

THE CLINICAL GAZE AND THE BODY IN ILLNESS: ADDRESSING
HEALTHCARE DISPARITIES THROUGH AN INTEGRATIVE
APPROACH OF PHENOMENOLOGY AND
SHARED DECISION-MAKING
IN MEDICINE

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ABSTRACT

A main challenge in medicine concerns questions of how to integrate the context and values of patient perspectives with general conceptions of illness and treatment. With medicine increasingly focused on patient-centered and individualized care, approaches to medicine must find ways to gain access to and understand the patient in such a way that recognizes her story as real while at the same time maintaining the value of medicine as an objective practice. Adding to this is the reality that under current models of medicine and decision-making in medicine, healthcare disparities persist for persons belonging to marginalized and vulnerable populations, including racial and ethnic minorities, women, and LGBTQ persons, amongst others. I argue that an approach integrative of shared decision-making built upon a phenomenological framework is a good alternative on which to try and understand questions like these and begin to address disparities in healthcare.

For Alexander

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TABLE OF CONTENTS

ABSTRACT.....	II
ACKNOWLEDGMENTS	IV
CHAPTER 1: INTRODUCTION.....	1
CHAPTER 2: HEALTHCARE DISPARITIES AND ISSUES OF DECISION-MAKING IN MEDICINE.....	7
Disparities of ‘At Risk’/Vulnerable Populations	7
Implicit Bias.....	8
Imperfect Models of Decision-Making.....	11
CHAPTER 3: THE BIOMEDICAL MODEL AND THE BODY AS MATERIAL OBJECT	13
Traditional Scientific Models of Medicine.....	13
The Material Body and Objectivity in Medicine	14
Issues of Scientific Models of Medicine.....	16
CHAPTER 4: PHENOMENOLOGY, EMBODIMENT, AND THE LIVED BODY EXPERIENCE	18
Merleau-Ponty’s ‘Phenomenology of Perception’	19
Phenomenological Reduction	20
One’s Own Body.....	21
Embodiment as a Condition of Subjective Experience.....	22
CHAPTER 5: PHENOMENOLOGY OF MEDICINE AND THE ILL BODY	25
Distinction between the Objective and Lived Body	25

Disruption of the Habitual Nature of the Body in Illness	25
Epistemic Value of the Patient’s Experiential Testimony	28
Epistemic Injustice in Illness	29
Testimonial Injustice.....	29
Hermeneutical Injustice	31
Empathy	32
CHAPTER 6: INTEGRATING A PHENOMENOLOGY OF ILLNESS INTO A MODEL OF SHARED DECISION-MAKING.....	34
Knowledge and Shared Decision-Making in Medicine.....	35
The Lived Body Experience in Shared Decision-Making.....	35
CHAPTER 7: ADDRESSING HEALTHCARE DISPARITIES THROUGH A PHENOMENOLOGICAL APPROACH IN SHARED DECISION-MAKING	40
Seeing Past Barriers	40
Epistemic Justice as Social Justice	42
CHAPTER 8: CONCLUSION	44
REFERENCES	46

CHAPTER 1: INTRODUCTION

A main challenge in medicine concerns questions of how to integrate the context and values of patient perspectives with general conceptions of illness and treatment. With medicine increasingly focused on patient-centered and individualized care, approaches to medicine must find ways to gain access to and understand the patient in such a way that recognizes her story as real while at the same time maintaining the value of medicine as an objective practice.¹ Adding to this is the reality that under current models of medicine and decision-making in medicine, healthcare disparities persist for persons belonging to marginalized and vulnerable populations, including racial and ethnic minorities, women, and LGBTQ persons, amongst others.² I argue that an approach integrative of shared decision-making built upon a phenomenological framework is a good alternative on which to try and understand questions like these and begin to address disparities in healthcare.

In medicine, phenomenology can help inform the decision-making process by bringing together the subjective experience of the patient as an individual with an objective understanding of medicine. By considering conceptions of illness and treatment in the context of the patient experience, and with a shared understanding of values and goals for treatment, the decision-making process can focus on the individual and be patient centered in a way that considers social and cultural factors that can influence

¹ In this paper, I use the term ‘objectivity’ in medicine to refer to those observable measures, such as the results of diagnostic and laboratory testing or a bruise, which are based on a view of the body as a material object. This view is contrasted with the notion that experience is real, albeit subjectively real, and should be afforded the same attention in medicine as objective measures.

² This is not an all-inclusive list of ‘at risk’ or vulnerable populations. Other groups include children, the disabled, the mentally ill, and the elderly, among anyone else considered to be vulnerable in a given context.

things like treatment options. Under a phenomenological approach to shared decision-making in the medical context, the patient's subjective experience can be recognized, and her autonomy preserved, while empowering her sense of agency, all without reducing her to a diagnosis or discrete medical category. At the same time, such an approach still affirms the value of objectivity in medicine, and does so without the issues that come from a view which favors the body as object.

Traditional models of medicine are biocentric, focusing on the biological body as object while ignoring the patient's subjective experience, as well as the patient's psychology and social situation. As a result of the influential, dominating force of the biomedical model in medicine, approaches to decision-making structured after it, such as paternalism and informed decision-making, have also failed to properly consider the subjective experience of the patient. In following the work on a phenomenology of perception by Maurice Merleau-Ponty, as well as others writing on phenomenology of illness, we can see that phenomenology and the lived body experience (the experience of things *as we live them*) can help us to better understand the subjective experience of the patient from her own perspective as an embodied individual.³

The importance of perspective and the centrality of the body is critical to a phenomenology of medicine and to understanding the subjective experience of the patient and her illness. How does the patient view and understand her own illness? How does her illness impact her life in a way that traditional medical models cannot or do not capture? And, how is a patient's experience of her illness compounded when she belongs to a

³ Most notably Havi Carel and S. Kay Toombs have advanced Merleau-Ponty's notion of phenomenology of the body to capture a phenomenology of illness.

group that is systematically marginalized by the institution of medicine? As an approach in medicine, phenomenology orients the focus of medicine away from the biomedical model, and so too from a view of the body as a material object, and towards the subjective experience of the patient. Thus, phenomenology rejects objectifying the patient while providing an alternative way of understanding her as an individual being, and in such a way that her subjective experience is acknowledged and considered. By focusing on the patient's lived body experience, the clinical gaze becomes oriented on the patient wholly and from a point free of all preconceived notions, theoretically allowing for the setting aside or 'bracketing' of biases and stereotypes held against the patient and her illness.⁴ When integrated into a model of shared decision-making, phenomenology can then provide for a theoretically bias free space that acknowledges and considers the patient's preferences, values, and subjective experience in the deliberation about her treatment options.

Shared decision-making, like phenomenology, emphasizes the importance of perspective, focuses on the patient as an individual, and demands a common space between practitioner and patient to deliberate and achieve a shared common outcome.⁵ A phenomenological approach to medicine within the framework of shared decision-making can enrich the overall medical encounter of the patient by by accounting for the

⁴ Merleau-Ponty, Maurice. *Phenomenology of Perception*. New York: Routledge, 2014. p. 70.

⁵ President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. *Making Health Care Decisions. The Ethical and Legal Implications of Informed Consent in the Patient-Practitioner Relationship*. Washington, 1982 (hereafter cited as President's Commission report); and Makoul, Gregory, and Clayman, Marla L. "An Integrative Model of Shared Decision Making in Medical Encounters." *Patient Education and Counseling*, no. 60 (2006): 301-12.

subjective experience of the patient, including various social and cultural factors, and by engaging the patient as an active agent in making decisions about her own care.

In this paper, I first address disparities in healthcare of ‘at risk’ or vulnerable populations, including, as mentioned above, racial and ethnic minorities, women, and LGBTQ persons. I argue that healthcare disparities amongst these groups exist, at least partly, because of biases and a neglect by medicine to value their perspective. More generally, I suggest that these groups suffer healthcare disparities because of issues arising from models of decision-making that focus mainly on treating the body as a material object.

