IS PHENOMENOLOGY THE BEST APPROACH TO HEALTH CARE RESEARCH?

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BEING ENCAPSULATED BY INTRODUCTION WITH EMMERSING INTO BODILY EXPERIENCES OF HEALTH AND ILLNESS

- Towards a Phenomenology of Illness
- Being-in-the-World: Health, Illness, and “Home”
- The Lived Experience of Illness

BEING HOLDED BY STARTING POINTS OF PHENOMENOLOGY OF MEDICINE

- The primary focus of phenomenology is the essence of particular phenomenon or lived experience. Phenomenology is both a school of philosophy associated with the works of Hans-Georg Gadamer, Edmund Husserls, Martin Heidegger, Maurice Merleau-Ponty and a methodology.

- Each of these philosophers created a slightly different school of phenomenological thought, e.g. Gadamer's work focused on the philosophical and historical aspects, Husserl's on transcendental psychology, Heidegger's on hermeneutic phenomenology, Merleau-Ponty on existential phenomenology,

- Ricoeur was particularly concerned with interpretation, primarily with interpreting text. He stated that human action should be understood as text and that such an approach would enable better understanding and interpretation.

- But all share important constituent elements.

- From methodological point of view, methodologist, who use / apply the philosophies of particular philosophers, are connected to particular research disciplines, for example,
- Giorgi and Malterud methodological versions of phenomenology in psychology (based on Husserl);
- van Manen methodological version of phenomenology in education (based on Heidegger);
- Holmes (publications from 1998) in clinical psychology, psychotherapy and health sciences (based on Heidegger);
- Anders Lindseth, Astrid Norberg, Sirkka-Liisa Ekman Helena Dahlberg (reflective life-world research) methodological versions of phenomenology in nursing (based on Ricoeur and Merleau-Ponty);
- Robert Keith Show methodological version of phenomenology in management;
- Fredrik Svenaeus methodological version of phenomenology in medicine (based on Heidegger);
- phenomenological sociology by Alfred Schütz, Max Weber, Edmund Husserl and etc.

- The philosophical foundation of hermeneutic phenomenology provides direction for phenomenological research, which focuses on uniqueness of the lived experience or essence of a particular phenomenon.
- As such, phenomenology is always anchored in the lifeworld of the individual and the meaning making associated with being-in-the-world.

From phenomenological point of view, to do research is always to question the way we experience the world, to want to know the world in which we live as human being. And since to know the world is profoundly to be in the world in a certain way, the act of researching-questioning-theorizing is the intentional act of attaching ourselves to the world, to become more fully part of it, or better, to become the world. Phenomenology calls this inseparable connection to the world the principle of "intentionality" (Max van Manen, 1990, p. 5).

- An important, yet challenging, principle to grasp in phenomenological research is that this lifeworld is prereflective.
- That is, uncovering the essence of experience means surfacing the meaning or the structure of the experience itself, rather than providing a conceptualisation of the experience. This requires great thoughtfulness and caring (Heidegger, 1926/1962).

- van Manen (1990) explained this distinction: “Phenomenology … differs from almost every other science in that it attempts to gain insightful descriptions of the way we experience the world prereflectively, without taxomizing, classifying, or abstracting it”, and it “offers us the possibility of plausible insights that bring us in more direct contact with the world (p. 9).

Central question of phenomenologists is the following: “What is the meaning, structure, and essence of the lived experience of this phenomenon for this person or group of people?” (Patton, 2002, p. 104).

PHENOMENOLOGY IN MEDICAL / HEALTH CARE RESEARCH

In 2000, Swedish philosopher Fredrik Svenaeus published a book where he proposes that the phenomenological hermeneutics of Martin Heidegger and also the reflections on health and illness of Hans-Georg Gadamer offer important ways to approach the nature of medicine.

In particular, Svenaeus argues that the goal of medicine is to promote and restore health, and that health ought to be seen as "homelike being-in-the-world".

Unhealth, illness, consequently should be understood as a situation where a person's "being-in-the-world" in characterized by that lack of the rhythm, balance and "tune" of everyday living that characterizes not "being at home”.

Medical discourse currently manages two broad visionary movements: “evidence-based medicine,” the effort to make clinical medicine more responsive to the medical research, and “patient-centered care,” the platform for a more humane health-care encounter.

There have been strong calls to synthesize the two as “evidence-based patient-centred care” (Lacy and Backer 2008; Borgmeyer 2005; Baumann, Lewis, and Gutterman 2007; Krahn and Naglie 2008).

