Invisible suffering: a phenomenology of breathlessness

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Can a phenomenological analysis reveal invisible or ineffable aspects of breathing/ breathlessness?

University of BRISTOL

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LIFE OF BREATH

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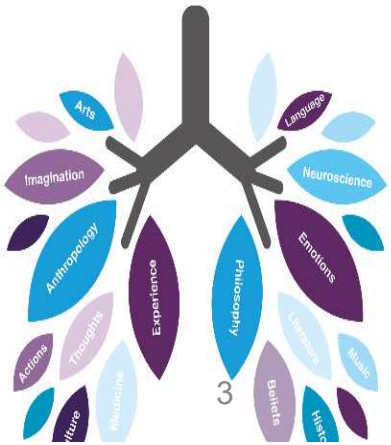
About

Life of Breath is a five year (2015-20) research project funded by the Wellcome Trust. It is led jointly by Prof Jane Macnaughton (Durham University) and Prof Havi Carel (University of Bristol). The Life of Breath team includes researchers from a number of different subjects including medicine, philosophy, anthropology, history, arts and literature. We also work with the British Lung Foundation, people affected by lung disease, healthcare professionals and people who use their breath in interesting ways (e.g. musicians).

Exploring Breathing and Breathlessness: Our Approach

Breathing isn't just a bodily function. It allows us to speak, laugh and sing. It connects us to the outside world. It reflects our state of mind and can be consciously controlled. Breath has inspired art and literature. For many it has spiritual significance. The personal and cultural meaning of breathing goes beyond the simple act of keeping us alive.



Breathlessness is also a very personal experience. It can be fleeting or a sign of something more serious. Some people deal with

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Today's most read

Singing for Breathing

Breathing

- Unique bodily function
- Unconsciously regulated but conscious override
- Connected to wellbeing and emotional state
- Cultural, psychological and spiritual significance

Breathlessness

- Symptom of a wide range of diseases
- Symptom, rather than disease
- Not a simple bodily sensation (Pattinson et al)
- An experience, shaped by past experiences, expectations, beliefs, and current complex sensations

Objective vs lived body

- Discrepancy between objective and subjective measurements
- Patients over- or under-perform (Jones 2001)
- Objective and lived body
- ‘life in slow motion’

Breathlessness

- Severe distress, but not pain
- Same brain pathways activated (Herigstad 2011)
- Overwhelming, but invisible, sensation
- ‘Invisible disability’ (Gysels & Higginson 2008)
- Nausea, dizziness, incontinence

First person articulations

- ‘trapped’
- ‘about to die’
- ‘suffocating’
- ‘drowning’
- panic
- loss of control
- Incontinence

Phenomenological features

- Embodiment determines possibilities
- World shrinks and becomes hostile
- Restriction of choices and freedom
- Projects delimited by restriction
- Vicious circle of self-limitation
- Helplessness, despair, fear, anxiety, depression
- Bodily doubt (Carel 2013)
- Becomes explicit

Phenomenological features

- Body loses transparency (Sartre, Leder, Leriche)
- Daily activities become *a problem*
- Heidegger – *Seinkönnen* – being able to be
- Existing as 'being unable to be'
- 'I can' → 'I no longer can'
- Intentional arc 'goes limp'
- Motor and psychological self-censorship

Loss of transparency

- Modulation becomes explicit
- Artificial and conscious engagement with breath
- Biological and mechanical
- Explicitness as second nature
- The breathless habitual body
- Novelty → censorship → new habits

The geography of breathlessness

- Creates a new terrain
- Freedom and obliviousness replaced by hesitation and limitation
- Distances increase
- Exclusion from shared norms
- Barriers to travel

Disruption of intelligibility

- Illness disrupts meaning structures
- Acute at pivotal moments
- Bodily betrayal
- Need to rebuild meaning
- Regaining foothold, but everyday shifts as disease progresses

Disruption and loss

- Lost opportunities & relinquished activities
- Continuous reworking the boundaries of the possible
- Habitual body reconfigured
- The body is a problem, an obstacle, a stranger
- Embodied normalcy disrupted

Breathlessness and loss (Toombs)

1. *Loss of wholeness* = loss of bodily integrity, bodily doubt
   - Pre-reflective sense of wellness is lost
   - Awareness and anticipation of loss cause distress
   - Knowledge constrains (odd case?)
2. *Loss of certainty* – pervasive, irreparable
3. *Loss of control* – causes anxiety, dysautonomy
4. *Loss of freedom to act*
5. *Loss of the familiar world*

Invisibly breathless

- Distress and panic internal
- Incommunicable
- Norms shift
- Pleasant breathlessness disappears
- Spectrum replaced by binary:
  - Unstrained vs strained breathing
  - Shift is sudden and recovery uncomfortable