I then move to discuss traditional scientific models of medicine, upon which popular models of decision-making are built, and the material body and objectivity in medicine. After presenting the view that contemporary medicine has grounded itself on a view of the body as a scientific material thing to be studied, I discuss issues of models of medicine, such as the exclusion of important psychological, social, and cultural factors of the individual from being included in the deliberation of a patient’s diagnosis and treatment options. I argue that these issues stem from models built largely on a biocentric view of the body that neglects a view of the patient as an individual subjective being.

I suggest an alternative approach based in the phenomenological method and highlight the theoretical notion of the presuppositionless starting point of phenomenology, which momentarily sets aside all preconceived thoughts and knowledge in order to focus on the individual first-person perspective of the patient. Using the philosophy of Merleau-Ponty, I explicate this view by moving to discuss in depth the importance of

perception in phenomenology and the experience of one's own body. In this way, the subjective experience of the patient is shown to be a fundamental condition of her embodiment.

Next, I move to expand on Havi Carel's work on a phenomenology of illness and how phenomenology can be applied specifically to the context of the patient in the medical encounter. Here, I distinguish between the objective body, as traditionally approached by medicine, and the lived body, as presented by phenomenology. This distinction is critical to understanding how illness disrupts our everyday lives. And because our lives are lived by us as human beings, illness is shown to disrupt our *whole being*, of both body and subject. Following this, I highlight the epistemic value of the patient's testimonial experience, knowledge often excluded or neglected in the decision-making process in medicine. I then note the role that the patient's testimony can play in helping to insert empathy into the clinician-patient relationship.

After introducing a view of a phenomenology of medicine and illness, I discuss the role of integrating the knowledge gained about and from the patient through a phenomenological approach in medicine into shared decision-making. Without denying the critical importance of scientific and medical knowledge, an integrative approach of phenomenology in shared decision-making highlights how the patient's knowledge about her own experience can be considered in the decision-making about her care and well-being. It asserts that knowledge about the patient's experience of her lived body should be included alongside knowledge about her objective body, in addition to the clinical and medical knowledge available to the clinician.

I conclude by suggesting that an integrative approach inclusive of phenomenology and shared decision-making can help begin to address disparities in healthcare by approaching the patient from a theoretically bias-free standpoint and by correcting the injustice of ignoring the stories of vulnerable persons. Doing so not only affirms the autonomy of such persons, but also encourages the patient to assert her agency by placing her at the center of the decision-making process. And the epistemic justice that comes about by valuing and including the experiences and stories of vulnerable persons, can begin to be seen as social justice in medicine, too, when adopted into the larger structure of medicine as an institution.

CHAPTER 2: HEALTHCARE DISPARITIES AND ISSUES OF DECISION-MAKING IN MEDICINE

Disparities of ‘At Risk’/Vulnerable Populations

Disparities in healthcare are complex and due to a multitude of factors, including among them stereotypes, biases, and an overall neglect by medicine to properly value and understand a patient’s preferences, emotions, and psychology during the decision-making process. Additionally, disparities in healthcare exist because of a perceived lack of individual attention to the patient by the clinician, with patients feeling as if they are not being heard or treated as individuals. While disparities in healthcare can exist amongst persons generally, vulnerable groups, including racial and ethnic minorities, women, and LGBTQ persons, are especially prone to experiencing disparities in health and healthcare.

Consider first that racial disparities are prevalent in both cardiac decision making and the quality of pain management. Fewer black patients receive invasive cardiac procedures than do white patients and report not being heard by their clinician or not being given personal, individualized attention.⁶ Such issues relate to an expressed need for a clinician-patient relationship whereby the clinician is empathetic to the symptoms and complaints of the patient in front of them. And similarly, with regards to the quality of pain care, black patients are less likely than their white counterparts to receive adequate treatment for pain management or to have their story about their pain heard by anesthesiologists.⁷ Likewise, women, especially of color, suffering from breast cancer

⁶ Ferguson, Jeffrey A., Morris Weinberger, Glenda R. Westmoreland, Lorrie A. Mamlin, Douglas S. Segar, James Y. Green, Douglas K. Martin, and William M. Tierney. “Racial Disparity in Cardiac Decision Making.” *Arch Intern Med* 158 (July 13, 1998): 1450–53.

⁷ Green, Carmen. “Racial and Ethnic Disparities in the Quality of Pain Care.” *Anesthesiology* V, no. 106 (January 2007): 6–8.

are also less likely to feel as if they are heard by their clinicians, resulting in disparities in treatment options. Women of color, low-income, and the uninsured are all observed to receive substandard care at higher rates than their respective counter groups with respect to the treatment of breast cancer.⁸ Lastly, LGBTQ persons are also at higher risk for health and healthcare disparities when compared to the general population, including for substance abuse, cancers, cardiovascular disease, mental health issues and suicide.⁹

Common ground for such vulnerable groups is their minority social identities and shared historical nature of being socially marginalized. Persons of color, women, and LGBTQ persons have all historically been socially isolated, mistreated, and had their views and opinions neglected or suppressed. While much of their historical discrimination has been due to biases and prejudices, problems continue to exist for each respective group, even as society becomes more diverse and inclusive. As a result, continued disparities in healthcare arise not necessarily from a place of conscious thinking, but, at least partly, from a standpoint of implicit, or nonconscious, bias which in turn has negative consequences on the decision-making process.

Implicit Bias

Implicit bias involves the association of stereotypes and prejudices outside of our conscious awareness that leads to an evaluation either in favor of or against a person or group of persons based on irrelevant characteristics. Any number of factors about a

⁸ Polacek, G.N.L.J., Mary Carol Ramos, and Robert L. Ferrer. "Breast Cancer Disparities and Decision-Making among U.S. Women." *Patient Education and Counseling*, no. 65 (2007): 158–65. This example additionally highlights the issue that whenever one vulnerable social identity intersects with another (e.g., a woman of color) the risk for stereotypes and biases is compounded.

⁹ Hafeez, H, M Zeshan, MA Tahir, N Jahan, and S Naveed. "Health Care Disparities Among Lesbian, Gay, Bisexual, and Transgender Youth: A Literature Review." *Cureus* 20, no. 9 (April 20, 2017): e1184.

person may be subject to bias, including age, gender, gender expression, sexual orientation, race, ethnicity, physical disabilities, and social factors like socioeconomic status and education level. Such implicit biases shape our attitudes, beliefs, and behaviors, and when directed against a person or group can result in the discrimination and victimization of others. And by virtue of varying exposure to social and cultural attitudes, we are all prone to having implicit biases.

In medicine, implicit bias refers to when a healthcare provider employs negative prejudices and stereotypes about a patient without being consciously aware of doing so. Such implicit biases may not be plainly expressed but are nevertheless applied in everyday clinician-patient interactions and are disruptive to the decision-making process in medicine. Especially concerning the implicit biases that are unfavorable towards and operate to the disadvantage of already ‘at risk’ or vulnerable patient populations.¹⁰ The application of implicit biases against vulnerable patient groups contributes to the cause of disparities in health and healthcare for such ‘at risk’ populations and perpetuates negative stereotypes generally.

For example, clinicians have been shown to exhibit implicit bias when deciding treatment options for black patients suffering myocardial infarctions.¹¹ Implicit stereotypes of black patients, such as being less cooperative with medical procedures, have led to a disparity in the use of thrombolysis as treatment for myocardial infarctions between black patients and white patients. This suggests that implicit biases may

¹⁰ Fitzgerald, Chloë, and Samia Hurst. “Implicit Bias in Healthcare Professionals: A Systematic Review.” *BMC Med Ethics* 18, no. 19 (March 2017). <https://doi.org/10.1186/s12910-017-0179-8>, p. 2.

