doctrine until the mid-19th century (Helman, 1990; Schober & Lacroix, 1991; Shorter, 1992; Thagard, 1999; Thomas, 1997). According to this theory, disease is caused by imbalances in the amount and flow of four bodily fluids ("humors") known to ancient people: blood, phlegm, yellow bile, and black bile. Medical treatment, therefore, was aimed at correcting the supposed

imbalance. The practice of bloodletting to cure illness is an example of one such treatment, and Philadelphia physician and Dickinson College co-founder Benjamin Rush was a staunch advocate (Stanovich, 2007). The cliché, "Feed a cold, starve a fever," is a holdover from humoral theory (Helman, 1990). Symptoms of the common cold suggested that the body was suffering from an excess of phlegm, a "cold" humor, so it was believed balance could be restored by ingesting warm liquids, such as soups and teas. Fever supposedly indicated the person had overabundant yellow bile, a hot humor, and food was thought to compound the excess by fueling the internal fires of digestion controlled by the gall bladder.

Versions of humoral theories are found not only in the Western tradition of thinking about illness but also in ancient India and in Chinese medicine (Helman, 1990). A common theme in all these explanatory models is an emphasis on *balance* among bodily substances and forces, a theme that continues today. We worry whether our diet is balanced, and sometimes blame illness episodes on failures to maintain a proper balance between sedentary behavior and physical activity.

Complementing humoral theory was the belief that illness results from inhaling the noxious fumes arising from swamps, decomposition, and rot: **miasma theory**. Whereas imbalanced humors were thought to cause individual illnesses, epidemics were attributed to miasmas (Thomas, 1997). The practice of fumigation, or burning substances to conceal bad smells, was adopted in cities during medieval plague outbreaks (Tesh, 1988). The sickness that caused tourists to evacuate and ultimately claimed the life of Gustave Aschenbach in Thomas Mann's (1930) novella, *Death in Venice*, was laid to the sirocco winds blowing across the Mediterranean Sea from North Africa. Tesh (1988) points out that miasmatic thought gradually was assimilated into alarm about industrial pollution in Dickensian Britain and can be heard as an echo in contemporary concerns about environmental illness. In contrast to the vile odors of miasmas or the smoky pall we associate with 19<sup>th</sup> and early 20<sup>th</sup> century industry, however, today's environmental health threats seem more insidious: colorless, odorless toxins that seep into soil and water, invisible electromagnetic radiation, or contamination of food during its production or preparation (Tesh, 2000).

**Contagion** explanations for illness were popular long before the biological sciences identified how disease could be transmitted between organisms, as was the practice of inoculating the healthy to

prevent disease (Copp, 1989). The concept of contagion shares with miasma theory the belief that illness-producing agents are spread by physical contact. The contact might be between the individual and an unseen substance carried on a noxious wind, or the body and belongings of a sick person. Both theories are physicalistic, but neither denies the possible existence of invisible agents that can transmit sickness. The physicalism of contagion and miasma theories helped provide the intellectual basis for bacteriology, virology, and environmental toxicology.

Interestingly, contagion was rejected by many medical practitioners of the 18<sup>th</sup> and 19<sup>th</sup> centuries, not because of the absence of scientific verification but rather because contagion beliefs were regarded by many physicians as prejudicial and xenophobic; merchants denounced contagion theories and the quarantines associated with them as disruptive of trade (Tesh, 1988). Since the mid-19<sup>th</sup> century, however, scientists have been increasingly successful in understanding the mechanisms of bacterial infection and its transmission from carriers to new hosts. More recently, scientific knowledge has expanded to include viruses and other biological agents that transmit disease. Nevertheless, contagion beliefs of well-educated Americans owe as much to ancient laws of sympathetic magic as to modern biomedicine (Nemeroff & Rozin, 1994). For example, college students and their parents expressed greater reluctance to try on a freshly-cleaned sweater or drive a car that had once been owned by a man with AIDS than by an unspecified male (Rozin, Markwith, & McCauley, 1994). The explanatory model of disease transmission revealed by such studies is, essentially, pre-scientific.

Still another class of historic explanations revolves around personal behavior or, as we would now call it, **lifestyle**. Defining individuals' behavior as a causal factor in illness went hand-in-hand with humoral theory, because food, drink, exercise, and moods were thought to affect the balance among humors (Schober & LaCroix, 1991). The ill were counseled by humoralist physicians to reduce their "intemperate" behavior, such as excessive eating or passionate indulgence, so as to restore balance and hence health (Thomas, 1997). Such behavioral theories inevitably incorporated moral concepts (Brandt & Rozin, 1997; Tesh, 1988). If illness can be caused by the individual's own, modifiable actions, then illness may be the foreseeable result of the individual's personal, moral defects – essentially, the individual's own

fault. Lifestyle explanations for illness are linked with moral censure in our contemporary attitudes toward persons with AIDS (Skelton, 2006), smokers (Gibson, 1998), fat people (Crandall & Schiffhauer, 1998), and alcoholics.

