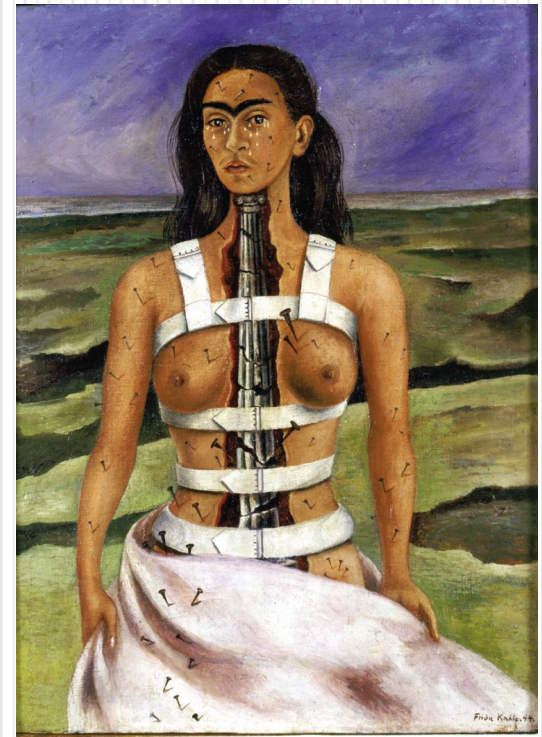


Phenomenology of Illness: a Philosophical Account of 'Patient Experience'

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The philosophical core of the experience of illness

- Near-universal
- Ill-understood
- What is the relationship between health (or its absence) and wellbeing?
- Is it possible to be ill and flourish?
- What aspects of the ill person's life are impacted by illness?
- What happens to the ill person's social world?
- How does self-understanding change in illness?
- Illuminate core features of the experience of illness
- Ask what physicians can do to alleviate painful aspects

Need for phenomenological account of the experience of illness

- Need to augment naturalistic approach *in clinical medicine*
- Illness: disruption of lived body, not just dysfunction of biological body
- Change in physical possibility transforms subjectivity
- Framework provided by phenomenology
- Can contribute to:
 - patient-physician relationship
 - self-understanding (patient toolkit)
 - improved care

Phenomenology

- Describes essential structure of experience
- Useful for illuminating:
 - Quality of subjective experiences
 - Their personal meanings
 - Their pattern and coherence
- Metaphysically modest
- Ideal content, not causal story



Pierre Bonnard, *The Bath*, 1925

Husserl on music apprehension

“The tone begins and “it” steadily continues. The now-tone changes into a tone-having-been; the *impressional* consciousness, constantly flowing, passes over into ever new *retentional* consciousness” (*On the Phenomenology of the Consciousness of Internal Time*, p.31).

Retention and protention –
conditions of possibility for
hearing a melody



Van Gogh, *A Pair of Shoes* (1886)



The Origin of the Work of Art (1936)

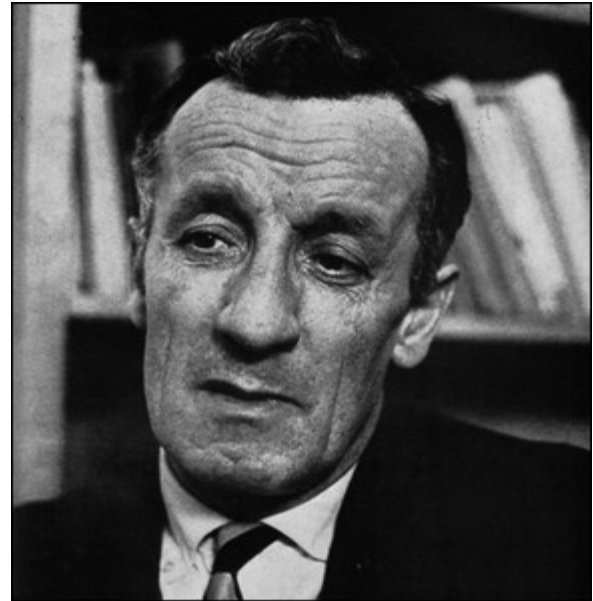
“From the dark opening of the worn insides of the shoes the toilsome tread of the worker stares forth. In the stiffly rugged heaviness of the shoes there is the accumulated tenacity of her slow trudge through the far-spreading and ever-uniform furrows of the field swept by a raw wind. On the leather lie the dampness and richness of the soil”

(*Basic Writings*, p. 159).