¹¹ Green, AR, DJ Pallin, LH Ngo, Li Iezzoni, and MR Banaji. “Implicit Bias among Physicians and Its Prediction of Thrombolysis Decisions for Black and White Patients.” *J Gen Intern Med* 22, no. 9 (June 27, 2007): 131–38. <https://doi.org/10.1007/s11606-007-0258-5>.

contribute to racial disparities in the quality of and access to healthcare. Similar issues of clinician implicit bias are experienced by women and LGBTQ persons, and likewise present significant challenges to their gaining access to an adequate quality of healthcare.

Much like persons of color, LGBTQ persons suffer forms of both implicit and explicit bias such as victimization, discrimination, and insensitivity, including in their interactions with clinicians and the healthcare system. When clinicians internalize heterosexism, they implicitly “hold and act in accordance with anti-LGBTQ stereotypes and attitudes.”¹² Unaddressed biases can lead to assumptions, like asking what one’s husband or wife’s name is, or thinking that all men play a singular role in sexual activity. This can lead to having negative consequences on the health and decisions for LGBTQ persons. For example, when clinicians fail to understand the nonheteronormative sexual roles of gay men, and so do not inquire about sexual activity beyond asking whether one is sexually active, gay men may miss critical screening for colorectal cancer and for human papillomavirus. And in the same vein, LGBTQ persons may be hesitant to disclose to their clinician their sexual identity, which could be important to an individual’s diagnosis and treatment. Not disclosing their sexual identity to their medical care providers, whether it be out of fear of discrimination, insensitivity, or a perceived lack of trust or empathy, could have adverse effects on the healthcare LGBTQ persons receive.

It is clear the role implicit bias and prejudice can play in the decision-making process, and the overall complexity in making decisions in medicine. This complexity

¹² Foglia, Mary Beth, and Karen I. Fredriksen-Goldsen. “Health Disparities among LGBT Older Adults and the Role of Nonconscious Bias.” *Hasting Cent Rep.* 44, no. 04 (September 2014): S40–44. <https://doi.org/10.1002/hast.369>.

can also extend beyond ‘at risk’ populations to all patients, especially when considering the goals, values, and knowledge of both clinician and patient and whether they align or are equally acknowledged. This is due, in part, to the popularity of the biomedical model in medicine which views the body as object, creating a gap between the patient’s subjective understanding of her own body and experience of her illness and the clinician’s goal of restoring the objective body to health or some sense of ‘normalcy.’ This and other issues can be seen arising from imperfect models of decision making, including traditional models like paternalism and informed decision-making, both of which fail to fully account for both the value of objectivity in medicine *and* the individual subjective experience of the patient.

Imperfect Models of Decision-Making

Paternalism is the practice whereby healthcare providers withhold information from the patient and make decisions entirely on their own, often without any discussion or input from the patient. In doing so, paternalism restricts the freedom, autonomy, and agency of the patient. And because models of decision-making grounded in paternalism ignore a full account of the patient experience, patient decisions are made based predominantly on the clinician’s preferences, goals, and values. Rather than including the patient in the decision-making process in any meaningful way, paternalism keeps the patient, as the person she is, at bay. If paternalism represents the extreme of decision-making in the direction of the clinician, informed decision-making is its antithesis.

A model of informed decision-making presents information to the patient and relies on the patient to make her own decision based on that information. While more approachable than paternalism, the information presented to the patient under informed

decision-making is likely to be based on purely objective or empirical factors and not tailored to the patient in any specific way that accounts for her individual experience or desires. And while necessary, information alone is not sufficient for a patient to make a medical decision; other factors like attitudes, culture, experience, and emotions all may affect the perception of information. In this way, informed decision-making still fails to consider the patient fully in the decision-making process.

Paternalistic and informed models of decision-making view the body predominantly as an object, disregarding a full account of the patient as an individual person. At least one reason for this is that paternalism and informed decision-making are built on medical models that also treat the body as a scientific object, including the biomedical model and arguably the biopsychosocial model, too.

CHAPTER 3: THE BIOMEDICAL MODEL AND THE BODY AS MATERIAL OBJECT

Traditional Scientific Models of Medicine

The prevailing popular approach to modern medicine has centered around the biomedical model, organizing our approach to medicine in scientific terms.¹³ Built on a framework that views the body as a material object, the biomedical model neglects any meaningful acknowledgement of the patient as subject and her subjective experience. It does not consider non-biological factors like a patient's psychology or social situation and defines patients based on a diagnosis of disease and discrete medical categories.

One apt description of the biomedical approach says that, "[p]atients suffer from diseases which can be categorised in the same way as other natural phenomena" and describes disease as being independent from the person who is suffering and from her social context.¹⁴ Thus, the biomedical model implicitly assumes that the idea of disease is separate from the person suffering from it. And the role of the clinician under the biomedical model is one of a detached observer whose "main task is to diagnose the patient's disease" and "whose effectiveness is independent of gender or beliefs."¹⁵ Distancing the clinician from the patient in this way implies that there is little or no value in the interaction and relationship between the clinician and patient. However, in order to get at the patient in a way that can help begin to resolve disparities in healthcare, any

¹³ Gifford, Fred. "The Biomedical Model and the Biopsychosocial Model in Medicine." In *The Routledge Companion to Philosophy of Medicine*, 445–54. New York: Routledge, 2017.

¹⁴ IR McWhinney. *A Textbook of Family Medicine*. London: Oxford University Press, 1988. p. 46.

¹⁵ *Ibid.*

model of medicine must at least see the patient as more than a diseased object that fits neatly into discrete categories.

In an attempt to resolve issues of the biomedical model, a biopsychosocial model was introduced to get closer to approaching the patient as an individual by urging the inclusion of psychological and social factors into how we conceptualize medicine.¹⁶ However, despite the urging to include more subjective factors about the patient into our knowledge of medicine, the biopsychosocial model nevertheless maintains an overly scientific view of both the patient and of medicine generally. While acknowledging some social and psychological features of the patient, methods in medicine under the biopsychosocial model still rely heavily on empirically based measures and an objective view of the body. In affirming a scientific, evidence-based approach, the biopsychosocial model leaves little to no room for the patient as an individual.¹⁷ As a result, the biopsychosocial model lacks its own robust framework apart from the biomedical model, leaving as the popular approach to medicine one that predominantly views the body as object.

The Material Body and Objectivity in Medicine

Viewing the body as a material object reduces the patient to a medical category or diagnosis and restricts our view of illness to nothing more than bodily dysfunction. For example, patients suffering from heart disease and cerebrovascular accidents are commonly defined by their disease category and grouped together in hospital units called

¹⁶ Engel, George L. "The Need for a New Medical Model: A Challenge for Biomedicine." *Science* 196, no. 4286 (April 8, 1977): 129–96.

¹⁷ Smith, R.C., A.H. Fortin, F. Dwamena, and R.M. Frankel. "An Evidence-Based Patient-Centered Method Makes the Biopsychosocial Model Scientific." *Patient Education and Counseling* 91 (2013): 265–70.

heart failure and stroke units, respectively. In similar fashion, patients are often applied general medical labels like ‘depressed’, ‘AIDS patient’, and ‘infectious.’ Rather than seeing the patient with a diagnosis as the individual person she is, a person who has beliefs, emotions, and real-world experiences, all of which affect her experience of her illness, the lens of biomedicine focuses on the body as a material object. Following this and based on the biomedical model, objectivity in medicine adheres to medically objective findings, such as radiographic images, laboratory testing, and other visible factors.¹⁸

Given this view of the body as material object and of epistemological objectivity in medicine, and the many kinds of advanced testing available to medicine today, one could imagine diagnosing a patient without ever examining or even laying eyes on her. For example, many cases of hypertension or pre-diabetes go unnoticed until diagnostic and laboratory testing show a problem to exist. These two disease categories, hypertension and pre-diabetes, like many others, could be applied to a patient by examination of knowledge from the medical chart alone. Doing so, however, would fail to provide a meaningful account of the patient’s individual subjective experience, which could provide additional information and knowledge—for example, the potential cause of the hypertension, such as stress or a high sodium diet. While the biopsychosocial model *may* capture this information, it does not do so necessarily. And, because of its reliance on empirically-based measurement, the biopsychosocial model is still ultimately

¹⁸ Solli, Hans Magnus, and António Barbosa da Silva. “Objectivity Applied to Embodied Subjects in Health Care and Social Security Medicine: Definition of a Comprehensive Concept of Cognitive Objectivity and Criteria for Its Application.” *BMC Medical Ethics* 19, no. 15 (March 2, 2018). This notion of objectivity in medicine is distinguished from objectivity in an ontological or ethical sense.

biocentric and overly scientific, primarily grounding itself in objective measures of the patient encounter.

