

## Pain and Suffering as

### Shifting Sands

Exploring differences and distinctions within  
subjective patient lived experience



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## Shifting Sands

- “Was he in pain?”
- “Did she suffer?”
- Pain and suffering as distinct categories of lived experience – phenomenological clarification
- “Shifting Sands” of patient subjectivity, embodied in time and place



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## Pain and Suffering

- Notions used interchangeably/together
- Not synonymous
- Intimate and idiosyncratic
- Cannot be objectively measured
- Problematics
  - Cartesian Dualism
  - Reductionism
  - Emphasis on biological/physical
- Disease and illness (Kleinman, 1988)



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## Philosophical Perspective

- Phenomenology
  - Nature and meanings of phenomena as humanly experienced
  - Privileging first person accounts
- Existentialism
  - Emphasis on meanings and problematics of human concrete existence
- Existential phenomenological
  - Attention to sentience and emotionality of human subject and idiosyncratic qualities of subjectivity

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## Occupation

- Occupation describes all the tasks and activities that a person does every day.
- These tasks and activities are identified, structured, valued and given meaning at both individual and socio-cultural levels
- Includes
  - Caring for and maintaining self
  - Taking pleasure from life
  - Active involvement in supporting communities

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## Occupational Therapy

- Occupation is focused on the individual person's relationship between agentic action and meaning making
- Through occupation, humans build and express a sense of self, learn to do new things, find joy in life and make important connections with the human and non-human environment
- Occupational Therapy is focused on the enablement of human engagement in everyday life, through occupation
  - Person, occupation, environment
- Well-being is a subjective state that emerges in response to a person's positive evaluation of their experience of occupational engagement. (McGrath, 2015)

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## The Occupational Subject

- Subjectivity is an ongoing process of constructing a sense of self that expresses one's place in the world and connections with that world
- Occupation can be seen as a practical form of subjectivity where people 'do' identity and is bodily lived.
- Acknowledgement of the integral embodied nature of embodied interaction with the world

(McGrath, 2017)

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## Pain

- Many life-threatening and life-limiting conditions are associated with the lived experience of both acute and chronic pain.
- Prophylactic and life-prolonging surgical and medical interventions can contribute to patient reporting of increased pain
- Assessment and management of pain is integral to palliative care

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## Pain

- Material 'felt' basis
- Physiological response to physical stimulus
- "Pain as experienced is itself the interpretation" (Cassell, 2004, p.268)
- Major cause of suffering
  - Out of control
  - Source unknown
  - Undesirable meaning
  - Unremitting, unresolved (Cassell, 2004)

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**What does your pain feel like?**

PAIN: ICY COLD, PAIN: NERVE PINCH, PAIN: CRAWLING, PAIN: STABBING, PAIN: HOT IRON, PAIN: TINGLING, PAIN: ELECTRIC SHOCK, PAIN: PINS & NEEDLES, PAIN: SHARP SPASM, PAIN: PECKING, PAIN: BARBED WIRE, PAIN: BURNING

Pain can be difficult to describe. Don't suffer in silence.

Log on to [mypainfeelslike.ie](http://mypainfeelslike.ie) for further information.

Chronic Pain Ireland

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## Suffering

- Occurs as consequence of
  - Disease processes
  - Iatrogenesis
- Sources
  - External to person/subject
  - Not confined to physical
  - Information pathway



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## Suffering

- Integral embodied experience
  - Affliction of the person, not the body (Cassell, 1999)
- Threat to subjective coherence of self in world
  - Symptom or process that challenges narrative (Mattingly, 1998)
- Alienation (Younger, 1995)
  - Self-conflict
  - Shame
  - Loneliness



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## Integrity

Pain and suffering exist in a complex relationship mediated by established personally attributed meaning and importance that recognises a threat to personal integrity

- Body “acts as an expressive aspect of the person....pain would appear to be doubly subjective
  - “Experienced by subject”
  - “Expressive of subject” (Cassell, 2004, p. 270)

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## Audre Lorde - The Cancer Journals

“I have periods of persistent and distracting visceral discomfort that are totally intrusive and energy consuming. I say this rather than use the word *pain*, because there are too many gradations of effect and response that are not covered by that one word.

One of the worst things about intrusive pain is that it makes me feel impotent, unable to move against it and therefore against anything else, as if the pain swallows up the ability to act”

(1996, p.330)

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## Paul Kalanithi – When Breath Becomes Air

“In physical therapy, I was not even lifting weights yet, just lifting my legs. This was exhausting and humiliating. My brain was fine, but I did not feel like myself. My body was frail and weak – the person who could run half marathons was a distant memory – and that, too, shapes your identity. Racking back pain can mold an identity; fatigue and nausea can as well

(2016, p.140)

“I had passed from the subject to the direct object of every sentence in my life. In fourteenth century philosophy, the word patient simply meant ‘the object of an action’, and I felt like one”

(2016, p.141)

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## Marianne A Paget – A Complex Sorrow

“Dying is a very ambiguous process, not at all a simple straightforward event. But it’s happening. Each day I lose ground. Each day my breathing diminishes. Each day I weaken.

But my spirit too weakens in my body, seeks a quiet place, seeks rest. Even so I miss my vitality. I hate being weak. I hate not getting better. I hate complaining about my ailments. I hate having ailments to complain about. I’ve been like this more or less for six weeks, since I caught a cold”

(1993, p.122)

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## Michael Paul Gallagher SJ – Into Extra Time

- “14.10.15 . Perhaps this is the biggest decision of all these ten months. I told the team that I did not want to return to chemo, because of the severe effects last week and because the cancer zones are already terminal and I am not likely to improve significantly. Dr D. after some questions agreed. It was a sensitive conversation and he will guide in the background even though I now pass to the palliative team. They too visited me and were equally kind and helpful.....All in all I was blessed with such meetings. And in myself I felt confirmed in this crucial choice. I seemed able to pray gently most of the day, with a sense of being confirmed by the Good Spirit and asking to be accompanied in this last phase and the approach of death”

(2016, p.130)

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## Reducing Suffering

- Ask and explore
  - Case history versus patient narrative
  - Objective versus subjective
  - Presence
- Frame interventions in terms of the person rather than a disease focus
- Prioritise optimal function rather than length of life
  - Creative adaptability (Carel, 2013)
- Actively work to minimise suffering collaboratively “even if pain or other symptoms cannot be controlled” (Cassell, 2004, p.287)
- Concentrate consciousness in the present (Carel, 2013)



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## Atul Gawande – Being Mortal

“We think our job is to ensure health and survival. But really it is larger than that. It is to enable well-being. And well-being is about the reasons one wishes to be alive. Those reasons matter not just at the end of life, or when debility comes, but all along the way.....”

“Whenever serious sickness or injury strikes and your body or mind breaks down, the vital questions are the same. What is your understanding of the situation and its potential outcomes? What are your fears and what are your hopes? What are the trade-offs you are willing to make and not willing to make? And what is the course of action that best serves this understanding?” (2015, p. 259)

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## Atul Gawande – Being Mortal

“But whatever we can offer, our interventions, and the risks and sacrifices they entail, are justified only if they serve the larger aims of a person’s life. When we forget that, the suffering we inflict can be barbaric”

(2015, p. 260)

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