Speaker:
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Annual LOROS Lecture

"They talk to me like I don't know my own body"

Understanding the experience of suffering of older people in hospital

28th February 2023
Lecture 5.30-6.30pm

They talk to me like I don't know my own body

Understanding the experiences of suffering of older people in hospital

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Background

Francis Report (2013): reports of “compassion deficit”

“Teach compassion”

“Recruit compassionate students”

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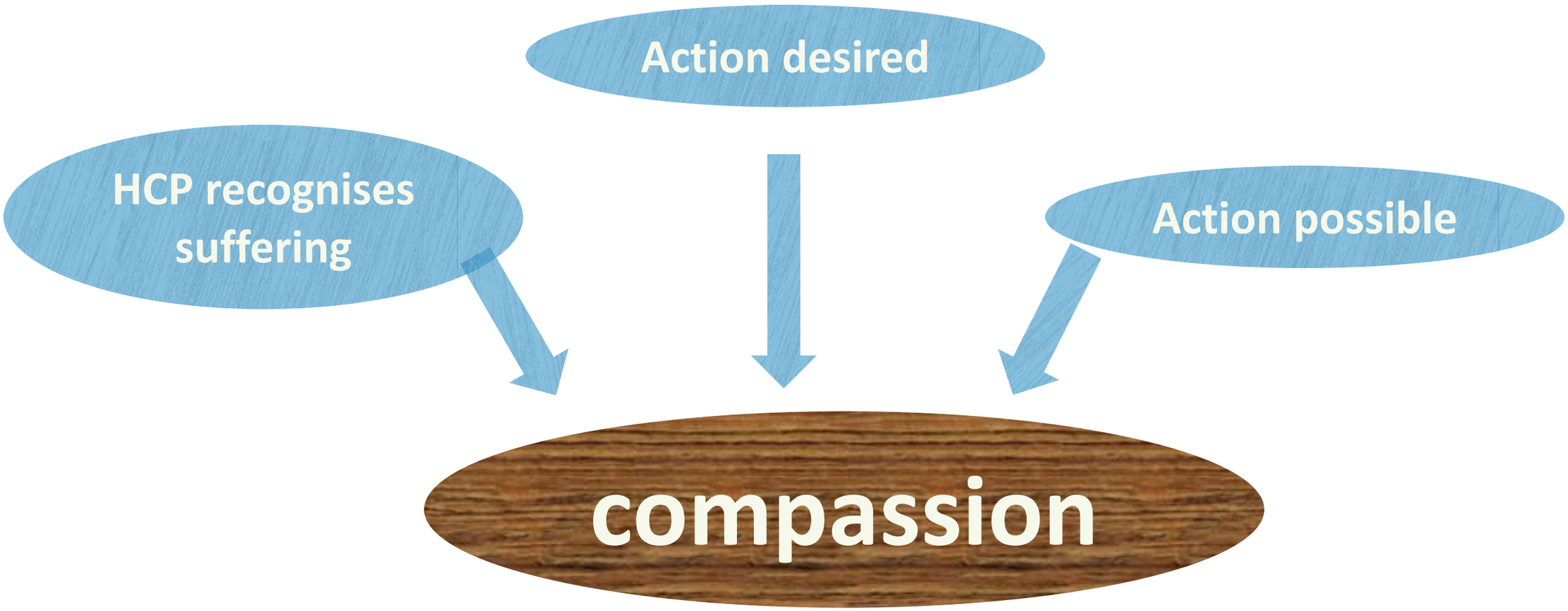
Compassion deconstructed