As such, both the biomedical and biopsychosocial models of medicine, and their intimate relationship with empirically-based medicine, make decisions based on evidence from well-conducted research, while neglecting the full and subjective experience of the individual patient. In this sense, objectivity in medicine builds itself on a view of the body as object and takes as its epistemological foundation primarily those objective measures readily available to medicine. While this kind of evidence provides critical insight into the pathology of a patient's disease, it ignores her subjective experience of illness and how her individual account could factor into the decision-making process.

Issues of Scientific Models of Medicine

Seeing the body as a material object excludes important psychological, social, and cultural factors from being included into the deliberation of a patient's diagnosis and treatment options. This kind of tunnel vision has significant implications, especially with respect to what treatment options should be considered best in the context of the patient's goals, values, and preferences. In order to properly address issues of decision-making arising from the biomedical and biopsychosocial models, especially those that contribute directly to disparities in healthcare, we must re-conceive of how we view the body and with it the distinction between disease as biological dysfunction versus illness as a person's suffering from a disease. In other words, we must begin to shift medicine's perspective of the body away from the view of the body as a medical object and towards a model that considers the patient's subjective experience and fully accounts for the patient as an individual person. Phenomenology provides a good alternative framework

on which to approach medicine by providing us with the means to distinguish between the objective body and our bodies as we experience them.

By the light of phenomenology, illness is conceived of from the experiential perspective of the patient and is described as a distinct way of being in the world “characterized not simply by bodily dysfunction but by a concurrent disruption of self and the surrounding world.”¹⁹ Phenomenology gives room for the appearance of illness as such by orienting our approach in medicine to a way that “account[s] for the body’s central role in human life and acknowledge[s] the primacy of perception.”²⁰ At the same time, phenomenology demands of medicine the space for a rich and meaningful interaction between clinician and patient by which one comes to better understand the other. Thus, phenomenology shows us that, by way of returning to a pre-reflective, pre-scientific world of experience, there is more to medicine than just disease and the notion of patients as objects in general.

In order to more fully understand the patient as the person she is and how her sense of self becomes disrupted in illness, phenomenology looks past the body as material object and to the experience of the subjective body and the first-person perspective of the patient. In seeking to understand the entire process and context of medical decision-making from the patient’s perspective, we can begin to address disparities in health and healthcare arising from issues in decision-making.

¹⁹ Toombs, S. Kay. “The Body in Multiple Sclerosis: A Patient’s Perspective.” In *The Body in Medical Thought and Practice*, edited by Drew Leder. Dordrecht: Kluwer Academic Publishers, 1992. p. 127.

²⁰ Carel, Havi. “Phenomenology and Its Application in Medicine.” *Theoretical Medicine and Bioethics*, no. 32 (2011). p. 35.

CHAPTER 4: PHENOMENOLOGY, EMBODIMENT, AND THE LIVED BODY EXPERIENCE

While the biomedical and biopsychosocial models of medicine describe the body, disease, and illness in the context of the objective or scientific world, phenomenology suggests focusing on what is immediately available to us, namely on our perception and subjective experiences. Conceived of as a different way of getting to the truth of things, phenomenology describes *phenomena* and concerns itself with what it is like for humans to exist in the world.²¹ The term phenomenology was first used to describe “a science of *appearance* which allows us to proceed from appearances to truth.”²² Rather than explaining knowledge in terms of pre-conceived mental representations, phenomenology focuses on our conscious experience, taking experiential evidence as its explanation of knowledge.

Contemporary philosophy grounds phenomenology in the work of Edmund Husserl where phenomenology is described as being a “presuppositionless science of consciousness” with its own distinct method.²³ The goal of phenomenology, in general, is to return to ‘pure consciousness’ so that we may understand the world *as it appears* to us, as if seeing it for the first time. In order to arrive at a presuppositionless starting point, and integral to phenomenology, is the suspension or ‘bracketing’ of beliefs and explanations, which involves a kind of phenomenological reduction by not assuming

²¹ Moran, Dorat. *Introduction to Phenomenology*. New York: Routledge, 2000. p. 4.

²² *Ibid.*, p. 6 – The term phenomenology is credited to Johann Heinrich Lambert when, in the eighteenth century, he used it to describe a science of appearance (*Schein*) which allows us to get to the truth of things by way of their appearances. It was later employed, in various ways, by others including Kant, Fichte, and Hegel.

²³ *Ibid.*, p. 60.

“any philosophical or scientific theory, and rejecting even deductive reasoning, mathematics, and empirical science, in order to focus on describing what is given directly in experience.”²⁴ Thus, an approach to science and medicine via the phenomenological method requires setting aside all beliefs and explanations before understanding the phenomena within. By suspending all theory and conceptual knowledge, phenomenology clarifies for medicine what the biomedical and biopsychosocial models cannot, namely that there is more to the patient than a diagnosis and any absolute path it is meant to follow. In this way, phenomenology challenges medicine, and science in general, as a universal enterprise that can be modeled and manipulated and the notion that everything appears to us as objects-in-general.

Merleau-Ponty’s ‘Phenomenology of Perception’

One account of phenomenology that builds on that of Husserl’s, and which is particularly fruitful for approaching the body in medicine, is that offered by Maurice Merleau-Ponty, where in his *Phenomenology of Perception* he provides a view of humans as embodied individuals, with a body-subject that arises from acts of perception.²⁵ Merleau-Ponty follows Husserl in rejecting the Kantian notion of the thing-in-itself and undertakes a phenomenological reduction to describe how our pre-conceptual experience aims to correct the distorted view that objective thought, itself unaware of the subject of perception, presents the world as already made. Instead, our view of experience must rely on our pre-conceptual experience through the world of perception.

²⁴ Carel, Havi. *Phenomenology of Illness*. New York: Oxford University Press, 2018. p. 25.

²⁵ The term ‘body-subject’ is used by Merleau-Ponty (2014) to refer to the inseparability of the objective and subjective body. Our bodies exist as physical things, but at the same time our physical bodies contain within it our subjective beings, that part of us that expresses things like emotions and preferences.

Phenomenological Reduction

In suspending beliefs and explanations, the phenomenological lens focuses on the origin of the thing left before us. Merleau-Ponty describes our pre-conceptual experience and what he means by returning to the things themselves when he tells us:

to return to that world which precedes knowledge, of which knowledge always *speaks*, and in relation to which all every scientific schematization is an abstract and derivative sign-language, as is geography in relation to the countryside in which we have learned beforehand what a forest, a prairie or a river is.²⁶

In order to understand things as they are before we attribute beliefs and explanations to them, we must return to the origin of the thing in the world. Before we learn that a large area covered with trees is a forest, we see just the geography of a large area with trees as such. The reduction in Merleau-Ponty's phenomenology thus seeks a return to our perceptual pre-conceptual experiences as a way to describe the real world.

