

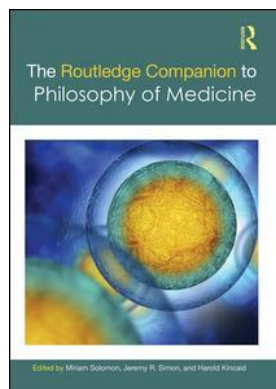
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2

DISEASE, ILLNESS, AND SICKNESS

Bjørn Hofmann

Background

There are many heated debates about the concept of disease: Is aging a disease? What about obesity, electromagnetic hypersensitivity, insomnia, and grief? How can we understand myalgic encephalomyelitis, chronic fatigue syndrome, and Lyme disease? In such cases, we often confer with definitions of disease to decide. However, as shown in Chapter 1, it is much more difficult to define disease (the general concept) than we might think at first sight. (It is also difficult to define particular diseases, and this is the topic of Chapters 16 and 17.) There are many diverging definitions of *disease*, and it is difficult to make a coherent and consistent synthesis. One of the reasons for this may be that our conception of disease is complex, comprising various dimensions of human malady (Hofmann, 2001). For example, it is covered by a personal perspective—i.e., how it feels to be ill (*illness*); a professional perspective—i.e., how health care professionals define, detect, predict, and handle disease entities (*disease*); and a social perspective—i.e., how a person's social role is defined or changed by social norms and institutions (*sickness*). These perspectives focus on different phenomena and entities, they comprise different types of knowledge, and they call for different actions from health care professionals. This can explain some of the controversies over the concept of disease (see Chapter 1) and help to reduce the complexity. At the same time, the perspectives have challenges of their own. The goal of this chapter is to introduce a more precise sub-classification of the general concept of disease into three parts: disease (strictly speaking), illness, and sickness. *Malady* will be used as a generic term covering a wide range of terms, such as disease, illness, sickness, but also injury, lesion, defect, disorder, deformity, disability, impairment, infirmity, etc. (Clouser et al., 1997, Sadegh-Zadeh, 1981, 2000). Accordingly, the objective of this chapter is to explore the three prominent perspectives on human malady: disease, illness, and sickness.

Defining the Triad *Disease, Illness, and Sickness*

The distinction between *illness* and *disease* has been noted in the theoretical literature on medicine since the 1950s (Parsons, 1951, 1958, 1964). The sociologist Andrew Twaddle was the first to elaborate on the distinction among disease, illness, and sickness in his doctoral dissertation defended in 1967 (Twaddle, 1968, 1994a, 1994b). The distinction has since become commonplace in medical sociology, medical anthropology, and philosophy of medicine. (For the literature on various perspectives on human malady, see for example, Boyd, 2000, Engelhardt & Wildes, 2004, Fabrega, 1972, 1979, King, 1954, Marinker, 1975, Parsons,

1951, Roths Schuh, 1972, Sedgwick, 1973, Susser, 1990, Taylor, 1979, Von Engelhardt, 1995, and Young, 1995.) The triad *disease*, *illness*, and *sickness* has been elaborated and more strictly defined (Susser, 1990, Twaddle, 1994a, 1994b), but also challenged (Nordenfelt, 2007, Twaddle, 1994b).

As can be seen in Chapter 1, there is still debate on how to define *disease*. The same goes for *illness* and *sickness*. However, there is substantial agreement that physiological, biochemical, genetic, and mental entities and events are the basic phenomena of *disease*, and most definitions contend that *disease* can be observed, examined, mediated, and measured, and is objective in this sense. It is also the target of health professionals who want to classify, detect, control, and treat *disease*, ultimately in order to cure.

Illness, on the other hand, has emotions and experience, such as anxiety, fear, pain, and suffering, as its basic phenomena. Although *illness* is in this sense subjective, it can be argued that we can have access to another person's illness through his or her verbal reports of introspection (phenomenology; Carel, 2013, 2014a, Svenaeus, 2014, Toombs, 1990), through a common language (the philosophy of language; Hofmann, 2015), or through brain states (Daniel, 1991). For example, illness is characterized in terms of bodily and/or mental awareness and a feeling of estrangement, unpleasantness, or uncanniness (Carel, 2014b). Health professionals' aim with regard to *illness* is comfort, care, and/or relief of suffering.

