

Acknowledging and addressing the many ethical aspects of disease

Author:

Bjørn Hofmann^{1,2}

b.m.hofmann@medisin.uio.no

¹ Department of Health Sciences, Norwegian University of Science and Technology (NTNU), Gjøvik, Norway

² Centre of Medical Ethics, University of Oslo, Oslo, Norway

Corresponding author at: Bjørn Hofmann,
Centre for Medical Ethics
Faculty of Medicine
University of Oslo
PO Box 1130, Blindern
N-0318 Oslo, Norway

b.m.hofmann@medisin.uio.no

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Acknowledging and addressing the many ethical aspects of disease

Abstract:

Diseases change the life of individuals, the social status of groups, the obligations of professionals, and the welfare of nations. Disease classifications function as a demarcation of access to care, rights, and duties. Disease also fosters social stigmatization and discrimination, and is a personal, professional, and political matter. It raises a wide range of ethical issues that are of utmost importance in patient communication and education. Accordingly, the objective of this article is to present and discuss a range of basic ethical aspects of this core concept of medicine and health care. First and foremost, disease evokes compassion for the person suffering and induces a moral impetus to health professionals and health policy makers to avoid, eliminate or ameliorate disease. The concept of disease has many moral functions, especially with respect to attributing rights and obligations. Classifying something as disease also has implications for the status and prestige of the condition as well as for the attitudes and behavior towards people with the condition. Acknowledging such effects is crucial for avoiding discrimination and good communication. Moreover, different perspectives on disease can create conflicts between patients, professionals and policy makers. While expanding the concept of disease makes it possible to treat many more people for more conditions - earlier, it also poses ethical challenges of doing more harm than good, e.g., in overdiagnosis, overtreatment, and medicalization. Understanding these ethical issues can be difficult even for health professionals, and communicating them to patients is challenging, but crucial for making informed consent. Accordingly, acknowledging and addressing the many specific ethical aspects of disease is crucial for patient communication and education.

Highlights

- Getting a disease changes your life, your social status, and the obligations professionals, institutions and society has towards you.
- Disease functions as a demarcation of access to health care but can also result in injustice, social stigmatization, and discrimination.
- When patients, professionals, and social institutions can have different perspectives causing moral problems.
- Acknowledging and addressing the many specific ethical aspects of disease is crucial for patient communication and education.

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Introduction

Not only in times of pandemics does disease change the world. Getting a disease changes your life, your social status, and the obligations professionals, institutions and society has towards you. Having a disease changes your rights and duties. Dis-ease indicates that something is bad and the concept functions as a gate-opener for access to health care, but also for social stigmatization and discrimination.

Hence, disease is something considered to be bad and implies things that can be good (cure) and bad (discrimination, harm). As such, disease is a value-active concept with a wide range of ethical aspects which have personal, professional, and political implications. While these aspects are crucial for successful counseling and communication between providers and patients, they are often ignored.

The literature on the concept of disease is vast and diverse [8-22], and the debates on its ethical issues are dispersed and addressed in specialized journals, in specific contexts (such as revisions of DSM and ICD), or for particular diseases (such as Alzheimer's disease)[23]. This makes it difficult for even well-educated and broadly oriented persons to get an overview. **Accordingly, the objective of this article is to present and discuss a range of basic ethical aspects of disease in order to improve patient communication and education.**

With support from the philosophical and ethical literature on the concept of disease this article presents the ethical aspects under six main topics:

- 1) The moral impetus from the phenomenon disease towards persons
- 2) The moral functions of the concept of disease (explaining suffering, guiding action, and demarcating rights/duties),
- 3) Ethical issues arising from patients, professionals, and social institutions having conflicting perspectives on disease
- 4) Ethical issues rising from the expansion of disease
- 5) Ethical aspects of classification of diseases
- 6) Ethical issues rising from the social function of the concept of disease (prestige, stigma, discrimination)

In order to improve communication and education it is crucial for patients, professionals, and policy makers to acknowledge and address the specific ethical aspects of this core concept for medicine. As the word "disease" is used in many ways, there are many theories [22] and classifications [1, 13] of disease, and as disease can easily be confused with other concepts, such as diagnosis, Box 1 clarifies some basic concepts.