Phenomenology shows us how we place ourselves into the world through our perception and bodily actions which in turn guide us into a world that is described and not constructed of pre-conceived conceptions.²⁷ Our bodies are intimately related to the world in such a way that we experience the world all at once, and such that the self and the world are seen as inseparable.²⁸ Merleau-Ponty tells us that, "Our own body (*le corps propre*) is in the world as the heart is in the organism; it keeps the visible spectacle constantly alive, it breathes life into it and sustains it inwardly, and with it forms a

²⁶ Merleau-Ponty – ix; iii.

²⁷ *Ibid.* – x; iv.

²⁸ *Ibid.* – x; iv-v.

system.”²⁹ A related and important feature of phenomenology then is the lived body, which gives us the means to see human beings as fundamentally belonging to the world and not merely as objects in the world.

One's Own Body

Merleau-Ponty distinguishes between the inanimate body as object and one's own lived body (*le corps propre*).³⁰ The body as object is a material thing, whereas *the lived body* describes the body as the human being that an individual is. The lived body is the body through which I feel and sense things, and through which I find meaning. In describing the permanence of one's own lived body Merleau-Ponty says that:

When classical psychology described *one's own body*, it already attributed 'characteristics' to it that are incompatible with the status of an object. It first claimed that my body is distinguished from the table or the lamp because *my body is constantly perceived*, whereas I can turn away from these other objects.³¹

That I can turn away from other objects while constantly perceiving my own body shows that my experience with my own body is distinct from my experience with inanimate objects in the world. And unlike inanimate objects, I do not just occupy space with my body, but I *inhabit* space in the world; I *live* in it.³² We project ourselves into the world via our lived experience and more specifically, through our perception and activity.

²⁹ *Ibid.* – p. 209 - *Le corps propre* is directly translated as 'the proper body' but is taken to mean 'one's own body.' Contemporary philosophers working on phenomenology have used the term 'lived body' which is more closely related with Husserl's notion of *Leib*. In this paper, I follow those contemporary philosophers in using the phrase lived body in reference to Merleau-Ponty's notion of *le corps propre*.

³⁰ *Ibid.*, pp. 92-95.

³¹ *Ibid.* p. 93 – Emphasis added.

³² Moran, p. 424.

Embodiment as a Condition of Subjective Experience

Merleau-Ponty's phenomenological account of human experience illustrates perception itself to be an embodied activity.³³ The foundation of human subjectivity is perception and the lived body is the body as we experience it from the first-person perspective. According to Merleau-Ponty, I experience the world as an embodied subject in the sense that my body *as I live it* represents how I perceive the world. And in order for me to sense and perceive things requires the capabilities of my body. For me to be able to touch and feel touch I must have skin and an intact nervous system. In order to see, I must have eyes and a working functional ability of my eyes. To smell, I must have a nose. Although Merleau-Ponty admits that the body is a physical thing, *to be* is more than to just have a physical body; it is to also have a lived body through which we consciously experience the world around us.³⁴ Merleau-Ponty does not make an empirical claim about perception but rather offers a transcendental view, asserting the body as the condition for our perception and actions which make possible experiencing the world.³⁵ As such, consciousness is seen as being inseparable from the body and embodiment becomes a condition for subjectivity.³⁶ Merleau-Ponty's notion of body-subject thus represents an experience of *being* peculiar to human beings as founded on perception.

Intertwined with the view that my lived body is the locus of my being is the idea that my lived body is also the focal point of my bodily intentions, intending itself "toward

³³ Merleau-Ponty, p. 23.

³⁴ Carel, Havi. *Illness - The Cry of Flesh*. Revised Edition. New York: Routledge, 2013. p. 27

³⁵ Carel (2018), p. 27.

³⁶ Merleau-Ponty, p. 146.

objects, directing itself at goals, and acting in a way that is ‘about’ aims and objects.”³⁷

When I reach for a fork I am intending toward a specific object, the fork. Contained in the action of reaching for the fork, picking up the fork, gathering food onto the fork, and bringing the fork to my mouth is the intention that I am doing so in order to eat food off the fork. In reaching for the fork, and in all of my actions, the lived body is central to what I am intending, representing the relationship between the body and its intending toward some object or goal. Thus, the body is not just the medium through which we act but is also the goal of our actions.³⁸

Central to being human then, according to Merleau-Ponty, is our ability to perceive and act and so experience things in the world. And as humans, our bodies are intimately involved with the world and respond immediately to changes within it. This emphasis on perception and the body is what makes Merleau-Ponty’s account of embodied phenomenology especially suitable for re-conceiving our approach to medicine and our understanding of the difference between disease and illness. Rather than seeing disease and illness as one and the same, a phenomenological understanding of illness sees it as the suffering and experience of having a disease from the first-person perspective of the ill person.³⁹ To understand the patient from her own perspective, including how she perceives her own illness and how it has affected her world, requires setting aside all pre-

³⁷ Carel (2013), p. 29; see also Kay Toombs, S. “The Lived Experience of Disability.” *Human Studies* 18 (1995), p. 11.

³⁸ Merleau-Ponty, p. 114.

³⁹ The concepts of disease and illness are too often conflated with one another. Bjørn Hofmann (2002) gives us a good distinction of of disease, illness, and sickness - disease being the condition treated by the clinician, illness as the experience of disease by the patient, and sickness as the social aspect of illness. He notes that the complexity of different perspectives on human ailment explains why it is so difficult to give strict definitions of basic concepts within modern health care.

conceived beliefs and explanations so that we may acknowledge her lived body experience and give value to the patient's experiential testimony.

CHAPTER 5: PHENOMENOLOGY OF MEDICINE AND THE ILL BODY

Distinction between the Objective and Lived Body

A phenomenology of medicine can be used to describe the experience of illness by focusing the clinical gaze on the individual, first-person perspective of what it is like to suffer from an illness. In this way, phenomenology provides a unique account of the subjective and embodied patient experience. Moreover, a phenomenology of medicine views disease and illness not as being equal to one another but distinguishes illness as the full human experience associated with a biological disruption of the body. Without diminishing the importance of a scientific or objective description of the body, phenomenology precludes any biological dysfunction of the body from being perceived as *purely* biological, because according to phenomenology there is nothing about the human experience that is solely biological.⁴⁰ As beings who are social creatures and exhibit culture, the experience of being human extends beyond the body as object; being human involves both the body as object *and* the lived body.

Disruption of the Habitual Nature of the Body in Illness

In the everyday experience of a healthy person, the body as an object of medicine and the first-person experience of the lived body are seen as being harmonious with one another. When the body is healthy it falls to the background of our various daily functions, and our attention is turned away from the body and towards our goals and intentions.⁴¹

⁴⁰ Carel (2013), p. 16.

⁴¹ Carel (2011), pp. 39-40.

For example, when my body is healthy and not encumbered with disease or injury, I do not consciously think about having to put one foot in front of the other in order to walk; I simply do so. My intention is to walk and so I walk. When my body is healthy, there is no disruption between my body and my surrounding world; my bodily intentions are unhindered. I go about my day-to-day activities, such as walking, showering, running, or riding my bicycle with little if any effort or thought. However, when the body becomes ill, our attention turns inward, towards the body, and rather than remaining in the background of our activities the body becomes our focus.⁴²

If I break my leg, walking will not be as easy and unhindered as before. I may now have to take several movements to stand and pivot in order to walk. I may even not be able to walk at all without the aid of crutches. When my leg is not broken, I perform such actions like walking with ease because they have become habitual, or second-nature, for me. In illness, however, a division erupts between the objective and the lived body, exposing how illness can disrupt our habitual bodily intentions.⁴³ When our bodies are ill, we have to re-learn how to navigate not only our physical world but our social world, too. When my body is ill, I may require extended time off from work or school. Or, I may receive unending questions from friends or worse, silence and distance. If my illness has any obvious external component—for example, it may require the use of a wheelchair or it may have a feature visible to others like a discoloration of the skin—I may receive awkward stares from strangers. Our awareness of our body and the role it plays in our everyday lives is thus heightened when confronted with illness. In this way, when the

⁴² *Ibid.*

⁴³ Carel (2013), pp. 32-35.

balance of the body is disrupted by illness, the distinction between the objective body and the lived body becomes noticeable.