As the 1970s critiques of biomedicine's inhumanity increased in force, phenomenological themes were invoked in order to overcome those challenges, creating the edgling study of "medical phenomenology."

This was a promising avenue: Edmund Husserl's (1970) insight that a comprehensive science requires the synthesis of first- and third-person perspectives seems to capture the problematic of the cold and distanced objectivity that characterized biomedicine as well as the missing empathy that patients so badly needed.

The lifespan of this phenomenological effort to unite the art and science of medicine proved to be brief, however; vigorous efforts ended in the early 1990s and related fields like narrative ethics and embodiment studies took off instead.

I argue for a return to the early efforts of medical phenomenology to unite science and the lifeworld, but to do so within a contemporized context.

The “intertwined medicine” that medical phenomenologists drew out of Husserl’s efforts to reunite science and the lifeworld captures the health-care goals built into the integrated “evidence-based patient-centered care” program.

Yet despite the successes in developing an innovative theory of illness, there are theoretical deficiencies that limit medical phenomenology’s philosophical relevance and the extent to which it can respond to the call for evidence-based patient-centered care.

The phenomenology of medicine, with its preoccupation with integrating science and humanism, has been weak on the issue of embodiment in its effort to conceptualize a model of medicine that is responsive to the lived experiences, and premised on the lived bodies of patients.

As a result, a problematic “absent body” has tacitly operated in phenomenological thought.

This problem has only been exacerbated by excellent advances in embodiment studies, especially the theorizing of the visceral body, which are not reflected in the medical phenomenology literature.

The second problem with medical phenomenology is in its conceptualization of modern medicine.

Medical phenomenology's targeted enemy "biomedicine" is now out of date and must be revised to reflect the new "evidence-based" medicine.

While medical phenomenology offered impressive theoretical insight—most significantly a rich alternative theory of illness—advances in both embodiment studies and medical research highlight the need for a new phenomenology: a phenomenology of the embodied subject in the age of evidence-based medicine.

Integrated medicine:evidence-based patient-centered care

Evidence-based medicine **(EBM)** was introduced into the medical literature 27 years ago (Evidence-Based Medicine Working Group 1992), and it quickly rose to become the largely undisputed standard of best practice in most areas of health care.

The program begins with the seemingly simple and defensible goal of basing health-care treatment on the best evidence.

Its founders, clinical epidemiologists from McMaster University in Canada, diagnosed the problems and shortcomings of modern medicine as stemming from the discipline's overreliance on intuition, habits, and unsystematic clinical experience in patient care.

They established the evidence-based approach as its remedy: a rigorous and methodical approach to clinical decision making that is grounded in the best and most current research evidence.

The randomized controlled trial holds pride of place as the gold standard in clinical research, and so it sits on top of the EBM's "hierarchy of evidence."

EBM distinguishes itself from pre-evidence-based biomedicine by its orientation toward outcomes research, while biomedicine is more dependent on bench science.

Biomedical research entails laboratory science that aims to reveal the mechanisms of medical cause-and-effect in order to determine what ought to be effective, while EBM seeks to generate probabilistic knowledge regarding what is likely to work, for whatever reason (Tanenbaum 1994, 28; Goldenberg 2009, 172).

When some of the doubters challenge that biomedicine had indeed *always* been evidence based—what other kind of medicine could there possibly be?—they are missing how EBM has introduced new standards for what counts as *best* evidence.

Such is the significance that clinical epidemiology is now held by some to be a *basic* medical science (Fletcher 2005, 3; Upshur 1999, 320).

EBM's promise of ridding medicine of its faulty intuitions and untested customs and elevating the scientific rigor of the discipline to improve patient care has proved to be enormously appealing.

It spread quickly to all other areas of health care.

At this point, it would be difficult to overstate the political and professional capital of this movement, as evidence-based health care is thought to increase professional responsibility and accountability, improve patient care, and make managed care and health research more cost effective by ensuring that only the most promising technologies are funded.

The minority opinion holds that evidence-based health care manages to create a linear decision-making framework in which evidence can be the *basis* of treatment decision making for individual patients by narrowing the modes of acceptable research methodology and forms of reliable evidence by imposing an overly rigid hierarchy of evidence.

To do this is to misrepresent the complexities of clinical decision making.

Furthermore, EBM's roots in epidemiology create a "fragmented" picture of medical knowledge that overprivileges aggregate measure and separates "expertise from expert . . . knowledge from knower, and the distillation of medical truth outside the clinical encounter" (Tanenbaum 1995, 102).