Box 1 Clarifying terminology

In this article *disease* is the phenomena that we refer to when we use the word “disease.” These phenomena can be biological, physiological, biomolecular, mental, or otherwise, and a disease can comprise many such phenomena.

The concept of disease is the meaning of the word disease, i.e., what we have in our thoughts (mental or neurological states) when we use the word “disease.” The word “disease” stands for the concept of disease which refers to the many instances of disease. We often say that instances of disease (characterized by the phenomena described above) fall under the concept of disease, and that the word “disease” stands for these instances (and expresses the concept of disease). When we say that a person “has (a) disease” this often means that the person has a condition (identified phenomenon) that falls under the concept of disease.

One issue that complicates matters is that we use diagnoses as labels for diseases. While we may be inclined to believe that diagnoses map diseases, this is not the case [1]. Diagnoses change all the time, and classification systems include many conditions that are not disease. For example, International Classification of Diseases (ICD 11) [2] includes a range of “related health problems.” Moreover, we are able to identify a wide range of risk factors [3], indicators [4], precursors, and predictors [5, 6] which we tend to “make disease” [3, 7].

Importantly, ethical issues are related to disease as a phenomenon (the ethical impetus), as concept (differentiating moral function), its labelling (stigmatization), and its identification (overdiagnosis).

The many ethical aspects of disease

1. As indicated, the ethical aspects are presented in in six specific topics: 1) moral impetus stemming from disease, 2) disease having moral functions, 3) conflicting perspectives of disease, 4) expansion of disease, 5) classification of disease, 6) social function. **The moral impetus of disease**

From a very basic perspective, having disease is considered as something bad, and the phenomena that we call disease are associated with pain, suffering, impairment etc. The reason that we group specific phenomena under the concept of disease is that they are considered to be bad [14, 24-30].

As we tend to have a moral impetus towards people with pain or suffering, we have moral obligations to help persons with disease [17]. Hence, we should help persons who suffer from disease, or more formally, there are moral commitments towards person where we can observe the phenomenon of disease.

These moral commitments can come in many forms (motivation, reason, obligation, imperative) and be justified from most positions in normative ethics, e.g., by minimizing bad consequences (consequentialism) and maximizing utility (utilitarianism); from duties towards others based on rational self-legislation (deontology), from compassion for those who suffer; through a caring

character with virtues such as sympathy, empathy, and care [31]; or as guided by ethical principles, such as benevolence [32]. Others would claim that the obligations towards the diseased is more profound than utility, duty, or virtue, e.g., as a “meta-ethical” fact about the human being [33, 34].

Hence, disease calls for moral attention, responsibility, and action [28]. However, the strength and extension of the moral impetus towards persons with disease is not settled, as illustrated by ethical debates on the goal of medicine [35-37] and on human enhancement [38]. This can pose problems for patient communication and education as there may be different expectations to and conceptions of the moral impetus of disease.

2. The moral function of disease: action guiding, demarcating rights and duties

Disease also has an epistemic and moral function. If a physician detects a phenomenon that is identified as disease (and falls under the concept of disease), then the patient can be explained why (s)he is suffering and oftentimes what causes it.

For health professionals detecting, identifying, and classifying disease is often action-guiding: they should know what to do. If they don't do what is professionally expected, they are doing morally wrong. Hence, to provide knowledge and guide actions are two core functions of the concept of disease with significant moral implications.

Another important moral function is to differentiate between people: between those who shall have access to health care and those who shall not. If you have (a) disease, you have certain rights, and health professionals may be obliged to give you specific health services; otherwise not. This demarcation connects to aspirations of just distribution of goods in a society [39].

First and foremost, having disease gives a person a set of rights, such as the right to attention, treatment, and care by health professionals, but also social rights, such as sick leave and sick pay [40, 41]. Second, having disease also frees from duties and obligations. In many situations, a (severely) diseased person is not expected to work or to fulfil his moral obligations, e.g., to take care of relatives.