One example that provides a clear illustration of the rift between the objective and the lived body can be observed in persons with panic disorder. When we view the objective body exhibiting an episode of acute panic, we may find a person to be hyperventilating and short of breath, have an elevated heart rate, have chest pains, and/or suffer from profuse sweating. These are all objective measurements that can be observed by examining the biological body. And while these symptoms are unpleasant, in the absence of a serious condition they are not typically life-threatening. However, if we ask the patient suffering the panic attack *how she feels* and *what she is experiencing*, she may describe a sense of terror or feeling of impending doom, as if her whole world is collapsing around her, all despite evidence pointing to the contrary. Her everyday tasks, and with it her habitual body, may become disrupted by her panic disorder. She may not go running because she fears an elevated heart rate will trigger a new panic attack. Or, she may be so fearful of suffering another episode of panic that she never leaves her house. Here we can see clearly the division between the objective body and the lived body, or the body as it is experienced, in illness. Properly understanding this division “gives us the tools to describe the impact of illness.”⁴⁴

The distinction between the objective and the lived body as revealed by illness is critical to a more holistic approach in medicine, which often is aimed at restoring the objective body to health, or some sense of biological normalcy, rather than addressing the patient’s lived experience. While medical intervention aims to restore the body to some

⁴⁴ *Ibid.* p. 35.

healthy measure of function, it neglects the complexity in the relationship between disease and illness. Illness as experienced by the first-person perspective of the patient is, by definition, unavailable to clinicians and healthcare providers, who take a second-person perspective in their observation of the patient. This can result in the disease being treated without acknowledging or treating the experience and suffering of the patient, too.

By demanding the space in medicine to describe one's experience and to have one's experience heard, phenomenology provides the patient with the resources and tools she needs to communicate to others about her experience of illness and suffering. At the same time, the patient's experience as described by her through phenomenology can be shown to be epistemically valuable, providing knowledge about the patient that we might otherwise not have access to. In turn, this knowledge can be used to assist in the decision-making process and can help to determine how best to address the personal, social, and emotional challenges that can accompany having an illness.

Epistemic Value of the Patient's Experiential Testimony

When healthcare providers fail to listen to the patient, or misunderstand, ignore, or otherwise reject what the patient has to say, they are also ignoring the value inherent to the patient's standpoint and thus also her situational knowledge. In doing so, medicine imposes an injustice against the patient, and against itself, too, by neglecting the possibility of collecting new information and knowledge about the patient and her condition. In other words, the patient suffers an injustice which is uniquely epistemic from her standpoint as a patient in her capacity as knower of her own experience.

Despite the awareness called to the epistemic dimension of complaints made by patients against clinicians not listening to them or recognizing their stories, patients

continue to be epistemically marginalized. Epistemic injustice in medicine is done when negative stereotypes and biases about the patient and her illness are applied to the patient in such a way that silences or fails to listen to or give recognition to her voice and her story. Patients' testimonial experiences are often met by clinicians with disbelief or dismissiveness. In doing so, a crucial opportunity is missed to learn something about the patient that may otherwise be unavailable to them. Two kinds of distinctively epistemic injustice are particularly notable and can readily be observed in medicine, including testimonial and hermeneutical injustice, both of which are important to patients generally but are especially significant for patients belonging to vulnerable groups.⁴⁵

Epistemic Injustice in Illness

Testimonial Injustice

Testimonial injustice occurs when prejudice causes a person's story or testimony of her experience to be disbelieved or dismissed, thereby deflating her credibility as a knower of knowledge unique to her individual standpoint. It is not difficult to imagine stories where clinicians and healthcare providers either fail to listen to the patient or, if they do listen to her story, consider it to be irrelevant and so exclude it from epistemic consideration. Focusing on the epistemic dimension of such cases, we can see how the patient's experiential testimony can be disbelieved or dismissed as confused, irrelevant, or emotional.

⁴⁵ Fricker, Miranda. *Epistemic Injustice: Power & The Ethics of Knowing*. New York: Oxford University Press, 2007. For a detailed application of Fricker's notion of epistemic injustice in healthcare, see Havi Carel's *Phenomenology of Illness* (2018), Ch. 8.

Take the example of a black woman with a history of pulmonary emboli who complains of difficulty breathing after giving birth via caesarean section.⁴⁶ Upon telling her care team what she felt was happening to her body, based on her previous experiences, and asking for further diagnostic tests and treatment, she was dismissed as being confused due to pain medication. And, given the prevalence of disparities in healthcare amongst women of color, it is not unbelievable that implicit bias likely played a role in the dismissal of her testimony by virtue of her identity as a black woman, putting her and her story at a disadvantage to being believed. Eventually, and only after further insistence from the patient, a scan of her lungs was performed, pulmonary emboli were found, and the patient was started on the appropriate treatment. Fortunately for the patient, her medical care team eventually came to validate her experiential testimony, even if they did not believe it until the scan of her lungs resulted. Not all patients are so lucky, however, and too often medicine ignores the testimony of a patient's experience.

While testimonial injustice is caused when a prejudice is inflicted against an individual's story in such a way that fails to consider it epistemically, hermeneutical injustice comes about "when a gap in collective interpretive resources puts someone at an unfair disadvantage when it comes to making sense of their social experiences."⁴⁷ Although hermeneutical injustices may be either structural or incidental, my focus is on those cases which are structural and more systematic, involving persistent hermeneutical marginalization of vulnerable groups as part of a general pattern of social power.

⁴⁶ I have adopted this example from the reported experience of celebrity tennis star Serena Williams. Haskill, Rob. "Serena Williams on Motherhood, Marriage, and Making Her Comeback." *Vogue*, January 10, 2018. <https://www.vogue.com/article/serena-williams-vogue-cover-interview-february-2018>.

⁴⁷ Fricker, p. 1.

Hermeneutical Injustice

In illness, hermeneutical injustice occurs when the patient's interpretations of her own experience are ignored or dismissed by the institution of medicine or otherwise "implicitly excluded through the establishment of a culture in which patient views are not respected or included within policy."⁴⁸ When medicine has not yet recognized or accepted the patient's interpretation of her story it also fails to consider the epistemic importance of their self-interpretation. For example, one reason for the marginalization of transgender patients is due to a social environment that is reliant on a dualistic notion of gender which pervades into the medical setting. Exacerbating their vulnerability is the fact that transgenderism is often treated pathologically and viewed in the literature as a kind of transsexualism, leaving a gap in our knowledge about what it means to be transgender.⁴⁹ Medicine as an institution has not yet developed the interpretative resources with which to understand transgenderism fully, thereby placing transgender persons at a disadvantage when it comes to making sense of both their experience as a transgender person and how transgenderism intersects with illness.

One step towards correcting epistemic injustices in healthcare is to incorporate the standpoint epistemology of patients, especially those of marginalized and vulnerable groups, into the broader medical knowledge. Doing so would reveal to us "that inclusion of patient perspectives has the potential to shift understandings of disease away from narrow biological processes to more holistic, socioculturally grounded understandings of

⁴⁸ Carel (2018) p. 188.

⁴⁹ Burdge, B.J. "A Phenomenology of Transgenderism as a Valued Life Experience among Transgender Adults in the Midwestern United States." Doctoral dissertation, Indiana University. Ann Arbor, MI: Proquest, 2013.

wellness and deviations from it.”⁵⁰ Additionally, by recognizing the story of the patient as told from her first-person perspective can help develop a more empathic relationship between clinician and patient.

