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PHENOMENOLOGY AND HERMENEUTICS IN MEDICINE
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Introduction
Phenomenology enables us to focus on the experience of illness itself, while bracketing the causal and ontological assumptions that accompany the biomedical model. This chapter gives an overview of phenomenology and hermeneutics, focusing on a core phenomenological distinction between the objective “biological” body and the subjective “body as lived.” It also links this distinction to the hermeneutical emphasis on the different horizons of patient and health professional. The distinction between the objective body and the body as lived is mapped onto the disease/illness distinction. This enables us to (1) differentiate between the different dimensions of the body and thus provide a detailed account of embodied illness experiences; (2) conceptualize the complexity of the intersubjective encounter in the clinic; and (3) understand particular embodied experiences that characterize illness, such as alienation, uncanniness, and bodily doubt (Carel 2014).

The chapter then turns to hermeneutics, focusing on the work of Fredrik Svenaeus (2000a, 2000b, 2001) to explain the usefulness of this approach. Using the notion of illness as “unhomelike being in the world,” I discuss the role of medicine in this context, which is to find a way to return patients to a more homelike being.

Emma’s Story
Emma, who lives in Manchester, England, is 29. Until recently, things were looking well for Emma. She was a fit and active young woman, about to start a family with her husband, George, and working in a job she loved that involved lots of travel and excitement. Emma loves horse riding, hiking, and travel. She loves seeing the world and being part of an exciting start-up business.

But this is all over now. Emma has recently been diagnosed with a chronic, progressive lung disease called lymphangioleiomomatosis (LAM, see http://www.thelamfoundation.org). The diagnosis shattered her life. She was forced to give up her job, because air travel caused her repeated lung collapses, requiring lengthy hospitalizations, and travel insurance costs have become prohibitive. She was advised not to get pregnant, as a pregnancy will accelerate the rate of disease progression and cause other, potentially life-threatening problems, like renal bleeding. There is a treatment she could try, which at best would halt the deterioration of her lungs but will not restore the lung function she has already lost. Approximately 30% of LAM
patients do not respond to the treatment. Emma’s prognosis is bleak. If she does not respond to the treatment and without a lung transplant, Emma would—say the doctors—be at risk of respiratory failure within two years.

Emma sinks into despair. She questions the benevolence of the world in which she lives. Why did this happen to her? Apparently, it was just bad luck: LAM is caused by a somatic mutation, causing cell proliferation that creates cysts in the lungs; it could happen to anyone. What can she do about it? Well, she could carry on exercising gently, she could use ambulatory oxygen to increase her ability to do things, she could go on the lung transplant waiting list, and she could hope that the treatment works for her. But there are no guarantees. Emma is paralyzed with fear and unable to think clearly; she can barely bring herself to talk about her illness or what she should do next.

Emma’s despair is exacerbated by the way she feels she is treated by the medical and health professionals in her local hospital. Although they are courteous, they are also cold, she finds. She thinks they are mortified to be dealing with such a difficult case and are sad that they are unable to offer her a cure. She has no one to talk to about her diagnosis who she feels can really understand her. Her parents are devastated. She feels alienated from her friends, who seem disgustingly lucky to her. She is worried that her partner may not want to take on the long-term prospect of living with severe illness and disability. Emma feels envy, bitterness, and confusion. More than anything, she is scared of what the future holds in store for her: how will she choose between the Scylla of lung transplants, with their modest survival rates, and the Charybdis of respiratory failure and premature death?

She notes the spiraling decline of her lung function; it scares her beyond words. Each week her world shrinks and things have to be given up. One day, she gives up cycling to work. A few months later, she gives up work altogether, as she is made so breathless by walking or bending down makes her too breathless. She can no longer climb stairs; she can no longer talk without needing to pause for a breath. She loses weight as eating makes her so breathless that she subsists mainly on protein shakes. A narrow, unchosen life descends on her. She feels trapped in a body and a life she never wanted.

Although she has lots of medical appointments, Emma doesn’t know how to explain her anguish and despair, as well as the ways in which her world has shrunk both geographically and temporally, to the health professionals involved in her care. What will they understand and how will they incorporate that knowledge into their interactions with her? How can Emma convey the life-changing impact of her illness on her?