Sickness, on the other hand, has expectations, conventions, policies, and social norms and roles as basic phenomena (Susser, 1990). Its criteria are discovered through social interaction, participation, and social studies. Accordingly, the knowledge about *sickness* is inter-subjective (i.e., it is knowledge shared by a social group). *Sickness* determines whether a person is entitled to treatment and economic rights, exemption from social duties, such as work (sick leave), but also whether a person is legally accountable for his or her actions. In such matters, *sickness* is established and governed by formal structures, such as social institutions (including laws). However, *sickness* can also be framed by overt or covert norms, which give diseases different prestige and render them stigmatizing or discriminating. For example, myocardial infarction has a higher prestige than fibromyalgia among medical doctors (Album and Westin, 2008); the fact that homosexuality was classified as a disease for many years was experienced as stigmatizing; and obesity can lead to discrimination in health care and society at large (Hofmann, 2010, Puhl and Heuer, 2009, Wilt et al., 2010).

All aspects of *sickness* do not apply all the time (e.g., hypertension found by a health check qualifies for treatment and additional check-ups, but not for sick leave). As *sickness* is constituted by social norms, *sickness* may vary from place to place. For example, pelvic girdle pain qualifies for sick leave in Norway but not in other countries (Dorheim et al., 2013). Moreover, although *sickness* is a societal construct, it is important to notice that both patients and health professionals are social agents influencing *sickness*. For example, health professionals are involved as gatekeepers and sometimes as "rescuers." At the beginning of the 20th century, health professionals argued that making homosexuality a disease would save it from being a social stigma (Hofmann, 2014).

Hence, the concepts of *disease*, *illness*, and *sickness* highlight different perspectives on important aspects of human life. These concepts reflect medical professional, personal, and social perspectives, respectively. Furthermore, *disease*, *illness*, and *sickness* are primarily negative notions (i.e., they refer to occurrences in human life of negative value). They may, however, also have positive aspects, such as increased attention, justified work absence, or economic support (Hofmann, 2014), but the positive aspects of human malady are beyond the scope of this chapter.

Moreover, each concept calls for action. *Disease* calls for actions by health professionals with the goals of identifying, treating, and handling the entities and events and to care for the person. *Illness* changes the self-concept, relationships, and activities of the individual (e.g.,

Table 2.1 Different perspectives of human malady: Disease, illness, and sickness investigated

| | <i>Disease</i> | <i>Illness</i> | <i>Sickness</i> |
|---|---|---|---|
| Field, Area, Primary agents/ stakeholders | Profession, medical and other health care professions | Personal, (experiential, existential) | Society, social institutions, health policy makers, lawyers |
| Basic phenomena | Physiological, mental, genetic, environmental entities or events | Subjective experience, first-person negative experience, suffering, pain | Social conventions, norms, roles (including social prejudice) |
| Access to phenomena through: | Observations, examinations, measurements (by the natural sciences and by the use of technology) | Introspection, intuition (phenomenology), interaction (language), mental states (psychology) | Participation, interaction, social (science) studies |
| Knowledge status | Objective | Subjective | Inter-subjective |
| Altruistic approach | Cure | Care | Resource allocation, justice |
| Entitles to: Results in: | Examination, diagnostics, treatment | Attention, support, moral and social excuse, reduced accountability | Economic support and compensation, sick leave, but may also result in discrimination and stigmatization |

making the person call for help). *Sickness* is a determination of the social status of the person being sick, in particular, with regard to entitlement to treatment and economic rights and exemption from social duties, such as work (sick leave).

Table 2.1 gives a summary of the main features of the three perspectives on human malady (i.e., most definitions of *disease*, *illness*, and *sickness* include such features).

Applying the Triad to Cases from Clinical Practice

Disease, *illness*, and *sickness* are neither mutually exclusive nor exhaustive. They are interrelated and partly interdependent, but there are no necessary connections among them. Although they frequently occur conjoint, they all can occur without the others. Figure 2.1 illustrates the relationship among the three concepts of the triad.