Adapted from Chochinov 2007

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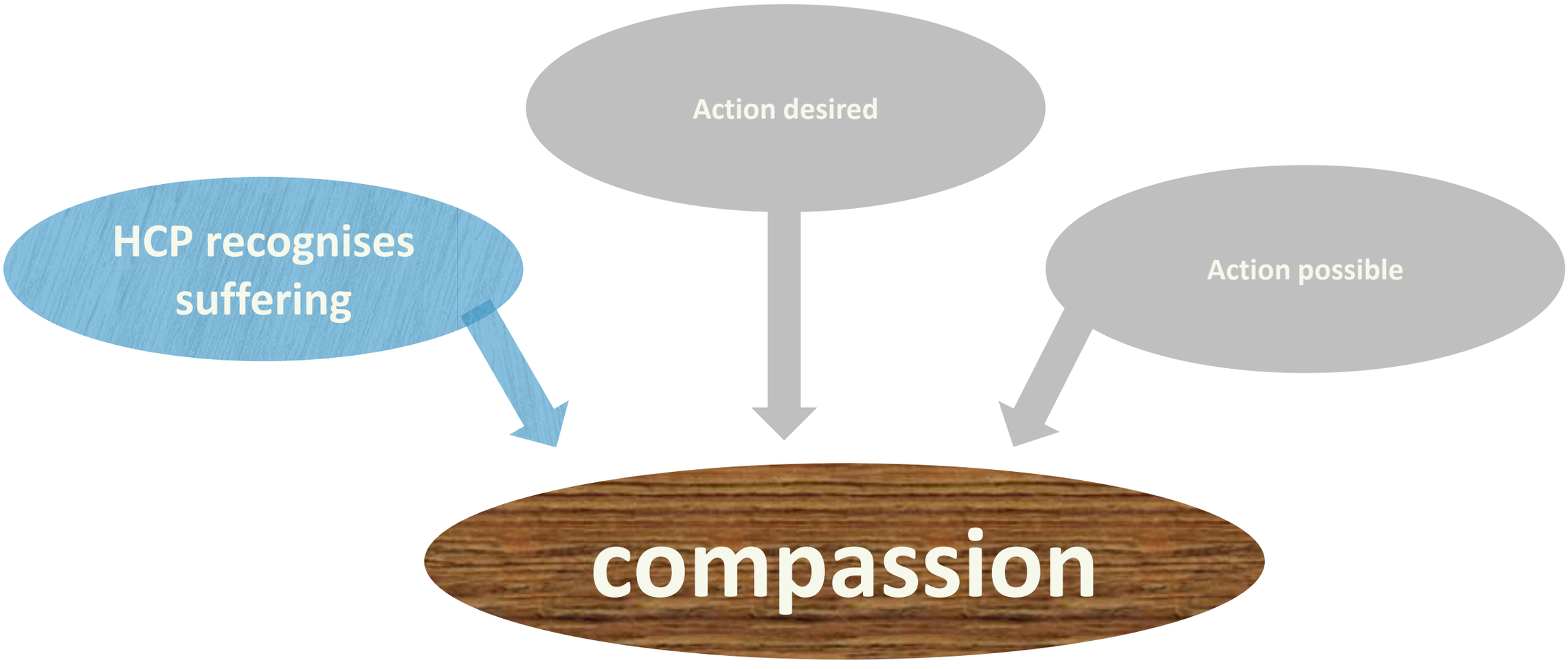
Compassion deconstructed



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Suffering and palliative care

Palliative care "prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual" (WHO 2002)

Background

Doctoral study exploring suffering in older people at the end of life

Setting: Acute hospital, older peoples' hospital ward in Northern UK

Ethnography: 186 hours observation

Informants: Patient (n=16), Staff (42), family & visitors (7) Patients: multiple morbidities, ambiguous prognosis, variable capacity, limited involvement in decision-making