There is an impasse between the medical staff’s focus on her disease, symptoms, and lung function, and Emma’s first-hand experience of these. The impasse is part of a broader problem: Emma needs concepts and language with which to describe what has happened to her. Her confusion and suffering might subside, but only if she is given tools with which to order, discern, and describe her illness experience. And she then needs to find a way to share it with her family, carers, and doctors. A phenomenological approach to illness offers a framework with which she can do that.

What Is Phenomenology?

Phenomenology is a descriptive philosophical method, developed in the first half of the 20th century in Germany and France. It aims to be a practice rather than a system (Moran 2000: 4). The goal of phenomenology is to accurately describe the relationship between a perceiving consciousness and the world. It has been used to describe aesthetic experiences; for example, the experience of looking at Van Gogh’s 1886 painting, Peasant Shoes.
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(Heidegger 1993: 158–161). It can be used to describe how something appears from a particular point of view, in a certain environment, as Merleau-Ponty's analysis of Cézanne's paintings does (1964: 9–25). Or it can be used to analyze the experience of listening to a melody (Husserl 1990).

Because of its sensitivity to acts of perception and its rich account of the relationship between perceiver and perceived, phenomenology is uniquely suited to describing the experience of illness as it is lived by the ill person. A particular approach within phenomenology, developed by the French philosopher Maurice Merleau-Ponty (1908–1961) in Phenomenology of Perception (1962 [1945]) has special utility here. In Merleau-Ponty's view, the body is the locus of subjectivity, the "null centre" from which consciousness radiates toward the world; he coined the term "body-subject" to capture the mind-body unity that is core to his view.

Merleau-Ponty rejects the mind/body separation traditionally espoused by philosophers and theologians. For Merleau-Ponty the body is "the origin of the rest, expressive movement itself, that which causes things to begin to exist as things, under our hands and eyes" (1962: 146, translation modified). This is not just an empirical claim about perceptual activity, but a transcendental view that posits the body as the condition of possibility of perception and action. As Gallagher and Zahavi write, "... the body is considered a constitutive or transcendental principle, precisely because it is involved in the very possibility of experience" (2008: 135). In other words, without the body, we would not be able to experience ourselves, the world, and others. Having the kind of body we have makes us the kind of beings we are.

In Merleau-Ponty's view, perceptual experience is the foundation of subjectivity. The kind of creature we are is circumscribed by the types of experiences we have and the kinds of actions we perform, which are shaped by our bodies and brains. Any attempt to understand human nature would have to begin with the body and perception as the foundations of personhood (Merleau-Ponty 1962: 146). To think of a human being is to think of a perceiving, feeling, and thinking animal, rooted in a meaningful context and interacting with things and people in its environment. To be is to be a body that perceives the world. This body is situated and intends toward objects around it. Human existence takes place within the horizons opened up by perception.

The body, for Merleau-Ponty, is the locus of human existence. Thus, when we become ill, this is not simply a biological dysfunction but a pervasive disturbance of our being in the world. On a phenomenological view, illness is not a localized dysfunction, although it may be located in a specific organ or system, but a pervasive concern. Thus, we see the habits that anchor our everyday routines disrupted in illness; Emma is no longer able to run for the bus. She can no longer cook for herself or do her own grocery shopping.

This disruption of habits is not a superficial disturbance. The habitual body, as Merleau-Ponty calls it, is very much at the core of lived experience. The ease and expertise with which we perform everyday actions leads us to view them as trivial tasks. But in illness the tasks that form a seamless part of our everyday life become demanding and require planning and attention. It is this kind of disruption to our plans and our ability to act in the world that changes both the ill person and her experience of the world.

Illness as Life-Transforming

The first insight phenomenology provides is that our agency, our ability to operate in the world, is restricted when our bodies are damaged. Emma's agency and freedom are radically curtailed by her failing lungs. She can no longer do any of the things she enjoyed or took for granted previously, and she is no longer independent. Her agency, ability to pursue her goals, and independence are restricted by illness.
An extreme example of such restriction would be Jean-Dominique Bauby's account of a stroke, which left him in complete paralysis, or “locked-in syndrome.” In the space of a few minutes, Bauby turns from being a successful man in the prime of life to lying helplessly in bed, unable to communicate or eat. Although his mind is alert, the total paralysis of his body imposes a complete halt on all the activities he previously enjoyed. His account of his illness was painstakingly dictated using the batting of his one functioning eyelid. (An assistant would read out the alphabet and Bauby would blink when she got to the letter he wanted—a process that took many months.) The laboriously produced account was published as a novel, *The Diving Bell and the Butterfly* (Bauby 1998), and later made into a film by Julian Schnabel.