Empathy

To approach the patient as an individual person and not just as a medical object, we must reorient our view of the body and illness towards one that still sees the objective body but also takes seriously the patient’s perspective of suffering and her experience. Medicine requires something more than than a view of the objective body; it also requires *listening* to the patient’s account and empathizing with the patient.⁵¹

In observing simultaneously the patient’s body as object and body as subject, clinicians take a second-person perspective that demands the recognition of the patient’s shared humanity, capacity for suffering, and mortality⁵² The patient is not composed just of an objective body for medical study but is fundamentally a body-subject, existing not just as a thing, but as a *living* human being whose objective body is inseperable from her subjective being. Upon examination, she is not stationary and abstract, rather she is alive and responsive; when touched, she touches back, and when spoken to, she responds. Seeing the patient this way and listening to the patient tell her lived body experience makes us aware that she is more than just an objective thing to be studied or categorically treated.

⁵⁰ Ankeny, Rachel A. “The Role of Patient Perspectives in Clinical Case Reporting.” In *Knowing and Acting in Medicine*, 97–112. New York: Rowman & Littlefield, 2017. p. 106.

⁵¹ Jaspers, Karl. *General Psychopathology*. Translated by JJ Hoenig and MW Hamilton. Baltimore, MD: Johns Hopkins University Press, 1962. p. 55.

⁵² Carel (2018) p. 54.

Patients have emotions, preferences, values, and distinct psychologies, all of which are important to understanding their illness and distinguishes them as beings who are more than abstract medical diagnoses. Listening and empathizing with the patient in a way that incorporates the patient's lived body experience into the decision-making process in a meaningful way requires a model that can account for both the value of objectivity in medicine *and* the individual subjective experience of the patient.

CHAPTER 6: INTEGRATING A PHENOMENOLOGY OF ILLNESS INTO A MODEL OF SHARED DECISION-MAKING

Traditional models of decision-making in medicine have been shown to fail to account for the whole patient as a body-subject and lack the capacity for an active dialogue between the patient and clinician. A model of shared decision-making offers the space for such dialogue, where information can be reciprocally shared between both clinician and patient. In offering the space for information to be shared, and particularly listened to, shared decision-making provides the opportunity to include the patient's experience and suffering in decisions about her care.

Additionally, shared decision-making not only preserves a patient's autonomy but recognizes and encourages a patient's agency, or her capacity to make decisions and advocate for herself. The principal of agency differs from autonomy in that it accounts for the fact that not everyone is given equal opportunity to make their own decisions, especially in the context of certain social factors like race, gender, sexual orientation, and gender expression. Integrating phenomenology into shared decision-making, explicitly recognizes a patient's agency through her capacity to provide the context of her experience of her illness and to make decisions for herself based on her experience and in collaboration with the knowledge brought to her situation by the clinician. As such, shared decision-making, like phenomenology, has the general quality of an individualized approach to the full patient experience of illness without abandoning the science of medicine.⁵³

⁵³ Makoul and Clayman, p. 305.

Knowledge and Shared Decision-Making in Medicine

Shared decision-making is defined as “an approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences.”⁵⁴ It requires mutual respect between clinician and patient, “consisting of discussions between professional and patient that bring the knowledge, concerns, and perspective of each to the process of seeking agreement on a course of treatment.”⁵⁵ When viewed this way, the patient’s experiential testimony enters as ‘new’ knowledge to be considered alongside professional knowledge during the decision-making process. Moreover, a process of shared decision-making “also has psychological, social and emotional factors that will influence this deliberation space and that will need to be managed by an effective clinician-patient dialogue.”⁵⁶ In other words, phenomenology is ripe for integrating into a model of shared-decision making as a way of more fully getting at the patient experience when considering concepts of illness and treatment. And there is a duality to phenomenology in the context of shared decision-making, allowing for easy application into the decision-making process.

The Lived Body Experience in Shared Decision-Making

Phenomenology provides the necessary tools for the patient to communicate her feelings and concerns about her illness and suffering to her medical care team.

Phenomenology, as well as shared decision-making, gives the space for the patient to

⁵⁴ Elwyn, G, A Coulter, S. Laitner, E. Walker, P. Watson, and R. Thomas. “Implementing Shared Decision Making in the NHS.” *BMJ*, no. 341 (2011): c5146.

⁵⁵ President’s Commission Report, p. 44 – Italics added.

⁵⁶ Elwyn, et al. p. 1363.

participate in an active dialogue with her clinician about her own experience of her illness and to share her concerns and desires, providing critical insight into the patient's first-person perspective of her illness. Additionally, by focusing the clinical gaze on the patient as an individual (rather than as an abstract medical category) and on her subjective experience, phenomenology provides a theoretical framework from which the clinician can set aside her own social and professional biases, stereotypes, and prejudices in order to approach the patient in a more holistic and meaningful way.

At the same time, there is nothing about either phenomenology or shared decision-making which abandons the value of objectivity in medicine, such as objective factors of the patient chart and evidence-based measures in medical decision-making. Integrating phenomenology into a model of shared decision-making only demands the space to acknowledge and consider the patient's subjective experience within the context of the decision-making process about treatment options and end goals. In general, such an integrative approach individualizes the patient encounter and does not make decisions solely on empirical measures, but at the same time does not abandon them wholly. Consider the following example about cases of perceived fear versus reality of colonoscopy as routine screening for colorectal cancer, which illustrates how such an integrative approach can be applied in medicine.

One of the primary barriers to colonoscopy is fear of the procedure.⁵⁷ When a patient declines a colonoscopy, and before offering less efficacious alternatives, the clinician should inquire of the patient her reasons why she does not want the

⁵⁷ Basch, Corey, Charles Basch, Patricia Zybert, and Randi Wolf. "Fear as a Barrier to Asymptomatic Colonoscopy Screening in an Urban Minority Population with Health Insurance." *Journal of Community Health* 41, no. 4 (2016): 818–24.

colonoscopy. If fear is identified as a motivating factor, the clinician should acknowledge her fear and recognize it as part of her story needing to be integrated into the clinician-patient communication as well as the decision-making process. In this way, the clinician can work to alleviate the patient's fear through an open discussion about the procedure and by the communicating that there is little negative consequence to routine screening by colonoscopy. Or, if discomfort and pain control is an aspect of the patient's fear, it can also be incorporated into the larger decision-making conversation about the procedure beforehand.⁵⁸ The patient could be offered the option of complete sedation and presented with the risks and benefits. Or, she could be given the option during the procedure to request more sedation if she feels she requires it or if the procedure takes longer than expected. Another example which highlights the application of an approach integrative of phenomenology and shared decision-making can be found in cases of autoimmune conditions.

Autoimmune conditions are historically difficult to accurately diagnose due to their overlap in presentation and common symptoms, such as fatigue and joint pain. In many such cases, it is not unusual for patients' stories to be dismissed or neglected for years before an accurate diagnosis is made by a competent clinician who values listening to the patient and believes her story.⁵⁹ Still, when they are finally diagnosed appropriately, decisions about patient care often fail to fully consider the patient's experience and day-to-day life, exacting still an injustice against the patient and her self-

⁵⁸ "Coping with Fear of Colonoscopy." *Consumer Reports on Health* 16, no. 7 (July 2004): 10.

⁵⁹ Falk, Ron. *Having an Autoimmune Condition...Without Having a Clear Diagnosis*. Audio. Accessed December 11, 2018. <https://www.med.unc.edu/medicine/news/chairs-corner/podcast/autoimmune-unclear-diagnosis>.

described experience.⁶⁰ Treatment options for autoimmune conditions vary, and some can be incredibly demanding on the body, both physically and mentally; this can often be overlooked as just a side-effect of treatment. However, if the patient is young, and active to the extent that her condition allows her, and she expresses a desire to stay as active as possible, then that should be considered in the context of deliberating her treatment options with her clinician. Or, if a patient describes that a treatment is overly taxing or has drastically altered her world, this should be valued and considered by the clinician and alternative options should be explored. In this way, phenomenology not only acknowledges the patient's story as real, but it also provides her with the tools to communicate her desires, values, and concerns to her clinician for consideration in the decision-making process. Additionally, because of the vast complexity of autoimmune conditions, there is sure to be a great deal of epistemic value bound up in the patient story which can help not only her own case but can provide knowledge more generally in the context of autoimmune conditions.