This triad can help clarify some of the issues in the philosophy of medicine (e.g., to address some challenges with naturalist and normativist definitions of disease). Descriptive or naturalist theories of disease have been accused of making pregnancy, excellence, and homosexuality into diseases (Boorse, 1975, Cooper, 2005, Zachar and Kendler, 2012). On the other hand, normativist or nominalist theories are charged with making ageing, shyness, and sadness into diseases (Horwitz and Wakefield, 2007). In the following section, some specific cases will be addressed to illustrate the potential fruitfulness of the distinctions among *disease*, *illness*, and *sickness*.

The paradigm case in health care is when a person feels *ill*, the medical profession is able to detect and treat *disease*, and society attributes to him the status of being *sick*. *Illness* alters the person's situation, explains it to himself, and calls for care, *disease* permits medical explanation,

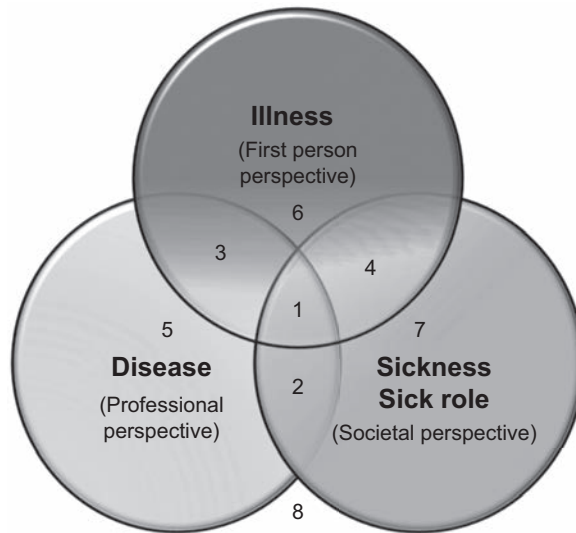


Figure 2.1 Visual outline of the triad disease, illness, and sickness (Hofmann, 2002)

attention, and action and *sickness* frees him from ordinary duties of work and gives him the right to economic support (case 1 in Figure 2.1). Examples of such conditions are numerous. Ischemic heart disease, stroke, chronic obstructive pulmonary disease (COPD), and lower respiratory infections are but three examples that top the World Health Organization's list of leading causes of deaths worldwide (2000 and 2012). There is no disagreement on such cases. Here negative bodily occurrences as conceived of by the individual correspond with negative bodily occurrences recognized by the medical profession and by relevant social institutions. Hence, cases of *disease*, *illness*, and *sickness* are paradigm cases of human malady and of health care.

Less agreement may occur when only two of the perspectives coincide (e.g., instances of conditions that satisfy the criteria for both *disease* and *sickness*, but not for *illness*; case 2 in Figure 2.1). For example, there are conditions in which certain signs or (bio)markers are identified by the medical profession before the patient experiences any illness and which leads to an entitlement to treatment and economic support (*sickness*). High blood pressure (without symptoms), human papilloma virus (HPV), pre-diabetes, biomarkers for Alzheimer's disease, ductal carcinoma in situ (DCIS), and other conditions found by screening, predictive testing, or as incidentalomas belong to this group. The professionals are confident that they are dealing with *disease*, social institutions designate the person in question as *sick*, but the person is (initially) not *ill*. The same situation can be found when patients are unconscious or have impairments recognized by the medical profession and by society, but not by the person in question.

We also have cases with instances of both *disease* and *illness*, but not of *sickness* (case 3 in Figure 2.1). Examples are the common cold and a headache after drinking alcohol. The medical profession is able to recognize these conditions as *disease* by various diagnostics, and the person in question certainly experiences them as negative, but it does not qualify as *sickness* for all, as they are expected to work (if they are not drunk).

Furthermore, there are conditions that are both *illness* and *sickness* but not *disease* (case 4 in Figure 2.1). Some cases of chronic Lyme disease, whiplash, candida, and irritable bowel syndrome (IBS) may be examples of conditions where the person certainly feels ill and society (in many countries) entitles the person to have the status of being *sick*, but where the medical

profession is not always able to identify or detect *disease*. It has been extensively debated in the medical literature and in the health insurance setting in many countries whether whiplash, as well as cases where persons are bitten by ticks but do not test positive on validated borrelia tests, have a *disease*. Correspondingly, pregnancy is commonly not conceived of as *disease* by the medical profession, although it might be experienced by many women as *illness* and accepted by society as a reason for sick leave (*sickness*).