It would be impossible for us to describe the changes to Emma's or Bauby's existence merely in terms of physiological changes. These changes have to be understood not just biologically, but also existentially (i.e., as impacting on one's entire existence, including one's psychological, social, and temporal being). We can begin to appreciate these changes by thinking about simple things, like going for a meal with friends, or having a shower, which can become impossible in illness. Illness, as opposed to disease, is not a physiological dysfunction but a shutting down of horizons and closure of possibilities.

Illness changes our relationship to the world, or more specifically, our relationship to the environment, to other people and to possibilities. The geography of our world changes with illness, when old invitations (a stairway leading somewhere) become new limitations (Carel 2013: 25). Toombs describes how a bookcase in her house was initially a place to store books, then became an object to hang on to as her walking became less steady, and eventually turned into an obstacle she had to wheel her wheelchair around (1995: 16). For Emma, the gym was once a place to exercise and enjoy physical activity and fitness. It is now off-bounds for her; a meaningless location.

Similarly, the social world is transformed by illness. As described above, Emma's relationship to her parents, friends, and husband have to be renegotiated. Some relationships become less natural, or weighed by guilt, awkwardness, and other responses to illness. Illness, especially if visible, may mark the ill person out, or put her in a “sick role,” in which she is expected to behave in particular ways (e.g., be grateful for her medical care, and want to get better) (Parsons 1991: 436–8). Heidegger's notion of being-with (*Mitsein*) captures the magnitude of the change brought about by illness. By being-with, Heidegger expresses the inherent sociality that lies at the core of a human being (1962: 149–50). Anything that modifies our ways of being-with will have far-reaching consequences, stretching beyond the physiological process of disease. In particular, Emma's relationship to her husband has changed. He will quickly become her carer, and the new restrictions on her life will also be his. He will witness from a second-person perspective how illness changes Emma's way of being.

Finally, Emma's relationship to herself, in terms of her possibilities, goals, and her experience of time and of her future, is also modified by illness. Emma is faced with a poor prognosis, substantial limitations on work and leisure, and a pressing need to change habits and to rethink plans for the future. Illness impacts on every dimension of her life. Heidegger views the human being as a temporal synthesis of past, present, and future; as a temporal creature whose actions are informed by her past and directed toward her future (Heidegger 1962: 376, 418). Emma feels that her future is tainted by fear, uncertainty, and grave prognosis. Thus, her experience of time also changes.

This temporal dimension also includes finitude, as plans for the future are always constrained by our finite existence, as a stretch from birth to death (Carel 2006: 70). When faced with a poor prognosis like Emma's, we need to rethink our life plans and to adjust our expectations to what remains possible. Again, this process of adjustment is reflexive and time-consuming.
Emma needs to invest considerable time and effort into adapting to her illness. But adaptation is possible, although it never fully compensates for the freedom that is lost (Carel 2007: 104).

**Varying Perspectives on Illness: The Objective Body and the Body as Lived**

In medicine we encounter two perspectives. First, we have the experiences of the patient and of her family and carers, which are first- and second-person perspectives, respectively. They are the lived experience of illness. Second, we have the experiences of health professionals for whom the perspective of the patient may be quite alien. Health professionals see Emma for short appointments, but they do not know what impact her illness has on different areas of her life, like her social world and her self-identity, unless they inquire or Emma shares this with them.

Health professionals focus on lung function measurements, rate of decline, and the secondary physical symptoms, such as a lung collapse. They have an interest in quality of life, but their understanding of the disease is theoretical, professional, and characteristically takes on the third-person perspective. The patients live the illness, and therefore primarily view it as a lived experience. As Toombs (1987) notes, the two partners in the conversation in the clinical meeting are talking about two different dimensions of the body. A second-person perspective is also possible in medicine, but health professionals are educated to primarily seek and occupy the third-person perspective.