Invisibly breathless

- Removed from shared norms
- Concepts take on new meaning
- Movement no longer part of *Mitsein*
- Discrepancy between perceived ease of task and challenge to patient
- Nature of task reconfigured

Elaine Scarry on pain

… when one speaks about "one's own physical pain" and about "another person's physical pain," one might almost appear to be speaking about two distinct orders of events. For the person whose pain it is, it is "effortlessly" grasped; while for the person outside the sufferer's body, what is "effortless" is *not* grasping it … for the person in pain, so incontestably and unnegotiably present is it that "having pain" may come to be thought of as the most vibrant example of what it is to "have certainty," while for the other person it is so elusive that "hearing about pain" may exist as the primary model of what it is "to have doubt." Thus pain comes unsharably into our midst as at once that which cannot be denied and that which cannot be confirmed (p.4)

Social architecture of breathlessness

- Unsharability undermines care and knowledge
- Breathlessness remains opaque, invisible, refractory
- Exacerbated by stigma →masking
- Trailed by tacit assumptions (smoking, contagion)
- Pity, terror, denial

Sartre's three orders of the body

- Difficulties lived in first person
- Perceived by others via masking, miscommunication, labelling
- Self-perception of myself *as perceived by others* – shame, self-consciousness, objectification
- Loss of pre-reflective ease
- Body as doubly problematized

Sartre's three orders of the body

- Embarrassment & shame
- The realisation that others perceive me in my 'inability to be' becomes part of the experience
- 'Witness vices' (Kidd): unkindness, empathy failure, inconsiderateness

‘Ill, but well’

- Life becomes a set of constraints
- Edifying impact
- Poorly documented
- Surprisingly small impact on wellbeing
- Resilience depleted
- ‘Muffled enjoyment’ as new norm

Conclusion

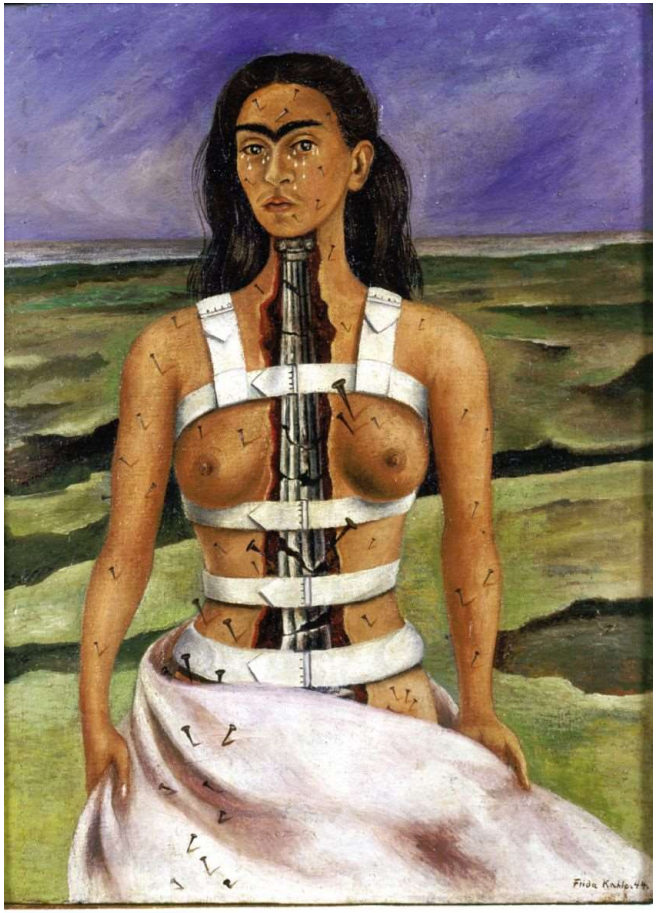
- Phen of breathlessness can:
  - account for richness and diversity of experience
  - articulate the positive and unintended consequences of suffering
- These include:
  - improving personal relationships
  - sense of purpose and focus
  - Resilience
  - posttraumatic growth

Role of phen in study of breathlessness

- Articulate wellness within breathlessness as achievable and significant
  - Shifting perspectives model (Paterson 2001)
- ‘Outsiders’ vs ‘insiders’ perspective
- Positive force of phen reflection
  - Ordering & discerning confusing experiences
  - Phen toolkit

Conclusion

- Breathlessness is a juncture of the physiological, psychological, existential, spiritual and cultural
- Cannot be studied solely as a symptom
- Phen framework provides conceptual tools



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wellcome trust Investigator

Thank you!

- Bodily doubt (*J Cons Studies* 2013)
- "How do you feel?": oscillating perspectives in the clinic. *Lancet* 2012 (with J. Macnaughton)
- The Invisibility of Breathlessness. *Lancet Respiratory* 2015 (with J. Macnaughton and J. Dodd)
- Breathlessness: the rift between objective measurement and subjective experience, *Lancet Medicine* 2018