Third, having disease can also be a criterion for depriving certain rights, e.g., the right to hold a driver's license or to raise children. Fourth, having disease is also used to decide who is morally and legally accountable [41, 42], and who can be punished. In these matters the concept of disease touches upon profound ethical issues, such as personhood, autonomy, and free will. Fifth, having disease gives the person some duties, e.g., to procure help and to avoid infecting others.

Table 1 gives an overview of the moral functions of the concept of disease.

Table 1 Examples of how illness attaches and exempts rights and obligations

| | Rights | Obligations |
|---------------------------|--|---|
| Exempting from | Holding driver's license, parental responsibility, freedom (freedom of movement, compulsion) | Work, moral responsibility, criminal liability (for lack of accountability) |
| Gives / Attributes | Sickness benefit, entitlement to health care, social security, support | Seek help, receive treatment, avoid infecting others |

Hence, disease has a significant moral function in demarcating people's rights and obligations. Certainly, legislation differs between countries, and having disease may not be the only criterion for demarcation. However, it is an important factor for such moral functions, and there are hefty public and professional disputes on which diseases qualify for specific rights. **Moreover, epistemic shortcomings pose ethical problems, as professionals can be wrong with respect to a person's disease status: The person has a disease, but professionals are not able to identify it (correctly). Clearly, these issues can undermine the moral impetus, generate injustice, and distort patient communication and education.**

3. Conflicting perspectives on disease

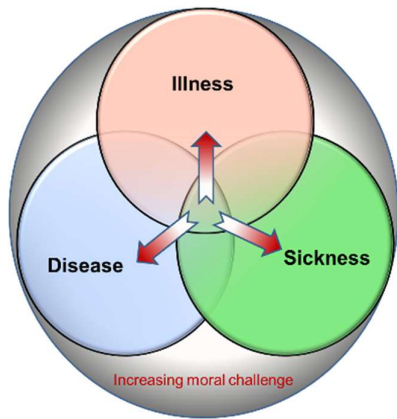
Yet another set of ethical issues stem from the complexity of disease phenomena and different perspectives on disease. A person with colorectal cancer may experience abdominal pain, aches, weight loss, fatigue, and cramps that do not go away. This experience of disease is oftentimes called *illness* [43-48]. For the health professional colorectal cancer is characterized by blood in the stool, change in bowel movements, cell change, gene mutation, tumor development, metastasis etc. This is usually called the *disease*. From the societal perspective, the person cannot fulfill basic obligations, such as work (sick leave), and needs attention from health care, and economic support (health insurance). The societal perspective on human malady is frequently called *sickness* [27, 49, 50].

While these three perspectives oftentimes align, this is not always the case. A person may feel *ill*, but the health professionals is not able to identify any specific *disease*, or/and society does not attribute a *sick role* to the person. This poses ethical challenges, e.g., what kind of moral obligations does the professional and society have in such cases? Correspondingly, there may be a range of discrepancies between the personal, the professional, and the societal perspective on disease, i.e., between *illness*, *disease*, and *sickness* respectively [49, 51, 52]. When these perspectives conflict, ethical challenges arise [53, 54]. The debates on ME/CFS and borreliosis are but two examples [55].

The cases are specifically challenging for patient communication and education. For example, when the professional says "I cannot find anything" or "I can't find a disease," the professional may well mean that "the tools that we have today are not good enough to identify what causes your suffering," but the patient may understand the statements as "the professional does not think there is anything wrong with me" or "the professional does not believe me." Moreover, the patient may experience to be deprived of treatment and care. Being aware of the discrepancies of the different perspectives is crucial in patient communication and education.

Another ethical issue is which perspective trumps, and why. While professionals have been powerful and society has gained authority, it may be argued that illness is of crucial import [56-59] because it is closely connected to pain and suffering, and thus the moral impetus of medicine [60]. Patient-centered care, patient-centered outcome measures, and shared decision-making are results of increased attention and acceptance of this. Figure 2 tries to illustrate the increasing moral challenge stemming from disparities between perspectives on human ailment.