The phenomenological literature distinguishes between the objective body and the body as lived. The objective body is the physical body, the object of medicine: it is what becomes diseased. Sartre calls this body the “body of Others”: it is the body as viewed by others, not as experienced by me (Sartre 2003). The body as lived is the first-person experience of this objective body, the body as experienced by the person whose body it is. And it is on this level that illness, as opposed to disease, appears. This distinction is fundamental to any attempt to understand the phenomenon at hand: the ill person is only and ever the one who experiences the illness from within (although others may have an experience of someone else’s illness, as second-perspective witnesses).

Only they can say if they feel pain or fatigue, or what a medical procedure or a particular symptom feels like. This is a source of significant and medically relevant knowledge, but also contains an element of unshareability. Thus, the experience of illness contains a measure of communication difficulties that should be acknowledged (Carel 2013). Or as Sartre put it more strongly: “the existed body is ineffable” (Sartre 2003: 377). Disease, on the other hand, is a process in the objective body that may be observed by any other person and may yield information that is not available through first-person reports. For example, one may have elevated cholesterol while having no experience of this. Often such knowledge comes from medical tests that yield objective facts with no experiential correlate.

The relationship between illness and disease is not simple: the two aspects do not just mirror one another. Illness may precede one’s knowledge of disease: disease is commonly, but not always, diagnosed following the appearance of symptoms experienced by the patient. These symptoms are part of her illness experience and are lived by the patient. Disease may appear without illness, as in asymptomatic disease such as high blood pressure. Or often we have both illness and disease, but the two do not perfectly cohere. For example, severe disease or disability (e.g., quadriplegia, COPD) may give rise to an illness experience that is tolerable, due to adaptation (Carel 2009). So although the disease may be clinically “severe,” the illness experience is not as correspondingly negative as might be expected. In fact, it has been well-documented that there is a surprising lack of correlation between disease severity and level of

Another difference that emerges in illness is the difference between the habitual body and the body as it is in this moment. Routine actions can be performed expertly and efficiently because they have become habit, and they form what Merleau-Ponty calls the "habitual body" (2012). The ease with which we perform habitual tasks often disappears in illness, where the body as it is in this moment is incapable of performing routines familiar to the habitual body. Illness thus reveals the difference between the habitual body and the body as it is at this moment (i.e., as no longer able to continue its habits).

Returning to Emma, we can see that a large part of her communicative difficulties stem from health professionals’ focus on the objective body and disease process, while for Emma it is the body as lived that is both experienced and central. The distinction between the objective and the lived body makes clear the fundamental difference between the two perspectives. The physician's perspective limits the physician, who can only ever perceive the disease through objective observation. The illness experience in its first-person form is not accessible to the physician, by definition, other than via Emma’s account. This means that Emma is the expert on her own experienced illness, and this expertise should be taken into account in medical epistemic practices.

Taking the objective perspective may lead the physician to seek to treat the disease (sometimes with inadequate understanding of the illness) or to have little understanding of the impact of the disease on the patient’s life as a whole. The patient, on the other hand, can observe the objective indicators of disease (e.g., look at blood test results or an x-ray) but also has unique access to the lived experience of the disease—namely, illness.

In this sense the patient may have, at least in principle, an epistemic advantage of having access to her own illness experience and to the objective knowledge about the disease. This double epistemic advantage, of both having direct access to the illness experience and of having both subjective and objective knowledge, often goes unacknowledged, and the patient experience may be subsumed under the medical view or discounted (Carel and Kidd 2014). The unique ability to oscillate between the two perspectives gives the patient a deeper understanding of the illness experience, and potentially to the dual nature of the body, but this may also cause confusion and miscommunication. As Toombs (1987) notes, the physician’s focus on disease may clash with the patient’s primary interest in her illness, so although they may seem to speak of the same entity, they in fact refer to two different entities (disease vs. illness), and therefore have a communicative and interpretative gap that must be addressed before effective communication becomes possible (Toombs 1987).

Hermeneutics of Medicine

A closely related approach to illness is hermeneutics. It shares with phenomenology the fundamental premise that human existence is inherently meaning-making and meaning-seeking. Therefore, the role of medicine is not merely that of repairing physiological dysfunction, but of creating sense, what Fredrik Svenaeus (2000a, 2000b) calls “homelike being in the world,” in an existence that has become unhomelike, alienated, due to illness.