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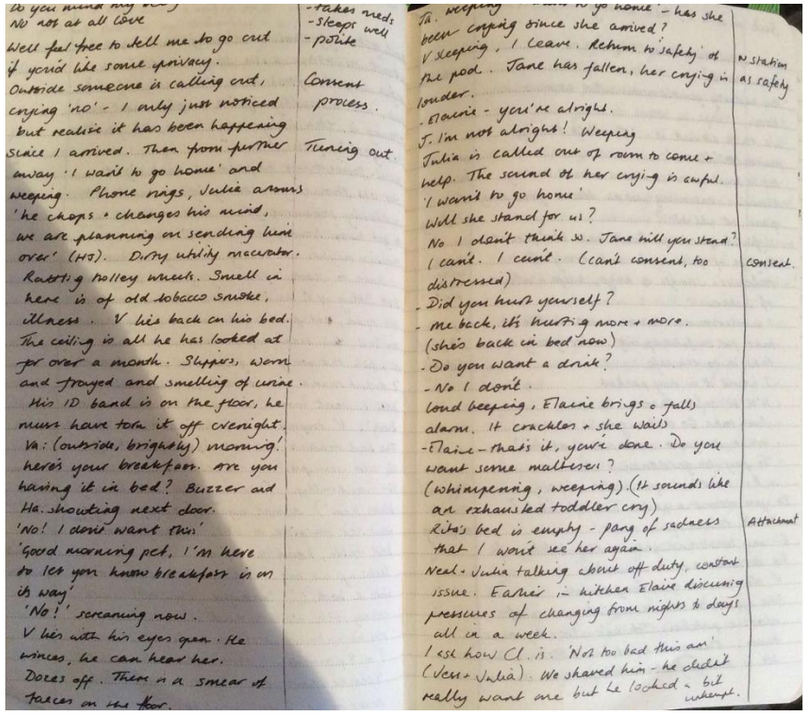
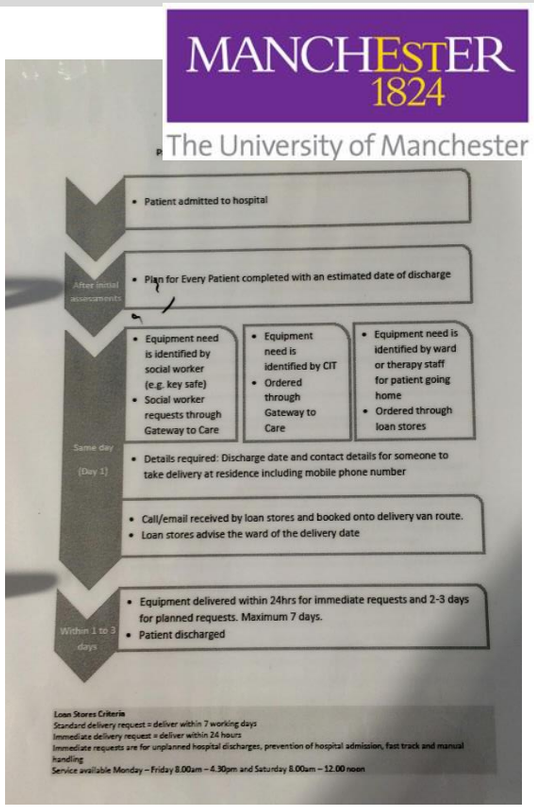
Methods

- Sensory ethnography
  - Observations – eyes, ears, nose
  - Informal interviews
  - Documentary analysis
- Ethics

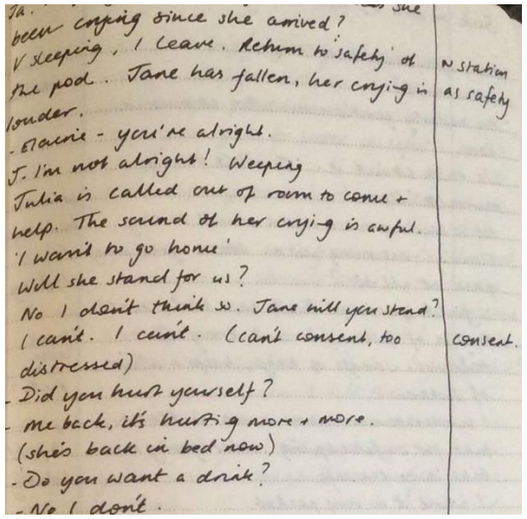
Analysis

- 300,000 words!
- NVivo
- Experts by Experience





NVIVO



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Key finding 1: Iatrogenesis

- **Iatrogenic suffering** can result from well-intentioned interventions:
  - Interventions (investigations, defensive medicine)
  - Environment (noise, routines, odours, time)
  - Interactions (malignant social psychology)

