Patient safety at the end of life: Patient expertise and the trouble with 'the logic of patient choice'

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Autonomy & choice: Overcoming "the doctor knows best"

AIM

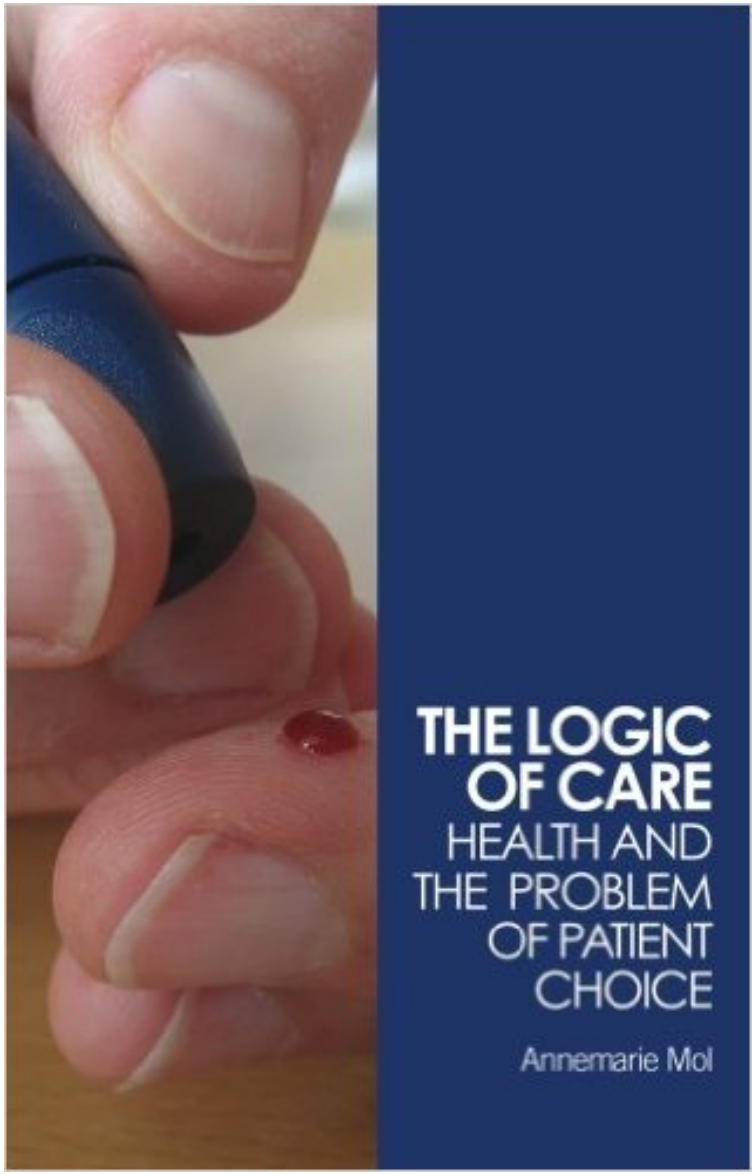
•Interrogate the dominant discourse of patient choice and end of life care

•Explore the concept of expert patient in the context of this discourse.

•Provoke further reflection and dialogue on what this might mean for patients and families, clinicians, policy makers and researchers.