Moreover, asymptomatic instances of hyperglycemia, hypertension (low or moderate), and various genetic mutations are examples of *disease* that are neither *illness* nor *sickness* (case 5 in Figure 2.1). The medical profession conceives of these and diagnoses them as *disease*, but the person does not experience them as such, and they do not normally qualify as *sickness*.

Correspondingly, instances of *illness* that are neither *sickness* nor *disease* (case 6 in Figure 2.1) represent cases that are experienced by the person as negative, but are neither recognized as *sickness* by society nor as *disease* by the medical profession. An intense feeling of fatigue, dissatisfaction, unpleasantness, incompetence, anxiety, or sadness might be examples. Decades ago, fibromyalgia, chronic fatigue syndrome (CFS), and myalgic encephalomyelitis (ME) also belonged to this group. Now they are commonly regarded as diseases, even though we still do not understand the mechanisms underlying them.

Cases of *sickness*, which are neither *disease* nor *illness* (case 7 in Figure 2.1) are also of great interest. Delinquency, dissidence, homosexuality, drapetomania, and masturbation may count as (historical) examples of cases in which social institutions have designated people as *sick*, but the person has not felt *ill*, and the medical profession has not diagnosed any negative bodily correlates, although some tried very hard to do so. The examples of *sickness* but not *illness* or *disease* are mainly historical examples, as we like to believe that today's society is free of such repressive actions. However, in China the members of Falun Gong have been hospitalized on the basis of their religion. Moreover, in many countries, prominent ears in children are treated without the persons feeling *ill* and the professionals necessarily thinking that they have a *disease*. Many instances of attention deficit/hyperactivity disorder (AD/HD) may also be deemed to be so in the future. Many children with this diagnosis do not feel *ill*. However, social norms for education and conduct make them *sick*. Health professionals may not find anything wrong in the children's organs or functioning, beyond their social behavior (defined by society, i.e., *sickness*).

These cases illustrate that the triad can account for controversial cases discussed in the literature. Note that these are not the only possible examples and that the cases may be interpreted otherwise (e.g., due to variations in professional knowledge and social norms with place and time). The point is that the concepts of *disease*, *illness*, and *sickness* represent a framework for analyzing controversial cases and for explaining controversies (i.e., several of the controversies result from conflicting perspectives of important stakeholders).

Epistemic and Normative Consequences

Accordingly, cases incorporating *disease*, *illness*, and *sickness* (case 1 in Figure 2.1) are not epistemically (or normatively) problematic. The person has some negative bodily or mental experience making him/her request help, the medical profession recognizes certain signs and (frequently) knows what can be done, and society and its institutions entitle him/her to treatment, economic support, and a release from certain obligations like work.

The three kinds of cases, in which only one member of the triad is applicable (cases 5, 6, and 7 in Figure 2.1) are quite challenging. First, when the medical profession classifies a condition as a *disease*, but the patient does not feel any *illness* and society does not find any reason to

change his/her social status (case 5), both epistemic and normative difficulties result. How can we know that people with asymptomatic diseases will actually develop symptoms and become ill? Should people with low or moderate hypertension be subject to extensive treatment? Is sickle cell trait a matter of the same medical concern in areas with malaria as without? Is a person with lactose intolerance only sick if he/she lives in areas where dairy products are part of the traditional diet? Can it be right to treat polydactylism and obesity if it does not bother the person?

Situations in which a person experiences *illness*, but no *disease* has been found, and where there is no change in one's social status (case 6 in Figure 2.1), also are challenging. Epistemically, it is difficult for the medical profession to uncover the cause of the person's suffering. Normatively, it is hard to see what society ought to do in such situations. A general feeling of dissatisfaction does not normally qualify the person for medical care or economic support. On the other hand, medicine has been criticized for medicalizing a wide range of everyday experiences. Moreover, aspirations to handle all cases of illness are also limited by resource allocation and prioritization.