Figure 2 Increasing moral challenge stemming from disparities between three perspectives on human ailment, i.e., illness, sickness, and disease. Moral challenges increase when only two perspectives agree or when only one perspective indicates malady.



4. The ethics of expanding disease

A major critique of modern medicine is that it has unwarrantedly expanded the concept of disease – doing more harm than good [7, 61-63]. Such critique has been voiced when medicine makes ordinary life experiences disease (medicalization)[64], when indolent conditions are labelled disease (overdiagnosis)[65], when aesthetic characteristics are treated as disease (e.g., protruding ears)[7, 66], when something becomes disease because it can be detected and treated (pragmatic expansion), or when biological conditions are made disease in order to sell diagnostic tests or therapies (disease mongering)[67]. Figure 3 gives an overview of various types of expansion.

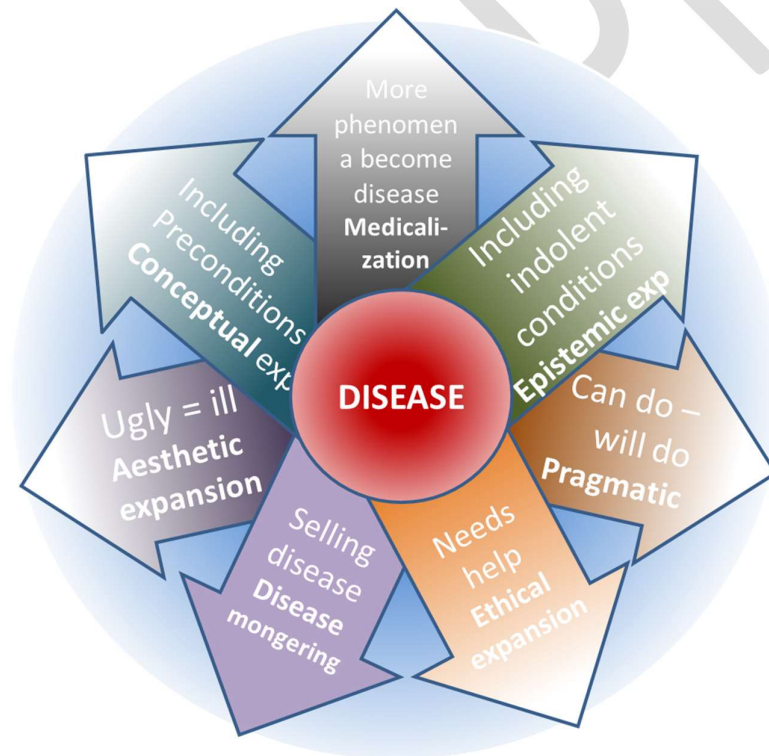


Figure 3 Seven types of expansion of disease. Adapted from [68].

The expansion of disease is of great normative impact and ethical relevance as it extends the field of medicine’s moral impetus and its moral functions (as described above). The expansions also touch on the duty and the character of the professional. Moreover, an extensive expansion is challenging. If

everything becomes disease, the concept will lose its differentiating function. As expressed by Aldous Huxley: “Modern medicine has made such tremendous progress, that there is hardly a healthy human left.” [69]

Some of the problems following for patient communication and education is that calling and treating something a disease may not turn out to be helpful (but harmful) for them. Overdiagnosis is but one example: This is when tests detect conditions that people would not experience during their lifetime (if not detected), in short: conditions they would *die with* and *not from*. However, when detected, these conditions are treated, sometimes with therapies that have side effects. For example, they may have their prostate or their thyroid gland removed unnecessarily. The problem is that overdiagnosis cannot be identified in advance. Thus, it is very difficult to explain to patients. Even more, it is difficult for professionals to understand as well.

5. The ethics of disease classification

As disease has many important moral functions as described above, there are vast and vivid debates on whether a condition is a disease or not and what kind of disease it is (e.g., somatic or mental). Obesity [70-75], grief [76-78], gender dysphoria [79], ADHD [80], ME/CFS [81, 82], as well as aging [83-85] are but a few examples.