In the above examples, an approach integrative of phenomenology and a model of shared decision-making shows how the patient's story can be made real and acknowledged by her clinician without denying the value of objectivity in medicine. While informed patient preferences may be the optimal ingredients of decisions, there is a critical need for a space to communicate with a patient about her preferences, and more importantly about her experience. Coupling a phenomenological approach with shared decision-making could help clinicians assist patients in their decision-making by listening to patients' stories as told from their perspective and providing relevant background

⁶⁰ Carel (2018), pp. 181-189.

information to the feelings and concerns expressed by patients. When decisions are made in a shared space that accounts for the patient's subjective experience, we can better understand decisions based on their negative and positive consequences and make decisions that are more consistent with personal preferences. Thus, phenomenology integrated into a model of shared decision-making offers to close the gap in patient-clinician communication regarding the distinction between the objective body and the lived body in illness.

Phenomenology in medicine is more than just asking the patient her preferences; it provides a methodological framework from which to approach the patient from a bias free starting point and to understand her as an individual being and so humanize her as the person she is. At the same time, a model of shared decision-making acknowledges the knowledge, preferences, and values of both the patient and the clinician. And both phenomenology and shared decision-making in medicine demand the space for an active dialogue between the patient and clinician. That we listen to the patient and consider her perspective, concerns, and experience in the deliberation about treatment options highlights important common features between phenomenology and shared decision-making. And because integrating phenomenology into shared decision-making shifts our focus away from the scientific medical body and towards one that is more socioculturally grounded in the lived body experience of the patient as an individual, such an approach has also the opportunity for addressing and correcting disparities in healthcare.

CHAPTER 7: ADDRESSING HEALTHCARE DISPARITIES THROUGH A PHENOMENOLOGICAL APPROACH IN SHARED DECISION-MAKING

As discussed above, healthcare disparities result from the neglect of patients' emotions, values, and preferences, a lack of a shared space for communication, issues of bias and stereotyping, and, more generally, issues of imperfect models of medicine and decision-making. By approaching the patient as an individual being and not just a medical object, an integrative model of phenomenology and shared decision-making can help begin to address disparities in healthcare. This approach continues the push by medicine towards more individualized, patient centered care by grounding itself in the individual experience of the patient, in addition to the science of medicine. It has the added benefit of theoretically setting aside biases so that we can see past our preconceived notions of things and begin our encounters with others from a bias-free starting point.

Seeing Past Barriers

The theoretically bias-free framework that phenomenology provides can allow for healthcare providers to see beyond everyday boundaries and barriers, like bias (both explicit and implicit), stereotypes, and prejudices, that pervade medicine and prevent equal access to healthcare for vulnerable and marginalized persons. When trained in the phenomenological method, clinicians can begin to focus on the whole patient more fully, without holding the kinds of biases and stereotypes that cause disparities in healthcare. This includes not only biases about the patient, but also preconceived notions of medicine and decision-making.

Approaching the patient from a bias-free standpoint gives room to understand the whole patient first before turning to understanding the patient's body as a medical object. The two views, when taken together, expand on the notion of epistemological objectivity in medicine, turning away from a view focused predominantly on diagnostic and laboratory tests and towards one that is more inclusive of the patient's subjective testimony of her lived body experience. This further gives medicine the opportunity to understand the perspectives and values of marginalized persons whose voices have historically been systematically silenced by society and in medicine. When listened to, these perspectives and values can be taken as knowledge of the patient's individual experience, and has have the ability to inform medicine more generally about those populations that have otherwise been ignored or neglected in medicine and excluded from medical knowledge.

Patients have the situational standpoint of being the ill person and so have knowledge of how a condition *feels* and whether a particular treatment is causing them pain or discomfort.⁶¹ Although clinicians have scientific and medical knowledge, patients have knowledge unique to themselves as individuals and the condition from which they are suffering. While traditional models of medicine and decision-making neglect or do not take serious the patient's perspective of her condition, an integrative model of phenomenology and shared-decision acknowledges the patient's first-person perspective and includes it into the decision-making process. Such a model does not ignore the scientific and medical knowledge available to the clinician, it only demands that it be temporarily set aside so that the knowledge the patient brings to the encounter is properly

⁶¹ Carel (2018), p. 194 (see also Carel 2011, 2013)

listened to and considered and not merely dismissed in light of the science. Listening to the patient and acknowledging her individual experience of her condition places the patient at the center of the decision-making process in medicine and takes the knowledge of her experience of illness into consideration when deliberating in a shared space about treatment options and goals.

Epistemic Justice as Social Justice

In calling attention to the patient's individual experience, phenomenology justifies the patient's story as real and along with it its epistemic value, all of which is further legitimized by the clinician in the space of shared decision-making. Thus, an integrative approach to medicine inclusive of both phenomenology and shared decision-making begins to make the patient's story epistemically just by reorienting the perspective of medicine in such a way that accounts for the epistemic value of the patient's experiential testimony. This is all the more important when the patient belongs to a marginalized vulnerable population who regularly suffers the injustice of having their voices silenced by those more privileged in medicine and society.

When we realize and acknowledge the lived body experience of persons of ethnic and racial identities, women, and LGBTQ persons, amongst others, we give value to their voices, as well as to their notion of agency. This is further advanced by giving rise to the notion that there is unique epistemological value bound up in the experiential testimonies of such marginalized persons. The experience of a black person is different from that of a white person. And the experience of women is different from that of men, and transgender persons, who themselves have different experiences from both men and women. The voices and perspective of systematically marginalized patients in medicine

are critical to their own wellbeing and should be acknowledged rather than suppressed; and their capacity to make their own decisions ought to be encouraged, not stifled. This is true not only for the individual medical encounter, but also for the larger conversation of medical knowledge and hospital policy. The more voices and perspectives that can be added to the conversation about what hospital policies should be, and more broadly about what constitutes medical knowledge, the more robust our knowledge and view of medicine will become.

CHAPTER 8: CONCLUSION

Phenomenology is a good framework on which to approach questions surrounding the concern in medicine about how to integrate the context and values of patient perspectives with general conceptions of illness and treatment, as well as the disparities in healthcare that come about as a result of these concerns. It provides an approach to medicine that views the body as more than a material object, realizing the patient's lived body experience as real and meaningful in the context of her illness. Rather than ignoring or only cursorily acknowledging the patient's subjecting experience, phenomenology seeks it out in order to understand more fully the patient as a whole. As such, phenomenology presents itself as a suitable replacement to the traditional biocentric models of medicine, offering a view of the patient as a human being with a body-subject, whose two features of objectivity and subjectivity are inseparable from one another.

Like phenomenology, shared decision-making emphasizes the importance of perspective, a focus on the patient as an individual, and the need for a common space between clinician and patient to deliberate and achieve a shared outcome that is in-line with the patient's values and preferences. A phenomenological approach to shared decision-making in medicine can help clinicians acknowledge the patient's subjective experience and incorporate it into the decision-making process. It goes beyond preserving the patient's autonomy by empowering her sense of agency and encouraging her to be an active participant in making decisions for and about herself.

Given the overlap of important features between phenomenology and shared decision-making, integrating one into the other seems logical in order to provide for a more individual, patient-centered approach in medicine. And by focusing on the patient

as an individual and placing her at the center of the decision-making process about her own care, medicine can begin to address the disparities in healthcare that have been caused by the marginalization and neglect of vulnerable patient populations. Additionally, the epistemic justice that can come about by this approach, by valuing and including the experiences and stories of vulnerable persons, can begin to be seen as social justice in medicine, too, when adopted into the larger structure of medicine as an institution.

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