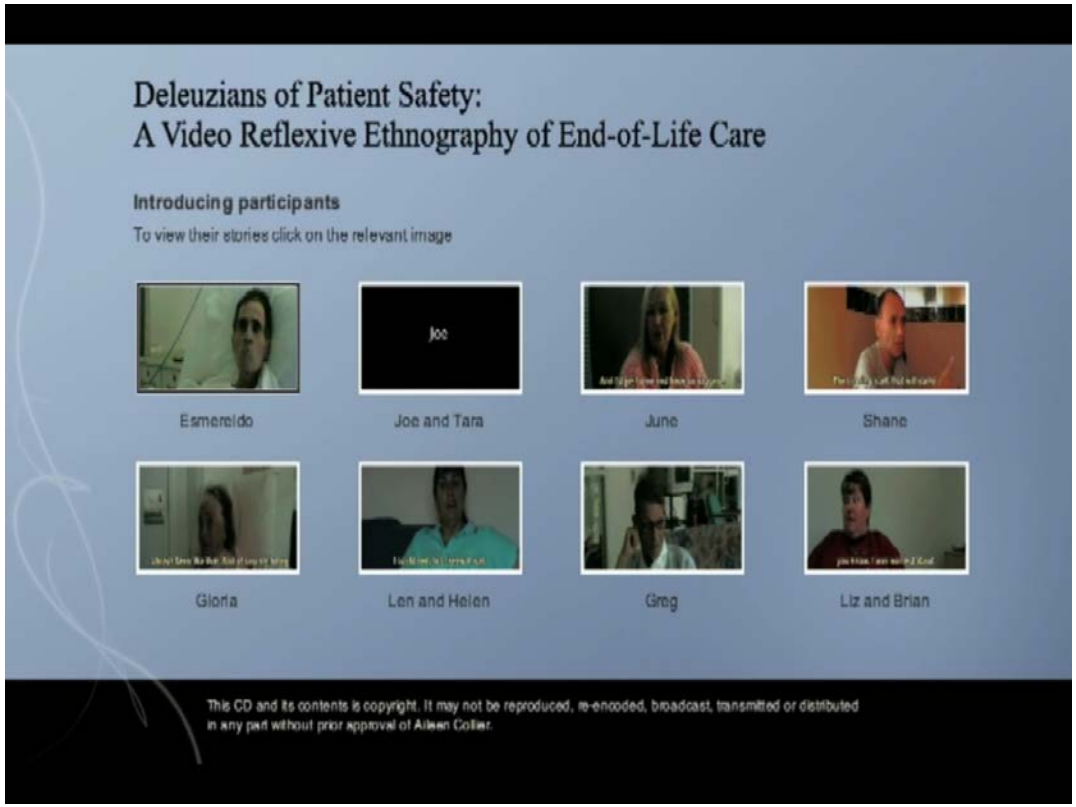
Patient Expertise: Autonomy & the choice discourse at the end of life

- Choice of place of death
- Choice of treatments
- Choice in advance (advance care planning, advance care directives)



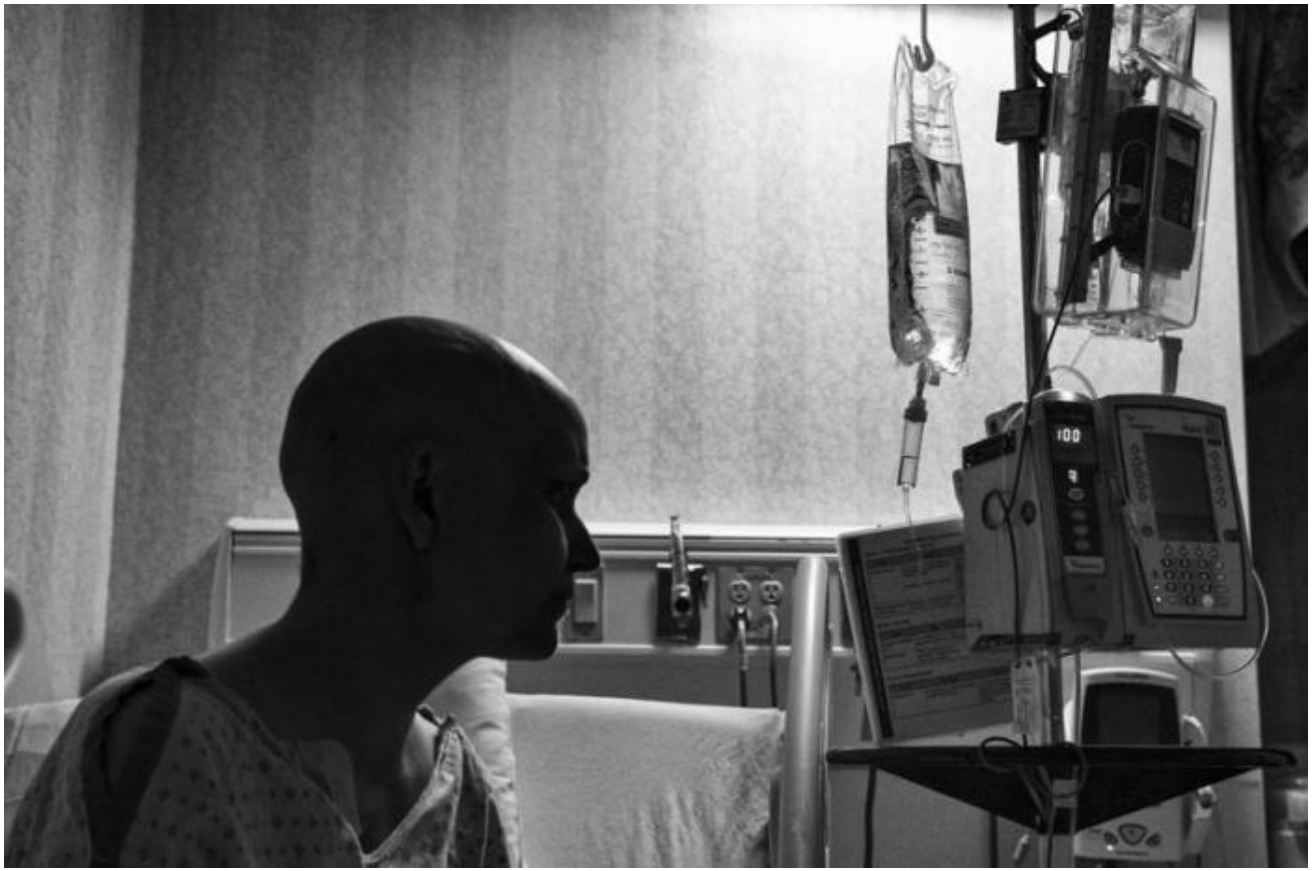
Ann Marie Mol: The logic of care: Health and the problem of patient choice