Cases of *sickness* that are neither *disease* nor *illness* (case 7) are challenging and may even be dangerous. Drapetomania (a "disease" that made slaves run away; Bynum, 2000), masturbation, homosexuality, and political dissidence are crude examples where society (with or without its institutions) has deemed the conditions as *sickness*. There appears to be no professionally accepted diagnostic criteria in these cases (any longer). The epistemic and moral norms that entitled a person to be *sick* in these cases have later been changed.

Hence, cases where only one member of the triad applies certainly call for special attention. However, cases in which two of the three apply (cases 2, 3, and 4 in Figure 2.1) *may be* epistemically and normatively challenging as well. First, cases of both *disease* and *illness* but not of *sickness* (case 3) are subject to pressure from professionals and patient interest groups (and industry) for support. There may be several reasons why the status of *sickness* is not granted, even though the person has both *disease* and *illness*, such as lack of resources, commonness, or where no treatment is available. Myopia and tooth decay are examples of cases that are not conceived of as *sickness* in many countries with "universal coverage," but are acknowledged to be *disease* by the medical profession and are experienced negatively by persons with these conditions. The epistemic challenge is to find effective and efficient cures, whereas the normative challenges are connected to questions of priority setting and to cases in which people are not able to pay for health care services themselves.

Second, cases of both *illness* and *sickness* but not of *disease* (case 4) put pressure on the medical research community to find mechanisms and causes of these occurrences, which are both personally experienced and economically supported. Low back pain, medically unexplained physical symptoms (MUPS), and sorrow may serve as examples. The etiology of and treatment for these conditions are not commonly agreed upon. They have, however, been accepted in various countries as *sickness*, and people certainly claim to experience them as *illness*. There is pressure on the medical establishment to see these conditions as *disease* as well. There is both an epistemic challenge to establish etiology and a normative challenge to find a treatment, since such conditions ought to be treated.

Third, cases of both *disease* and *sickness* that are not *illness* (case 2) generate some profound challenges. Epistemically, we are challenged by the question of whether a person will actually become *ill* when test results indicate *disease*. Many cases defined as *disease* will not develop to *illness* if left untreated. Ductal carcinoma in situ (DCIS) is but one example. In such cases of overdiagnosis, the person may die with the condition rather than from it (Welch et al., 2011). Normatively, we are faced with a series of questions: How are we to handle the results from

screening and predictive testing? Are there limits to the treatment of asymptomatic diseases? Are we going to tell the patient about the findings? The discussion on genetic testing (including incidental finding of uncertain significance), hypercholesterolemia, and hypertension illustrates some of these normative challenges (Fanu, 1999). How far can we go in treatment of cases in which the patient is not *ill*? How is patient autonomy preserved? Who is to balance the risks and benefits of such treatment?

Hence, cases that fall outside of case 1 in Figure 2.1 (i.e., where only one or two of the triad's concepts apply) represent epistemic and normative challenges. Moreover, it may be argued that cases that belong to only one of the spheres of the triad may be more challenging than cases that belong to two. Cases are less controversial if they are recognized by two of the agents as being both *disease* and *sickness* (case 2 in Figure 2.1), both *disease* and *illness* (case 3), or both *illness* and *sickness* (case 4) than if they are only recognized by one of the agents as *disease* (case 5), *illness* (case 6), or *sickness* (case 7). That is, we appear to be more challenged by medical treatment of incompetence, dissatisfaction, homosexuality, dissidence, and low or moderate hyperglycemia than we are by the treatment of asymptomatic breast cancer, common colds, and seasickness. The pressure on medicine to accept an occurrence as *disease* is strong when it is recognized both as *illness* and *sickness*. In the same way, there is pressure on society to provide necessary resources and to admit that an occurrence is *sickness* when it is recognized both as *disease* and *illness*.

In cases of only *illness*, the ill person has to convince both the medical profession and social institutions about his or her situation. Many have found media to be helpful in this regard. Similarly, social institutions have to convince both the medical profession and the person in cases of *sickness* alone. This can be done through funding, regulation, and education. In cases of *disease* alone, both society and the person have to be persuaded (e.g., through scientific and popular publications). Thus, cases in which only one member of the triad is applicable appear to be challenging. When more perspectives coincide, the cases become less controversial.