By giving credibility to the belief that better knowledge of what is efficacious or appropriate medical action is obtained outside the clinical encounter by individuals who have no direct familiarity with the patient (biostatisticians, epidemiologists, etc.), the evidence-based approach to health care takes authority away from the practitioner and silences any epistemic legitimacy that patients may claim to have pertaining to their illness and treatment.

EBM remains noticeably silent on the values, preferences, and other subjective content that inescapably enter into all decision-making schemas.

This critique regarding the erasure of the patient is particularly forceful given the parallel vogue of “patient-centered care” in clinical medicine.

Like evidence- based medicine, “patient-centered care” is widely broadcasted on the websites and other media outlets of major health-care institutions with an eye toward instilling public trust and con dence in their institutional practices.

EBM is implicated in this move to make the patient, rather than the evidence or other possible candidates, central.

The calls for patient-centered care challenge at some level EBM's strong assumption that the evidence somehow dictates best practice.

Leaving aside the familiar post-positivist critique that the evidence cannot dictate theory choice (or, if you like, not without considerable interpretive and subjective qualifications; see, for example, Goldenberg 2006), patient-centeredness is certainly supportive of medical research and EBM's commitment to finding the *best* evidence.

However, it rejects the foundational model of an evidence-*based* medicine.

Furthermore, it seems to flip the evidence-based hierarchy of evidence on its head when its advocates suggest that it is qualitative research that will likely illuminate the intrinsic holism of the therapeutic relationship that is so central to patient-centered care.

Medical phenomenology

Phenomenology is the study of phenomena ("that which appears") as they present themselves to consciousness (or how they appear to us from a first-person perspective). This philosophical approach is grounded in Edmund Husserl's belief that the objectivism of science precludes an adequate apprehension of the world (Husserl 1970).

Phenomenological methodology involves radical reflection on everyday objects and events—phenomenologists take on a "phenomenological attitude" that suspends one's taken-for-granted presuppositions about the nature of "reality" and one's commitments to certain habitual ways of interpreting the world.[4]

“Medical practice, though it has gained much of the last century in clinical efficacy, has lost something as well. Most importantly, it has progressively lost the human touch. Patients are often treated in a depersonalized, even dehumanized fashion within the modern health-care system. Their suffering is not heard and responded to; their wishes are not incorporated fully into treatment decisions; their resources for self-healing are not called into play” (Leder 1992b, 1)

“Staying abreast of the new developments often meant that while physicians were obliged to be and to remain technically competent, they rarely had the time or inclination to be alert to moral issues, religious values, or social concerns”
(Zaner 1988, 4; Cassell 1973; Pellegrino 1979)

"A great gulf exists between the way we think about disease as physicians and the way we experience it as people. Much of this separation derives directly from our basic assumptions about what illness is. Our medical world view is rooted in an anatomicopathologic view of disease that precludes a rigorous understanding of the experience of illness. What we need to remedy this problem is not just the admonition to remember that our patients are people, but a radical restructuring of what we take disease to be. The philosophic discipline of phenomenology is used to present a vision of disease that begins with an understanding of illness as it is lived. "Nonmedical" descriptions of illness show how we can reorient our thinking to encompass both our traditional paradigm and one that takes human experience as seriously as it takes anatomy" (Baron 1985, 606)

The body in medical epistemology

Biomedicine is argued to rely on a vision of the body as machine that undercuts the subjectivity of patients. The mechanical body was a feature of the mechanistic philosophy that marked the Scientific Revolution, where Cartesian thought replaced the scholastic teleological view of nature with the materialist *res extensa*.

The body was similarly desouled, depurposed, deanimated, and understood instead to be driven by mechanical forces.

Michel Foucault points to the historically significant conceptual mechanization of the body that took place in late-Renaissance European human medicine as the study of anatomy and pathology flourished (Foucault 1994, 122).

This cognitive shift permitted a necessary relaxing of social and religious taboos regarding autopsy.

The phenomenology of illness and dis-ease and intertwined medicine

Rather than being defined by its disease category or symptomology, illness is reconceived from an experiential perspective.

Illness, phenomenologists explain, is experienced as a sense of disorder (Baron 1985, 609) and is a distinct way of being in the world "characterized not simply by bodily disfunction but by a concurrent disruption of self and the surrounding world" (Toombs 1992, 127; Toombs 1988).

Pain, disease, and disorder oblige a loss of the taken-for-grantedness of our bodies and disrupt the previous ease and "everydayness" of things (Scarry 1985; Toombs 1992).

The concept of health is thus recast not as the absence of disease, but rather as “a state of unselfconscious being that illness shatters” (Baron 1985, 609; Toombs 1992, 127).