Svenaeus developed a hermeneutical account of medicine. He writes: “medical practice is not only essentially a meeting, it is also interpretation: clinical hermeneutics” (Svenaeus 2001: 148). This interpretation takes place through language, and more specifically, through the “fusion of horizons” in the clinical encounter, a fusion that serves as a meeting point for patient and physician interpretations. This particular kind of interpretative work has a specific productive goal—namely, the restoration of homelike being in the world, helping patients feel
at home in their bodies and environment, despite changes to embodiment and despite the alienation and objectification of their bodies that typically occurs in illness. Svenaeus also draws on Drew Leder’s hermeneutic analysis (Leder 1990, and discussed in Svenaeus 2001), according to which the patient constitutes a primary text and is interpreted in a process of hermeneutic circling, moving between the primary text and secondary texts (experiential, narrative, physical, and instrumental texts), which are derived from the primary text or stand in some relationship to it.

Medical hermeneutics pays close attention to the language of the body and to the process of inscription, documented also by Getz et al. (2011). On this view, what a patient has lived through and experienced is etched into her body and gives rise to her health state, in ways that demand careful interpretation, and a holistic-therapeutic approach. As Getz et al. document, particular forms of childhood trauma, sexual abuse, and disturbed domestic environment can give rise to permanent changes to one’s body (e.g., elevated cortisol levels) that then give rise to further illness and suffering that are only treatable in the context of understanding the trauma as the causal source of the illness.

In The Enigma of Health (1996), Hans Georg Gadamer suggests that medicine is a dialogue aimed at reaching a mutual understanding of why a patient is ill. The health professional must practice empathy in her effort to understand the patient’s situation. The health professional is here the reader or interpreter, while the patient is the text, albeit a text that can question and engage in dialogue. Here hermeneutics is not understood as a method for analyzing patient data but an attitude of curiosity and openness, aimed at securing an improved health state for the patient. This work in hermeneutics of medicine remains theoretically very close to the phenomenological approach described above. I now turn to survey recent work on the phenomenology and hermeneutics of illness.

Work on Phenomenology of Illness

A growing number of philosophers have in recent years turned their attention to illness, using a phenomenological or hermeneutical lens. This has generated a small but rapidly growing literature, starting with S. Kay Toombs’ seminal article, “Illness and the Paradigm of Lived Body” (1988). Toombs’ article applies Merleau-Ponty’s distinction between the body as lived and the biological body to the case of illness, demonstrating the problems and limitations arising from understanding illness as merely a disruption of biological function. Rather, Toombs argues, illness disrupts the lived experience of one’s body, leading to an overarching disruption of the ill person’s way of being in the world and their lifeworld.

Toombs’ work also explores temporal changes in illness using Sartre and Husserl, as well as examining the patient-clinician encounter through a phenomenological lens (1990, 1987). She also uses phenomenology to characterize the general features of chronic illness and disability, weaving together examples from her life with multiple sclerosis and phenomenological analysis (1995, 1993).

Toombs’ trailblazing work was followed by Fredrik Svenaeus, Matthew Ratcliffe, Luna Dolezal, Jenny Slatman, Darian Meacham, and Havi Carel, among others. As discussed above, Svenaeus published a series of influential articles developing a Heideggerian and Gadamerian analysis of illness as an unhomelike experience. He describes medicine’s role as showing the patient the way home, back from an uncanny experience (Svenaeus 2000a, 2000b). His work was further developed in The Hermeneutics of Medicine and the Phenomenology of Health. In this book Svenaeus provides a novel account of medicine’s aim, using a hermeneutic phenomenological approach to describe medicine as an interpretive practice (Svenaeus 2001). This emphasis on hermeneutic aspects of the patient-clinician encounter, as well as on the
interpretative work involved in diagnosis and in other epistemic aspects of medical work, draws on Gadamer’s account to provide a view of illness as based in social and interpretative practices of generating meaning.

Within philosophy of psychiatry, Matthew Ratcliffe (2008) developed a novel account of what he calls “existential feelings” and how these underpin our sense of belonging in the world, a sense that is disturbed in a variety of ways in mental disorder. In addition, Ratcliffe has in recent years written a number of influential papers using phenomenology to describe mental disorders such as depression. Giovanni Stanghellini (2004) draws primarily on Merleau-Ponty in his work *Disembodied Spirits and Deanimated Bodies*, also examining a phenomenological understanding of mental disorder.