Embodied phenomenology

- Merleau-Ponty: beyond consciousness to the body; rejects mind-body dualism
- Perception as constitutive and embodied
- “... the body is considered a constitutive or transcendental principle, precisely because it is involved in the very possibility of experience” (Gallagher and Zahavi 2008, p.135).



Phenomenology of perception

- Sense-structure of experience
- Elucidates pre-reflective lived experience
- How we interpret everyday world



Motor intentionality

- Perceptual experience & subjectivity
- Intentional arc
- Habitual body
- Body-subject



Jessica Cox, armless pilot, US

Bodily intentionality

- Perceptual experience & subjectivity
- Intentional arc
- Objective body/ body as lived
- Habitual body
- Body-subject



Phenomenology of illness

- Asks how patients experience their disorder
- Disorder as embodied, enacted and situated
- How are embodied states lived as meaningful in an environment?



Jean-Dominique Bauby, *The Diving Bell and the Butterfly* (Julian Schnabel)

Phenomenology of illness

- Patient as 'being-in-the-world'
- Goals, action, attunement
- Illness as disruption of lived experience
- Physical possibility transforms subjectivity



Biological body vs. lived body

- Illness removes the body's transparency
- Rare opportunity to perceive the gap
- Experience of otherness and alienation
- Objective facts cease to tally with lived experience
- Focus on biological body: objectification



Experience of illness

- Redefines relationship to the world
- Physical, psychological, social and temporal adjustment (adaptability, creativity)
- Loss of agency, productive function, social participation and freedom; suffering
- Cannot be accounted for without appeal to lived experience



Frida Kahlo, *Henry Ford Hospital*, 1932

4 phenomenological accounts

1. Illness as Dis-ability
2. Illness as breakdown
3. Illness as
homelessness
4. Illness as loss



Amelia Kerr (www.outofourheads.net)

1. Illness as dis-ability

- Heidegger: existence as possibility
- Merleau-Ponty: possibility as ability to perform actions in the world
- Young: 'throwing like a girl'
- Impact on motility, comportment, spatiality



Throwing like a girl



2. Illness as breakdown

- Heidegger's tool analysis
- Breakdown: tools become conspicuous
- Health is transparent
- In illness the body becomes conspicuous
- Is the body a tool?
- No, but analogy works
- Local or overarching



3. Illness as homelessness

- The ill body as uncanny (Svenaeus)
- Illness as disorientation
- Medicine: providing a way home
- Health within illness



4. Essential features of illness

- Essential features of illness transcend particular features of different diseases
- Constitute the meaning of illness as lived
- This enables a shared world of meaning



4. Essential features of illness

**Kay Toombs: five losses
characterise all illness:**

1. Loss of wholeness
2. Loss of certainty
3. Loss of control
4. Loss of freedom to act
5. Loss of the familiar world

**Not all cases of illness
experience these losses**



Harriet Johnson

“Are we "worse off"? I don't think so. For those of us with congenital conditions, disability shapes all we are. Those disabled later in life adapt. We take constraints that *no one would choose* and build rich and satisfying lives within them”



Patient-physician relationship

- Illness represents two distinct realities ('worlds'), with two different meanings
- Decisive gap between patients' experience of illness and physicians view of disease
- These views are often in conflict



Patient-physician relationship

- Phenomenology discloses how individuals constitute the meaning of their experiences
- Illness is not an objective entity, but determined by how it is experienced by patient and physician
- Experience is encountered and attended to in terms of an individual's Situation
- Patient and physician attend to different aspects of illness