Illness is a problem of embodiment, as the usual effortless and unself-conscious unity of the body and the self is disrupted, making one pay explicit attention to the body as suddenly problematic (and separate or alien from the self).

The phenomenological theory of illness has been further developed into an alternative model of medicine: an “intertwined medicine”—built on physiology *and* intentionality, empiricism *and* phenomenology.

Much like the proposed integration of the evidence-based and patient-centered platforms, intertwined medicine is supposed to synthesize the specialized experiences and perceptual insights offered by scientific medicine with the lived experience of illness, and manage to do so without overwhelming the humanistic variables of health care.

Science perspectives are understood by phenomenologists to reveal aspects of corporeality unavailable to ordinary vision and to clarify the structural correlates to intentional capabilities.

Thus rather than replace the scientific perspective, phenomenologists instead challenge its monolithic status.

The absent body in medical phenomenology

This theory of illness as rupture of the previously taken-for-granted body and self is phenomenological in its use of the experiential center as the conceptual starting point.

In trying to understand what *is* this "lived body" on which an intertwined medicine would be premised, however, one still has a better sense of what it is *not* rather than what it is.

Similar to the way in which patient-centered care was defined earlier largely by what it is not, the lived body is similarly captured in its opposition—*not* anatomically or physiologically described, not a machine, not a corpse.

While this insight amply challenges many of the defficiencies identified in scientific medicine, we have yet to see a phenomenology of the embodied subject.

My legs carry me toward a desired goal seen across the distance. My hands reach out to take up tools, reconstructing the natural surroundings into an abode uniquely suited to my body. My actions are motivated by emotions, needs, desires, that well up from a corporeal self. Relations with others are based upon our mutuality of gaze and touch, our speech, our resonances of feeling and perspective. (Leder 1990, 1)

“When reading a book or lost in thought, my own bodily system may be the farthest thing from my awareness. I experientially dwell in a world of ideas, paying little heed to my physical sensations or posture. Nor is this forgetfulness restricted to moments of higher-level cognition. I may be engaged in a fierce sport, muscles exed and responsive to the slightest movements of my opponent. Yet it is precisely upon this opponent, this game, that my attention dwells, not on my own embodiment” (Leder 1990, 1)

The malfunctioning body intrudes itself into our everyday existence, becoming the focal point and object of attention. In particular, the body presents itself as an oppositional force which curtails activities, thwarts plans and projects, and disrupts our involvements with the surrounding world. In various and varied ways, the body is experienced as essentially alien, as that which is Other-than-me. (Toombs 1992, 127)

An important consequence, vis-à-vis the history of ideas, of this empirical–experiential support for a phenomenology of bodily absence and presence is an *experiential affirming of the mind–body dualism*.

Indeed, Toombs uses language of separation of body and self in the bodily otherness that her progressive disability invokes.

The Cartesian dualist paradigm is frequently argued by its critics to prevail in our cultural imaginary due to rigid ontological commitments at the expense of lived experience.

The “experience” of illness as rupture of the absent body instead offers a deep-rooted experiential basis for Cartesian dualism.

This maligning of the body in the mind–body binary will raise concern for the numerous philosophical schools that variously deny binary thinking.

For feminists, for instance, this phenomenology of illness reinforces the dualistic thinking and again privileges the mind and other “male-coded” binaries (culture, reason, abstract) over their “feminine” counterparts: body, nature, emotion, concrete.

Denying the absent body

What these examples amount to is a *very* present body—one that is constantly monitored and examined for fear of immanent breakdown.

Bodily absence appears to be a luxury bestowed to only some privileged men.

Women, people of color, people who do not meet heterosexist norms, and people with disabilities experience a bodily presence in part because their bodies mark them as vulnerable to violence.

The phenomenology of illness rightly acknowledges the “able-ist” dimensions of the absent body: people with pain, mobility and motility issues, and acute or chronic illness have a present body.

But bodily absence is not the shared experience of health and functionality.

In sum, we see that what began as an intuitively appealing theory of illness—the experience of problematic bodily presence—suffers in its healthy converse: the alleged experience of bodily absence.

…while bodily states of rapid change need not be dysfunctional, they are indeed problematic. This might be seen as analogous to the time of mastering a new skill. The pregnant woman must attend to her body as its new functions and shape require alternations in patterns of movement, diet, sleep, etc. The very temporal and spatio-functional unity of her body are called into question. (Leder 1990, 91)

An objection

It is the object body that is reflected back to women when they are objectified.

It is also the strange and present body experienced by people in pain.

The phenomenal body is our primordial openness to the world and to others and is the (bodily) *basis* of experience.