This touches upon basic philosophical questions of what disease is (ontology) and how we gain knowledge about disease (epistemology). However, it also raises the question of whether classifying something (such as specific phenomena) as disease will help the persons who are classified or not. Historically, drapetomania (“runaway disease” amongst slaves) [86], dissidence [60], and homosexuality [87] have been classified as diseases.

Both in cases where patients have insisted that specific conditions are (certain types of) disease and when health professionals have made particular conditions disease, one of the main arguments for classifying conditions as disease has been (to provide or gain) access to care.

As mentioned in the introduction, diagnoses are nametags for diseases and oftentimes obtain the same moral functions. **Accordingly, having a diagnosis may make a crucial difference to a person in terms of self-understanding, access to care, and economic support.** This is why there are so heated debates when classification systems are revised [1, 13, 88]. **It also generates challenges for patient communication and education, especially when patients and health professionals disagree on disease status, disease classification, and etiology, for example as seen in the case of ME/CFS.**

In addition to ethical aspects related to whether conditions fall under the concept of disease, and go in or out of taxonomies, taxonomies themselves play ethical roles. Classifications shape the way diseases are understood and medicine is practiced [89]. Moreover, patients may adapt to conceptions and classifications of disease [90]. However, the form and content of taxonomies also shape the normative function of taxonomies. Including non-diseases [91, 92] and a wide range of health-related conditions that may be better dealt with elsewhere [93] may undermine the differentiating function of taxonomies.

6. Social function: social status, professional prestige, stigma, and discrimination

Another ethical aspect of disease is identified in the social functions of disease [13, 94-99]. One such feature is that diseases differ in prestige amongst professionals. For example, MDs consider

myocardial infarction, leukemia, and brain tumor to have much higher prestige than hepatocirrhosis, anxiety neurosis, and fibromyalgia [100, 101]. Studies have shown that diseases located in specific organs placed high in the body and that can be diagnosed or treated effectively with advanced technologies have high prestige amongst medical doctors [100, 101]. When such prestige hierarchies influence the way health professionals behave towards patients or prioritize diseases, it is of great moral import (especially if prestige hierarchies do not correspond to differences in suffering). Moreover, disease hierarchies are rarely talked about explicitly neither amongst professionals nor in patient-professional communication [100, 101]. This poses challenges for patient communication and education.

Related to this, there is also a problem with objectifying or stigmatizing the individual by reducing the person to the disease [102], e.g., when health professionals talk about “a diabetic” [103] or “epileptic” [104] etc.

Relatedly, disease naming influences how conditions are conceived and managed, e.g., whether it includes the term “carcinoma” [105]. If naming (and not the nature of the disease) influences people’s understanding and decisions, it undermines valid consent and challenges patient communication.

Correspondingly, diseases influence peoples’ self-conception, their psychic response, their behavior (sick role), and their decisions about the future [105, 106]. Having a disease (and/or diagnosis) directs a person’s trajectory through the health care system and rewrites their biography, alters their identity, and decides their future (prognosis)[107]. A disease name can help a person to understand one’s suffering and explain it to others [29]. It can provide relief. However, it can also induce guilt and blame [108], worries, and stigma [109-111].

Diseases related to life-style may stigmatize, such as lung cancer [110], HIV [112], and obesity [111, 113-117], but also in other cases, such as CFS [109], ADHD [118], and dementia [119]. Moreover, diseases may also result in discrimination, e.g., obesity [120-122]. Notably, health professionals seem to share the attitudes and prejudice of ordinary people [117, 123]. Clearly, disease discrimination and stigmatization are morally challenging and cause problems for patient communication and education.

Hence, avoiding negative ethical aspects of the various social functions of disease, such as prestige hierarchies, objectification, stigmatization, misguiding naming, and discrimination, is crucial for ethical communication with patients and proper patient education.

Table 2 provides an overview over the values and ethical aspects involved in disease.