Until very recently, physicians were themselves a luxury available only to the most privileged classes, and the advice they gave presupposed that patients had the means to overindulge and thus could also change their lifestyles at will (Tesh, 1988); lifestyle was a viable explanation for illness only among the rich. However, since the 1950s lifestyle has emerged as a focal point for everyday explanations of illness in the US (Brandt, 1997), and it is not an accident that this period also saw rapid increases in standards of living for Americans. Although it is now a truism to say that most illnesses are caused by people's lifestyle, we should remind ourselves that this "truth" that doesn't apply when people survive by foraging or subsistence farming.

#### Current Perspectives on How People Understand Illness

Up to now, we have concentrated on the historic bases for explanatory models. In the remainder of the chapter, we look at two empirically-based perspectives on illness explanations. Each is rooted in the assumptions and methods of experimental psychology, the field with which I am most familiar. Pragmatically, this means that we deliberately compare people whose explanatory models differ, to see whether these differences are associated with outcomes that have health implication. Alternatively, we may *create* comparison conditions by varying the kinds of information people have work with, so we may observe the effect on health judgments and/or behaviors.

We'll begin by looking at a theory that aims to discover the content and structure of people's explanatory models and to examine interactions among structural elements of these models.

#### The Common-sense Model of Illness Representations

Explanatory models reflect people's "common sense" understanding of illness. One influential theory about explanatory models is actually called the **common-sense model** (CSM) because it purports to describe how people apply their everyday knowledge and reasoning to achieving an understanding of

their own illnesses. The CSM was developed by psychologist Howard Leventhal and his colleagues and evolved from their attempts to solve two practical problems faced by health educators and care providers: (1) motivating people to take precautionary health actions, such as getting inoculations or attending cancer screenings, and (2) getting individuals with chronic health problems, such as high blood pressure, to follow their recommended treatment. Traditionally, these problems have been thought to arise from patients' ignorance and poor education, their failure to grasp the severity and seriousness of health threats, or even their personality traits. Such characterizations tend to assume people are passive and uninvolved in their own health care. In contrast, advocates of the CSM adopted the assumption that people actively use information from their own experience, from their social networks, and from the larger culture to create a mental model of their illnesses (Leventhal, Nerenz, & Steele, 1984). Once a model or **representation** is formed, people take actions based on the understanding contained in the representation. If these actions produce desired outcomes, people feel their representation is valid; if actions are unsuccessful, however, they may doubt the accuracy of their initial representation and change one or more of its elements to generate a new set of actions. But what are the elements of an illness representation? <sup>1</sup>

- Identity, a set of one or more bodily symptoms (for example, fever and diarrhea), and an identifying label (e.g., flu) that names the illness.
- Cause, beliefs about why the illness has occurred. Is it because of contact with an infected family member or environmental toxins? Has it been brought on by overwork or other strains, which have undermined one's resistance to pathogens? Is it the result of bad genes?
- Timeline, beliefs about the temporal course of the illness. Is it an acute problem that will be resolved by treatment or by the passage of a few days? Or is it perhaps a long-term, chronic illness that will worsen over time? Will it wax and wane, going through periodic cycles?
- Controllability, beliefs about the curability or, at least, the manageability of the illness. For infectious diseases with which Western middle-class people are most familiar, curability beliefs

are strong. For many chronic conditions, the major issue is how to manage the illness – to retard its progress, to adjust oneself to the changes it requires in one's habits, etc.

- Consequences, people's answers to such questions as, what will be the effect on me of this illness? Will it prevent me from completing a work assignment or joining the family vacation? Will it require mutilating surgery? Will it force me to retire earlier than I planned? Some consequences may be immediate; others may be anticipated over the long run.

Changing any component of the representation influences other components. The identity of a cough that was first thought to be a bronchitis episode is transformed when it persists for several weeks. The timeline has changed, so causal explanations and potential cures that applied to an acute episode are no longer plausible. The person wonders and worries about what the cough signifies – both its identity and its consequences.