This openness tends to shut down when we are ill and our world closes in.

At this point, the object body comes to the fore.

The phenomenal body can never disappear entirely, however, as it is our phenomenal openness to the world that underlies our embodied being.

This ontology explains the concept of "bodily absence," the body's disappearance when we are engaged in the world, without the gendered problem of the privileged body.

The experience of illness as rupture of absent body is also explained: when we are ill, we are reminded deeply of the object aspect of our bodies, yet this reminding is possible because we are fundamentally open and experiential.

According to Merleau-Ponty, for the body to exist as a transcendent presence to the world and the immediate enactment of intentions, it cannot exist as an ***object****. . . . As subject, the body is referred not onto itself but onto the world's possibilities. "In order that we may be able to move our body towards an object, the object must first exist for it, our body must not belong to the realm of the 'in-itself.'"* (Merleau-Ponty quoted in Young 1990b, 150)

[F]or feminine existence the body frequently is both subject and object for itself at the same time and in reference to the same act. Feminine bodily existence is frequently not a pure presence to the world because it is referred onto ***itself*** *as well as onto possibilities in the world*. (Young 1990b, 150)

By offering grounds for challenging the phenomenologically presumed separation of phenomenal and object body, the concept of absent body can be charged with upholding a tacit masculine bias.

Much like the medical scientists have been indicted for holding the male body as the norm—a move that underscores such widespread objectionable practices as the testing of most new medical interventions only on male subjects in clinical trials (see Dresser 1992; Marshall 2005a, 2005b; Holdcro 2007)—medical phenomenology must employ theoretical concepts that recognize and respect difference.

Conceptualizing modern medicine:

This is the age of evidence-based medicine

Phenomenological efforts to create an intertwined evidence-based patient-centered care will likely encounter problems because phenomenological approaches criticize an outdated picture of biomedicine that does not reflect the evidence-based movement's dramatic impact on medicine.

Picking up from my earlier comment that clinical epidemiology is now held by some to be a *basic* medical science,

I want to highlight the corporeal significance of this insofar as until the ascendancy of "clin epi," the only branches of scientific research held to be basic to medicine were those that directly studied the structures and functions of the inner corpus—physiology, anatomy, biochemistry, and so on. us medical research and practice are working from a very different conceptual framework than the biomedical focus on bench science.

The body-as-machine is still implicitly operating in evidence-based medicine insofar as this theory of body represents the reductionism of scientific medicine.

But this framework does not capture the changes that **EBM** has enacted in scientific medicine—away from the pathophysiology and bench science of biomedicine in favor of a more data-driven and statistical approach. Th*is* feature of the evidence-based program suggests the erasure of the individual body (mechanistic or not) as a consequence of this epistemic effort to create more universalizable biomedical knowledge.

As practicing physicians find themselves “straight jacketed” by the clinical guidelines and protocols that they are expected to follow (Loewy 2007), the patient’s voice has little resonance.

Even informed patient decision making may be reduced to “take it or leave it” with respect to the pre-established treatment protocol that follows from the patient’s clinical indicators (Bluhm 2009).

While biomedicine advanced the generic mechanization of the patient’s body, now the once allegedly interpretive “art” of clinical practice is being systematized via protocols, algorithms, and guidelines.

Further investigation into the implications of this epidemiological influence on the medical body is needed.

While a feminist bioethical focus on concretely situated living bodies is part of the necessary critical response to current discursive elements of medical epistemology, so is an account of the body within a data-driven framework.

Feminist technoscience studies provide an avenue into the latter issue.

Katherine Hayles (1999) investigates the doomed fate of “post-human” embodiment in an information age. In *Data Made Flesh* (2003), Robert Mitchell and Philip Thurtle similarly examine the status of the organic body in this era of biotechnology.

In *Data Made Flesh* (2003), Robert Mitchell and Philip Thurtle similarly examine the status of the organic body in this era of biotechnology. These ominous commentaries regarding the loss of the fleshy, mortal body due to cybernetics and informatics highlight the risk, described by Donna Haraway, of being "raptured out of the bodies that matter in the lust for information."

These comments are meant to inspire necessary questioning among feminist and nonfeminist health researchers alike regarding the status of the body in the data-driven health-care context.

The issue of how to incorporate the individual's first-hand experience of illness into broader medical understanding is a major question in medical theory and practice.

In a philosophical context, phenomenology, with its emphasis on the subject's perception of phenomena as the basis for knowledge and its questioning of naturalism, seems an obvious candidate for addressing these issues.

THANK YOU FOR ATTENTION

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