Table 2 Values and ethical aspects involved in disease

| Type | Explanation | Example and ethical aspects |
|---|---|---|
| Moral value | a) Disease is bad (dis-ease) and incites moral impetus to help b) Something is made a disease because it is considered to be bad, and we need to help people | a) Pain and suffering from disease urges individuals and professionals to help b) We want to help people with their grief – we therefore make grief a disease |
| Moral function | Action guiding Attributing rights Freeing from duties Depriving from rights Attributing accountability | Professional know what to do for specific diseases Patient has right to attention and care Patient is freed from duty to work (sick leave) Person is freed from moral and legal responsibility |
| Values related to different perspectives on disease | Patients experience and dis-value disease differently from professionals and society and social institutions | Conflicting perspectives on malady (such as Illness, Sickness, Disease) raise ethical issues |
| The social value of disease | The moral functions (above) make it interesting for stakeholders to expand the concept of disease Diseases have prestige and social status Defining disease gives power | Expanding the concept of disease may make more harm than good (overdiagnosis, overtreatment) Prestige and social status of diseases can result in stigmatization, discrimination, and injustice There is power in classifying diseases and applying classifications |

Discussion and conclusion

Discussion

This brief review underscores why disease makes a great difference to patients, health professionals, and health policy makers. The phenomena of disease, and the corresponding concept of disease, have a wide range of ethical aspects, which have many interesting and important implications for patient communication and education.

First, as disease differentiates rights, obligation, as well as social role, status, and prestige, it has become impetus to provide clear and delimiting definitions of disease. However, there is no agreement on definitions of disease. Those who argue that disease is defined in terms of social or cultural norms and values (“normativists”) cannot provide any objective criteria for differentiating disease from health. That is, the criteria for deciding who should have access to attention and care and those who should not are relative. Others, who believe that disease is objectively defined by phenomena in nature, e.g., in terms of abnormal dys-function [9, 124], the so-called “naturalists,” appear to be more confident in drawing the line between health and disease [125]. Nonetheless, where to draw the line between normal and abnormal functioning has been heavily debated [126, 127]. Differentiating good and bad by referring to distinctions in nature, seems widely contested [25, 28, 125].

Second, disease furthers reasoning from nature to moral norms, from is to ought, and vice versa. As described, when a person has a condition that falls under the concept of disease, we have a moral

impetus to help. Hence, when something *is disease*, we *ought to help*. Conversely, when we experience an urge to help, we tend to make the corresponding condition disease. For example, in order to help people with grief (without bereavement), we make it disease [77]. That is, we *ought to help*, and thus it *is a disease*, as illustrated in Figure 4. This reciprocity between facts and values, between ontology and ethics, is distinct for the concept of disease.

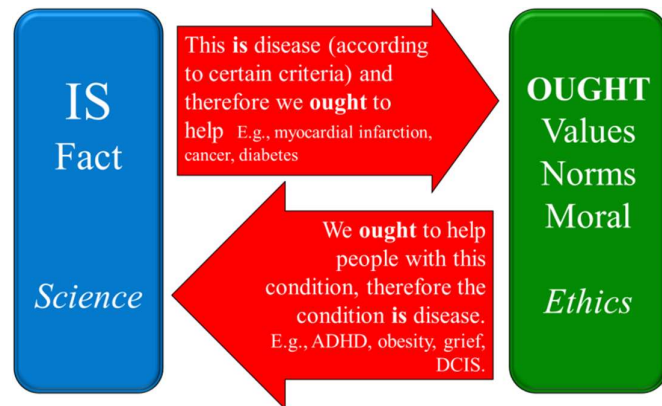


Figure 4 Disease mediates between facts and values, between *is* and *ought*

Moreover, it may be argued that many of the moral aspects of disease that are discussed here are really aspects of diagnosis. However, as stated in the introduction (Box 1), diagnoses are labels of disease. The moral impetus stems from pain and suffering, which is related to disease (more than to diagnosis)[5, 68]. Clearly, many diagnoses do not refer to diseases that cause pain and suffering. As pointed out, this is one reason for ethical concern in itself.

One important observation is that many of the ethical aspects identified and discussed here are hidden and may result in professionals and health care systems doing more harm than good. Implicit prioritization, stigmatization, discrimination, overdiagnosis, and overtreatment are but a few examples. This provokes basic ethical principles, such as nonmaleficence, justice, beneficence, autonomy (by lack of information)[128], and solidarity. Moreover, it poses problems for patient communication and education.