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Interactions

- *Tom and Vincent*
- *Rita and ‘the ward round’*

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Environment

“I wanted, I thought, only a little, two teaspoons of silence”
(Hirshfield, 2015, p63)

- Janice and the commode
- Vincent and drilling
- Alfie and the doors

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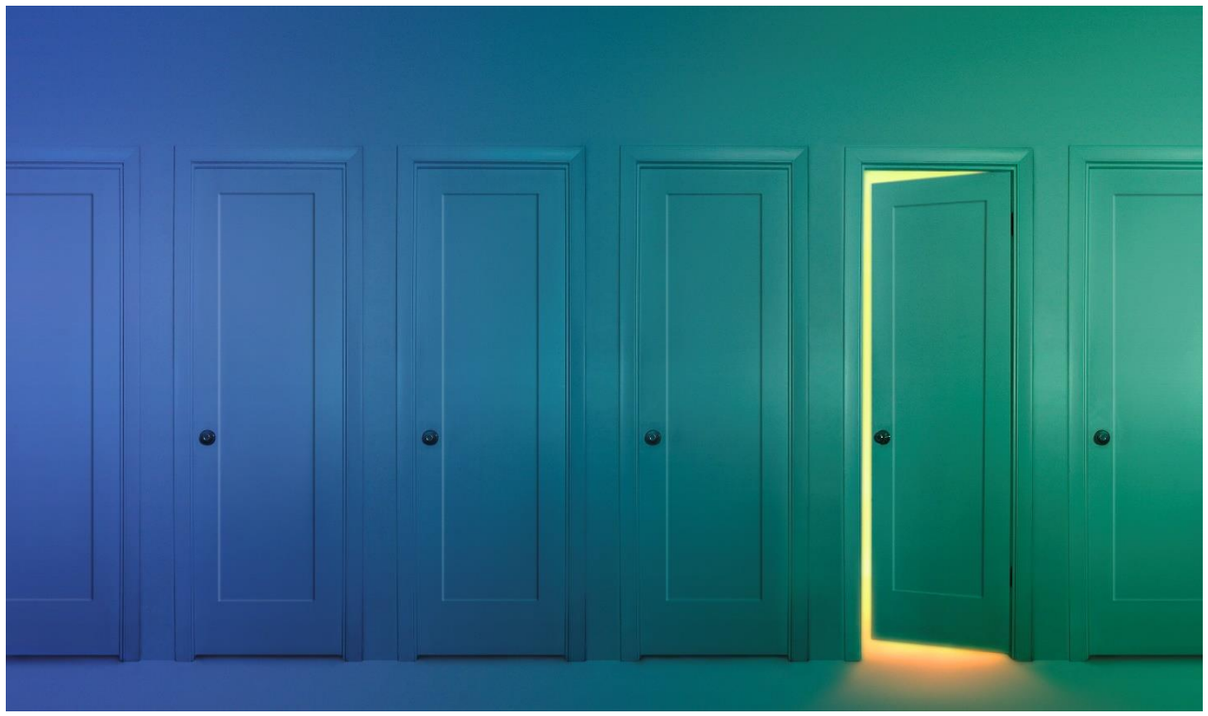
We leave Alfie's room. "He thinks he's going home", I say to Kirsty.

"They all think they're going home", she replies.



Interventions: Ned

94 years old

Dementia for past 4 years

Widowed

Admitted with chest infection - ?aspiration pneumonia

Weight loss, response to antibiotics uncertain

Deemed no capacity

Interventions: Ned

Consultant: “I think of it as a battlefield, when we have someone in front of me who is moribund we do everything. But my other hat is as a human being...he's 94, lives alone, wife died...is it treating with all the tubes and things that are giving more trouble? The only reason I support the feeding is that he wasn't bedbound, he was mobile. If he had been bedbound, incontinent, needing all cares, I would have been different.”