The Dynamics Among Disease, Illness, and Sickness

The concepts of *disease*, *illness*, and *sickness* are not independent. Making something a *disease* (e.g., by making something subject to medical attention and manipulation) influences the attribution of a social status to the condition (i.e., making it *sickness*). *Infertility*, which was traditionally not considered a *sickness* in many countries, now qualifies for economic support because it became treatable as a *disease*. Conversely, many conditions, including sorrow, pregnancy, and obesity, have become *disease* because they have gained social attention (e.g., by being covered by health insurances).

Similarly, the experience of *illness* is affected by medical knowledge. The personal experience of ailment is influenced by the medical terminology (e.g., a soccer player might state that he has some pain in his *meniscus*, or a patient can feel her "large intestines a bit bound") (Nessa and Malterud, 1998). New imaging technology may also influence both *illness* and *disease* (McCabe and Castel, 2008).

Conversely, the experience of *illness* influences the activities of the medical profession. Research into lower back pain, whiplash, and myalgic encephalomyelitis (ME) was initiated by people's suffering and need for help. The status of pregnancy and childbirth as *illnesses* and *sicknesses* has made the medical establishment hospitalize pregnant women as if they were having *disease*.

Correspondingly, professionals preoccupied with *disease* are influenced by the social status and prestige of *sickness*. As already mentioned, disease entities vary greatly in their prestige

(Album and Westin, 2008). The search for a causal explanation for fibromyalgia is supported by its status as *illness* and *sickness*. On the other hand, cases of the common cold are not always accepted as *sickness* (Copeland, 1977). Furthermore, the social sphere to a large extent governs medical education and research, and the social and psychological influences on the concept of disease are clearly reflected in the influential biopsychosocial model of disease (Engel, 1977).

Moreover, the class membership of the areas may vary over time. To a person, none, one, or more of the triad's concepts may apply at the same time (Twaddle, 1994a). Even more, the membership may be complex and change with time. Both the medical professionals and ill people are members of society, and thus all influence the sphere of *sickness*. In particular, in many countries, the physician is society's gatekeeper and manages both *disease* and *sickness* at the same time. Furthermore, all members of society, whether medical professionals or not, may become *ill*. Social and behavioral criteria may also feed into professional criteria for *disease*.

The concept of disease changes with time, depends on practice, and influences medical taxonomy. Diseases are defined according to abnormalities of morphology, physiological aberrations, biochemical defects, genetic abnormalities, ultrastructural abnormalities, and etiologic agents (Copeland, 1977), technology (Hofmann, 2013), and behavioral criteria. Hence, it has been difficult to provide a consistent medical taxonomy. There is no unified nosology (Hofmann, 2013), and the taxonomy seems to be more influenced by prognostic and therapeutic capacity than by formal definitions (Scadding, 1967). Figure 2.2 illustrates the dynamic relationship among *disease*, *illness*, and *sickness*, and Figure 2.3 illustrates the influence from various stakeholders.