Revealing and discussing these aspects is but a first step. The next step, addressing them in clinical practice, professional communities, health policy making, and patient communication and education, is not an easy task. One reason for this is ignorance. For example, a person being overdiagnosed (and overtreated because what is identified and treated as disease would never have caused disease) may think that the test has saved her or his life and recommend it to others. While making homosexuality a disease may have seemed reasonable (in order to reduce social stigma by making it a medical issue), doing so turned out to be stigmatizing. What then should be done to address the revealed ethical aspects?

First, the moral impetus stemming from disease (to avoid or ameliorating suffering) makes it crucial to limit the expansion of disease to cases where making something disease actually helps people. Checklists to curb unwarranted expansion may be helpful [129]. We should be careful in making risk factors or indicators disease [6].

Second, the moral (discriminating) function of disease (e.g., with respect to access to care), makes it crucial to provide as clear definitions of disease as possible, and to make the line between disease and health as sharp as possible. As acknowledged, this is not easy [22]. But we should try.

Third, awareness of different perspectives on disease (illness, disease, sickness), can increase understanding and reduce conflicts and improve communication between patients, professionals, and social roles.

The same goes for the social functions of disease entities and classification systems. Those who define and classify disease have power. Awareness of such mechanisms is crucial for transparency and justice in health care. Moreover, we must make sure that those who have the power of defining and classifying disease use it for the best of patients.

Fifth and foremost, it is crucial to address the ethical issues related to the phenomenon, concept, classification, and practice of disease for good communication with patients and proper patient education. Such tasks are not easy, as several of the issues are not explicit. It is easier to talk about facts than about (hidden) norms. Nonetheless, increasing the awareness of these issues is the first step to addressing them.

No doubt, this study has several shortcomings. It gives only a birds-view of a vast terrain. This comes at the cost of being exhaustive and addressing important issues in depth. Scholars in the philosophy of disease or sociology of medicine may certainly miss their favorite issues or references. The same goes for scholars in moral psychology, in communication science, and other fields. These are all valid objections to the approach and the results. Nonetheless and hopefully, the article provides a useful conceptual overview inspiring a broader audience of readers to dive into the details of how the ethical issues related to disease are relevant for patient communication and education.

Conclusion

Having disease is a universal and basic human experience, and if something falls under the concept of disease it prompts a moral impetus to help. Hence, the concept of disease connects to the moral basis of medicine and its goals.

Moreover, the concept has several moral functions, especially because it distinguishes those who have from those who don't have specific rights. Conflicts between patients', professionals', and society's perspectives on disease may also result in ethical challenges crucial for patient communication and education. The same occurs when the concept of disease is expanded beyond what is helpful for reducing people's pain and suffering.

The concept of disease is value-active. It does more than describing specific conditions in the world. It also says something about the value of these conditions. Classifying something as disease is to say that it is bad. Moreover, it can also say something about its social status and prestige, and it can lead to stigmatization and discrimination. This gives power to those who define and classify disease and it is crucial that they use this power for the best of patients.

Many of the ethical aspects of disease are hidden and rarely addressed openly. Therefore, it is crucial for patients, professionals, and health policy makers to be aware of and actively engage with these specific ethical aspects of this very core concept for medicine and health care. This is especially so in patient communication and education.

*Practice implications [This section could be part of a Conceptual paper]

The ethical aspects of disease are crucial to patients, professionals, and policy makers. However, they are hidden and need to be addressed explicitly. In order to address the ethical aspects of disease, we should:

- Pay attention to the moral (differentiating) function of disease and do not expand what falls under the concept of disease beyond what actually helps people (reducing their pain and suffering).
- Apply as clear and explicit definitions of disease as possible and make the line between disease and health as distinct and transparent as possible.
- Make sure that those who have the power to define and classify disease use it for the best of patients.
- Acknowledge that patients, professionals and social institutions can have different perspectives on disease (illness, disease, sickness) in order to avoid unnecessary conflicts.
- Acknowledge and address the ethical issues related to the phenomenon, concept, classification, and practice of disease in patient communication and education.

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