The headache and nausea example used in the introduction to this chapter illustrated the search for identity and cause that accompanies a symptom episode. It also showed that we generally assume that symptoms are related to recent events. Using CSM terms, our timeline generally has a default setting of "acute" for newly-experienced symptoms. Our tendency to assume symptoms signify an acute illness is rooted in personal experience. Most childhood illnesses begin quickly and have a short time course. We may visit a doctor for treatment that reduces the discomfort associated with our symptoms, and once symptoms no longer bother us, we are "well" (Leventhal *et al.*, 1984). Unfortunately, the expectations generated by these experiences do not serve so well in cases of chronic illness.

For example, persons who are newly-diagnosed with hypertension (high blood pressure) tend to drop out of treatment if they think hypertension is an acute disease (Meyer, Leventhal, & Gutmann, 1985). High blood pressure is a silent, asymptomatic condition; people cannot reliably tell that their blood pressure is elevated by sensing bodily changes. This leads to two patterns of dropping out of treatment. First, individuals who do *not* associate symptoms with blood pressure elevations can rely only on feedback from objective blood pressure measures, not symptom remission, to assess whether treatment is successful. Thus, when the family doctor praises them after a month's treatment for having lower blood

pressure, they conclude the illness has been cured by medication and diet; they now are "well" and need no further treatment, a conclusion that makes sense in light of previous illness experience.

In the second pattern, those who *do* associate specific symptoms with blood pressure may drop out if treatment *fails* to eliminate these symptoms; the conclusion, why continue a treatment that doesn't make you feel better?, also fits with prior experience. In both cases, the person's representation of the illness assigns it to an acute timeline, but this doesn't fit the biomedical understanding of hypertension and its treatment and contributes to the much-lamented problem of patients failing to follow treatment.

Who *does* stay in treatment for hypertension? Individuals who stick with treatment overwhelmingly believe it has had beneficial effects on such felt symptoms as headaches. These patients readily acknowledge that "most people" cannot detect variations in blood pressure, thereby conforming to the accepted medical view; however, they regard themselves as *exceptions* to this general rule (Baumann & Leventhal, 1985). Moreover, they report varying self-treatment according to whether they are experiencing symptoms (Meyer *et al.*, 1985). When they have "hypertension headaches," they carefully take their medication and follow diet recommendations; once headaches abate, however, they may scale back their medicines. In other words, they act as if hypertension were an acute illness. Such findings highlight how central bodily experience is in people's understanding of illness.

Elderly people have more illnesses and receive more treatments than people who are younger, so the explanatory models of elders have been of particular interest in CSM research. The tendency for people to normalize symptoms is especially evident in this age group, and it leads to delays in seeking treatment for symptoms that are thought to be caused by "old age." This causal attribution makes symptoms seem normal, so treatment-seeking may be put off. A further complication is that the aging person may feel less confident that illnesses are controllable (Keller, Leventhal, Prohaska, & Leventhal, 1989). This can further decrease the person's likelihood of seeking treatment, unless symptoms are very severe (Prohaska, Keller, Leventhal, & Leventhal, 1987).

The CSM framework has been applied to many health problems, including recovery from heart attack (Petrie & Weinman, 1997), Huntington's disease (Helder, Kaptein, Van Kempen, Weinman, Van

Houwelingen, & Roos, 2002), rheumatoid arthritis, chronic obstructive pulmonary disease (COPD), and psoriasis (Scharloo, Kaptein, Weinman, Hazes, Willems, Bergman, *et al.*, 1998). Hampson (1997) reports that “controllability” beliefs are important for elders with diabetes. Those who believe treatment is effective in controlling symptoms are better able to maintain their regimen – especially the demanding diet required for diabetes control – than those who regard their condition as largely uncontrollable. Horowitz, Rein, and Leventhal (2003) recently interviewed people with congestive heart failure (CHF) and discovered that their mental representations were of an acute not a chronic illness; however, unlike people with hypertension, they did not connect their very perceptible symptoms (e.g., shortness of breath, water retention, etc.) to CHF. Because of a weak-to-nonexistent “identity” for their illness, these individuals often failed to use medicines appropriately, thereby bringing on crises requiring emergency room treatment. In summary, then, the CSM is a useful framework for clarifying how ordinary people understand and cope with illness, and it is now helping to generate interventions to improve both (Cameron & Leventhal, 2003).