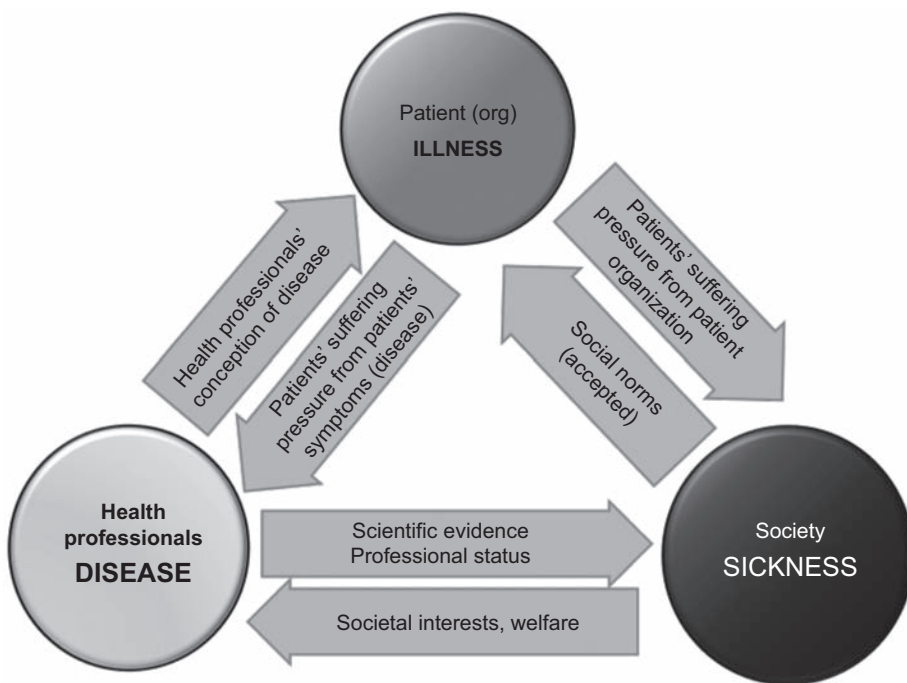


Figure 2.2 Sketch of the dynamic relationship among disease, illness, and sickness (Hofmann, 2001)

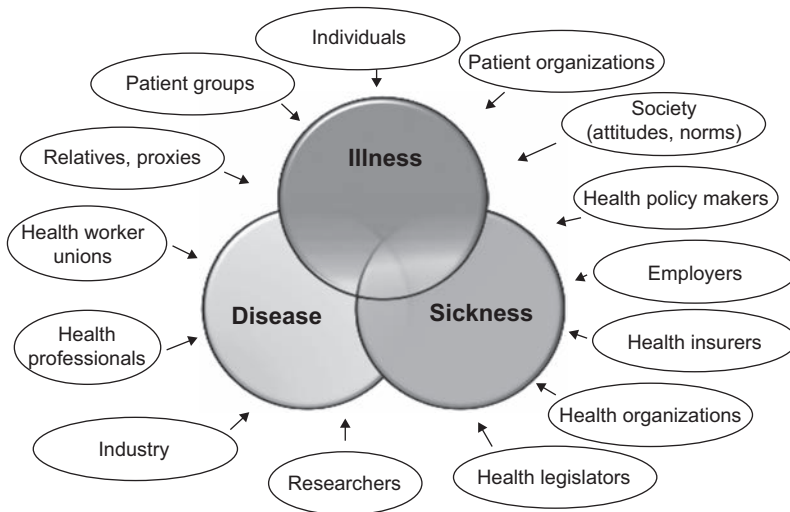


Figure 2.3 Overview of some of the actors influencing the conceptions of disease, illness, and sickness (Hofmann, 2001)

Other Perspectives

Although *disease*, *illness*, and *sickness* have been sustainable theoretical concepts referring to pertinent perspectives and providing fruitful frameworks for analyzing and addressing hard cases, it is far from obvious that they are the only relevant and fruitful concepts. One obvious candidate to add to the model is *disease risk*. Although it has been argued that risk has converged with disease, it can also be argued that disease risk is so special and influential that it warrants to be differentiated from the existing concept of *disease*.

Moreover, it may also be argued that existential aspects of human malady are special and different from *illness*, and therefore warrant a specific concept in the model of human malady. For example, Seneca wrote in his *Epistulae morales ad Lucilium* about loss of joy (*intermission voluptatum*) and fear of death (*metis mortis*).

Furthermore, it can be argued that sickness is too broad of a concept, as it includes both formalized norms, such as structures and regulations for sick leave, as well as informal norms, such as status, prestige, prejudice, stigmatization, and discrimination. It could be argued that these aspects should be differentiated into two perspectives (e.g., “warranted sickness” and “non-warranted sickness”). However, what in a specific time in history is considered to be (warranted) *sickness* by its institutions may in other times not be (warranted) *sickness*.

Although these and many other perspectives readily can be added to better explain certain aspects and challenges with human malady, they also add complexity, potentially making the model less (theoretically and practically) useful.

Conclusion

Disease, *illness*, and *sickness* are three interrelated concepts that refer to three pertinent perspectives of human malady (i.e., the professional, the personal, and the societal perspectives). They provide a fruitful framework for explaining and addressing several of the epistemic and moral challenges in the philosophy of medicine and in clinical practice.

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