Daughter: “It's difficult, isn't it? How long would it be for? Forever? He loves shepherd’s pie”

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MANCHESTER 1824
The University of Manchester

“I will be guided by you. We can take a risk and feed him by mouth”

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Ned’s daughter goes back into his room and takes the NBM sign from the door. "guess what dad, they've said you're allowed some lunch" "oh good" - a mug of soup is brought and she begins to feed him.

He slurps a spoonful, coughs, smiles and sighs.

"I were bloody starving."

Interventions: Ellen

Ellen (64) : Background: Stage IV heart failure, deteriorating renal function

Unconscious on arrival following seizure/stroke. Does not wake up fully

Family with her most of time; telling her to get better

Family concerned because: she has not eaten for 3 days and staff don't seem to be concerned

Nurses (outside room) discuss probably dying: this has not been discussed with family – "the consultant needs to make the decision"

Over weekend, family distressed - on-call dietician places nasogastric tube, feed is commenced

"You've just given up on her"

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Ellen

Increasing oedema
Vomiting and aspiration
Metoclopramide syringe driver commenced
Sited in arm – oedema – ineffective – resited centrally
Pressure sore to nostril
Nurses distressed ++

Ellen

Discussions about dying curtailed twice due to family distress and anger, & professional anxiety about talking about dying

Medics retract due to clinical ambiguity

5 days later doctor tells family Ellen is dying. Feed discontinued, tube removed, other family called to bedside. Dies three hours later.

Nurses angry ++

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I enter Ellen's room. Her family have gone home and mercifully her nasogastric tube has now been removed. Her light has been turned down low; I can hear her breath, rasping. Alvar is leant over her; with a piece of soft gauze and a plastic tub of warm water he is gently and methodically wiping the crusted blood and mucous from her nostrils, lips and tongue. She is not responding - her tongue is swollen and her eyes bulge. The swelling in her arms has worsened and her skin is shiny, mottled, cold. I stand in silence and watch. He does not respond to me other than to acknowledge my presence. Then, some moments later, says "there are two kinds of nurses, there are those who spend an extra five minutes after the main jobs are done and those who don't. When my grandfather was dying, I noticed this". He dabs vaseline on to her lips. "When people are old, it's like organic, the body starts to fail. It is natural. I could never do paediatrics because that is not natural. She is not suffering now".

It's the fourth day of my observations, and the first time I have heard the word "suffering" mentioned. I look at Ellen.

"No", I agree, "she is not suffering".

Key finding 2: ideologies of care

Clinical practice informed by **ideologies** and bound by (unspoken) **rules**

The rules:

- are often shared by members of professions
- dictate decisions at key times
- help individuals navigate uncertainty

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Acute care


COURT SEJOUR
GERIATRIQUE
Care of the Elderly


Palliative care

RESCUE

"Scoring 4 on the MEWS"

REHABILITATION

"I'll just go through my green crosses"

RELEASE

"The gift of a good death"

Not all ideologies are equal

Care is generally good when team agree on approach

Problems arise when:

- Care transitions from one approach to another
- Patient, families or professionals disagree about correct approach

Society values heroism, battling against death, power of medical technology and bioscience

The “rescue ideology” dominates

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Rescue

Ellen: Dying on admission. Palliative approach indicated

uncertainty of diagnosis → **uncertainty of prognosis**

Uncertainty → rigid adherence to rules

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Rescue

- Uncertainty is difficult; leads to increased adherence to “the rules”
- The **"ideology of rescue"** dominates: default position in acute hospital ward
- **Iatrogenic suffering** can result from well-intentioned interventions

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Recommendations – for practice

Multidisciplinary meetings; goal of care

Schwartz rounds / mortality review

Asking “the question”

Informant involvement: making the invisible visible

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Interprofessional learning

Observational methods in health professional education

Reflection without proficiencies

Recommendations – for education

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Do observational methods offer insight into situated nature of ethically challenging situations?

What is the impact of professional differences in capital in terms of agency and decision-making?

What policy developments can enable development of shared habitus?

Recommendations – for research

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"We are the guardians of what we witnessed" [Behar 2014]

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