Recently, Luna Dolezal (2014) has written on the phenomenology of shame in the medical encounter. Jenny Slatman’s (2014) work has systematically explored the phenomenological alternative to historical dualistic notions of embodiment. Darian Meacham has edited a volume on phenomenology, politics, and health (2015). Finally, Havi Carel’s *Illness* uses Merleau-Ponty and Heidegger to provide a comprehensive description of the first-person experience of illness (2013). The book confronts the tendency of philosophy to work from a third-person perspective and criticizes the central debate in the philosophy of medicine, between those advocating a naturalistic value-free description of disease and those claiming that disease is fundamentally a social and normatively laden concept. Carel argues that this debate excludes the experience of illness, which is highly relevant, and intersects with, the concept of disease. She suggests augmenting the debate by providing a phenomenological account of the first-person experience of illness, examining the personal, social, physical, and temporal dimensions of illness.

**Phenomenology as Research Method**

Phenomenology is primarily a philosophical method, but it has also been applied as a framework for qualitative research. It is used as an interpretative technique in the social sciences, which helps researchers distill salient themes emerging from interviews. Van Manen’s work has been influential in this regard, and many researchers have used his description of the six activities involved in phenomenological research in the social sciences, including in health care research. On van Manen’s account, phenomenology can be used to select a phenomenon of interest to the researcher (namely, lived experience); investigate this experience as we live it, not as it is conceptualized; reflect on essential themes characterizing the experience; describe the experience through writing and rewriting; maintain an oriented relationship to the experience; and finally, balance the research context by considering how the parts relate to the whole (1990: 31–32).

Another research method used in qualitative interviews in nursing and health care research is Interpretative Phenomenological Analysis (IPA). IPA is a qualitative research method with an idiographic emphasis. Its aim is to offer insight on how a particular person or small group (usually between 5 and 15 interviewees), in a particular context, experience a certain phenomenon (e.g., their illness or another aspect of their lives). IPA normally uses interviews, focus groups, or diaries to gather data. IPA is a unique method in that it does not set out to test a hypothesis, but rather is a more self-reflexive and open-ended method, in which the researchers acknowledge their own biases and preconceptions and attempt to bracket these in order to produce an account of the experiential world of their subjects. IPA is influenced by hermeneutic phenomenology and is ultimately aimed at understanding meaning-making processes, using both a phenomenological description of an experience and a multi-layered interpretation of that experience (Larkin et al. 2016).
There is scope for developing further phenomenological research tools. Existing tools include “walking with” exercises and a host of research techniques that go beyond the traditional qualitative interview. For example, some have argued that researchers need to notice the body language and facial gestures of interviewees, rather than merely their words, in order to understand the meaning they are trying to convey. Miczo (2003) recommends the use of video recordings, rather than merely using transcripts of interviews, as is commonly done. The phenomenological methods used to understand and report the experience of illness can be developed and taken beyond the existing paradigm of questionnaires and interviews, to include a host of nonverbal embodied methods.

Phenomenology in Teaching and Training

Phenomenology is also starting to be used as a teaching and training tool. Basic phenomenological concepts, like the distinction between the biological and lived body, motor intentionality and habitual body, are used to instruct health care professionals and trainees about the changes to their patients’ lives. Phenomenology as a pedagogical tool has proved useful in pilot workshops and in medical school teaching (Carel, unpublished reports). Providing health care professionals with an understanding of basic phenomenological concepts of embodiment would enable them to understand the holistic and embodied nature of illness. By understanding their patients as body-subjects, clinicians would be able to appreciate the impact illness has on patients’ lives, not just as a secondary effect of the biological disease, but as a primary phenomenon.

Another future application is the development of a “phenomenological toolkit,” which would enable patients to systematically and comprehensively describe their experience (Carel 2012). Such a toolkit would enable patients to take a fractured set of experiences and to make sense of them through describing and ordering. This information can then be presented to the clinician, as well as aiding the patient’s self-understanding. Bringing to light the different perspectives on illness can help construct a shared meaning of illness. This would improve communication and understanding in patient-clinician dialogue, which could in turn improve patient trust in physicians and compliance.

References


Further Reading