### Mind/Body Dualism

In everyday thinking about illness, the boundary between mind and body, between “mental” and “physical” is blurry but important. At the same time that we recognize the brain is a physical organ, we also ask whether some symptoms and illnesses are *not* physical but rather have “psychological” causes. For example, attributing your sick headache to having learned about an unfaithful romantic partner is an instance of a psychological explanation. When we label symptoms and illness as *psychological*, we transform them into very different phenomena than when we believe they have been physically caused. They can become less real or serious, as is implied by such expressions as “it’s all in your mind,” or “*just* psychosomatic.” In this dualistic explanatory framework, *real* illness has physical causes; when there are doubts about physical causation, there are inevitably doubts about the validity of a person’s claim to be ill.<sup>2</sup>

There is a physicians’ cliché dating back many centuries claiming that many (perhaps most) doctor visits are made by people who are not “really” sick. If it has a grain of truth, then what could

explain doctor visits for symptoms that turn out to have no clear-cut medical cause? First, some (unknown) fraction of unexplained symptoms actually are *diagnostic failures*. In these cases, the doctor's inability to explain reflects genuine limitations of medical science; as another cliché states, "Absence of evidence is not the same as evidence of absence." Still, it's unlikely that diagnostic failure is the whole story.

Another possibility is *misattribution of symptoms*. As stated at the beginning of the chapter, symptoms often are ambiguous. People in general are not very good at identifying specific bodily sources of symptoms, and we can be led to identify "symptoms" that result from normal, physiological background activity (Skelton & Pennebaker, 1990). A further complication is that our bodies have only a limited supply of reactions that we can sense consciously, and these reactions have several possible causes. How different does hunger feel from a "nervous" stomach? How different is the flush of embarrassment or anger from a fever? Feelings alone may be insufficiently distinctive, so our explanations may draw heavily upon cues we pick up from the surrounding environment. If those cues prompt us to think we are ill, we may seek medical attention.

Besides the susceptibility of each of us to symptom misattribution, we also acknowledge that some individuals seem more ready to interpret bodily experience as signifying an illness. Most of us, most of the time interpret physical sensations as benign; we *normalize*. However, each of us probably knows a least one person who bucks the general trend by *somatizing*, or labeling most symptoms as illness-related (Moss-Morris & Wrapson, 2003). Physicians' claims about needless medical visits may reflect their experiences with individuals who somatize.

Our intuitive understanding that symptoms *are* ambiguous is evident in our reactions when a symptom has alternative explanations. For example, people are less likely to seek treatment for ambiguous symptoms that occur in conjunction with short-term life stresses than when stress is prolonged or symptoms are obviously medical. In these cases, "stress" serves as an alternative explanation for symptoms (Baumann, Cameron, Zimmerman, & Leventhal, 1989; Cameron, Leventhal, & Leventhal, 1995). The availability of alternate explanations also affects how we assess *other people's* symptoms. In

several separate investigations, I asked students to read case descriptions of a peer who reports having a sore throat and a congested nose. In some of the cases, the peer was also described as having a heavy load of schoolwork, problems with a romantic partner, and/or sleep disturbances (Skelton, 1991; 1995). In these cases, students rated the peer's health problem as less credible and less physically caused than when no stresses were mentioned. They did this even when the case description stated explicitly that the peer had tested positive for a strep infection.

Finally, somatization-related stereotypes also influence reactions to others' symptoms. In the US, it is widely believed women are more likely than men to interpret ambiguous symptoms as being illness-related; even women themselves hold this belief. Martin and Lemos (2002) combined this stereotype with the tendency to discount illness claims that are accompanied by stress. They found that people who read a case description of a woman who had chest pains and concurrent life stress were less likely to recommend that she seek treatment than people who read a case of a man with identical symptoms and stress. Apparently, somatization stereotypes about women made people doubt that the woman's symptoms were cardiac-related. Given the growing incidence of heart disease among women, misusing a gender stereotype in informal diagnosis could have catastrophic effects.

### Conclusions

The key message of this chapter is that it is important to pay attention to how people explain illness. We cannot take for granted that everyday illness explanations are based on a valid scientific understanding of disease, because our explanatory models are *not* concerned with the question, what disease process is at work in this case? Instead, we want answers to a much more personal question: why do I feel this way? Whereas disease is about biology, illness is about one's *experience* (Radley, 1994). People's understanding of illness – even when it is scientifically ill-informed – forms the basis for their health-related choices and actions. Therefore, if we hope to develop effective health policies, educational programs, and interventions, it is crucial that we take these understandings seriously, on their own terms.

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## Notes

1. Some of the material in this section is adapted from "Cognitive Representations of Illness," © 2004 by Kluwer Academic Publishers. Permission to reproduce pending.
2. Dualism is a metaphysical position well-known to philosophers and theologians. I cannot address its underlying assumptions or its basis in human language and experience in the available space. Instead, I have chosen to focus only on the implications of dualistic thinking for the understanding of illness.