Patient-physician encounter

- Physician construes the illness as 'disease state',
- Patient encounters suffered illness *and* the disease
- Patient encounters the body as painfully-lived
- Different explanatory models



Deborah Padfield

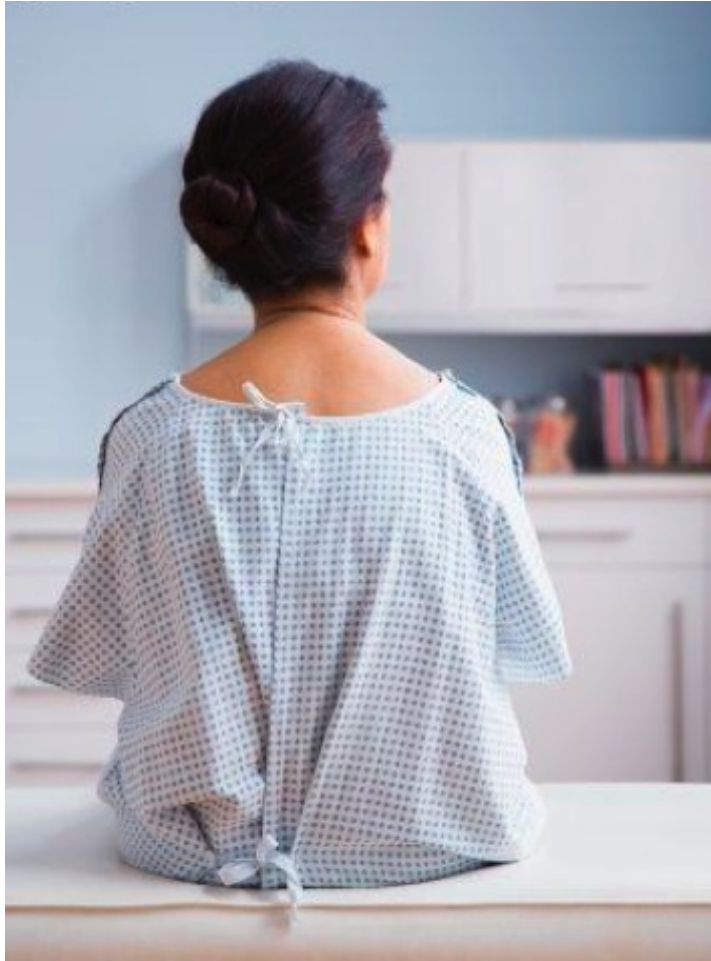
Systems of relevances

- Different goals:
 - diagnosis/ explanation
 - Treatment/ cure
 - Prognosis / prediction
- Patient attempts to integrate experience into daily life
- Patient seeks validation of experience
- Patients do not explicitly state what their values are
- Patient and physician do not share a system of relevances

Experience as evidence?

- Standpoint epistemology
- How else would we find out about:
 - Daily living with a health condition
 - Expertise gained by lived experience
 - How interventions are experienced/ felt/ remembered
 - Changes to self as a result of illness
- What is most important?
- Positive – yet unexpected – outcomes of illness:
 - Personal growth
 - Existential clarity
 - Posttraumatic growth

Conclusion



“What the phenomenological approach is concerned to show is not simply that the patient’s experience should be taken into account as a subjective accounting of an abstract ‘objective’ reality, but that the patient’s experiencing must be taken into account because such lived experience represents the reality of the patient’s illness.” (Toombs, p.236)

Thank you



- Phenomenology and its contribution to medicine (*Theoretical Medicine and Bioethics* 2010)
- Philosophy as a resource for patients (*Journal of Medicine and Philosophy* 2012)
- Bodily doubt (*Journal of Consciousness Studies* 2013)
- “How do you feel?”: oscillating perspectives in the clinic (*Lancet* 2012)
- Illness, phenomenology, and philosophical method (*Theoretical Medicine and Bioethics* 2013)
- Seen but not heard: children and epistemic injustice (*Lancet* 2014)
- Forthcoming book on PI & EI

Thank you!

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