“ Choice, let alone ‘autonomous informed choice’, may be promoted by western medical ethics, but rarely fits lived reality at a crossroads (Borgstrom, 2014; Ellis, 2013).



- Collaborated with patients, families & clinicians on quality & safety issues for people with life-limiting illness
- Explored the complexities of how safety & quality are enacted in the 'real world' .
- Provided a 'disruptive innovation' to cultivate improvements in palliative care
- Worked at the interface of social science and clinical research to emphasize opportunities & issues that patients & families hold dear

Introducing ‘Amy’



As the staff specialist (Palliative Care) relays it to me, Amy had a palliative operation for a bowel fistula secondary to metastatic ovarian cancer three weeks ago in a private hospital. She has been readmitted to ICU following a second operation for the same reason. After the first operation, Amy tried to explain to the healthcare workers looking after her that she was still passing faeces and that there was nothing in her colostomy bag. This went on for five days.

The staff specialist exclaims, *"No one, not even the nursing staff had examined her during that time. Instead they tried to reassure her that a small amount of discharge was to be expected and that everything would settle down. Eventually, Amy was operated on for a second time".* (Field interview, Acute Hospital, Staff Specialist (Palliative Care,

"*Isn't it a solicitor I need to do this"* Amy responds angrily. I (researcher) briefly explain again the purpose of the research. Again, she expresses in an angry tone *"Document my experiences, isn't that a solicitor's job?* You should have been here five weeks ago", she exclaims, *"Seeing me in excruciating pain; doctors who won't listen to you and speak to me as though I am an idiot; nurses who don't believe you are in pain, when you are sitting in excruciating pain."* She breaks down in tears. (Field interview, Acute Hospital)

Amy has been seeing a Chinese medicine doctor. His advice to her was to avoid having CT scans. Amy had clinical symptoms indicating malignant fistulae. Her surgeon respected her choice not to have a CT scan with contrast and made a clinical assessment based on ultrasound. Amy proceeded to surgery on the basis of fistulae located with the aid of the ultrasound. The ultrasound did not locate the higher resulting in continued symptoms significantly affecting Amy's quality of life and eventually her requirement of a second surgical procedure.

(Field interview, Acute Hospital, Staff Specialist (Palliative Care)

Amy, patient choice and the problem of patient safety

- Choice in circumstances of threat to ‘oncological’ security
- Choices within the social complexity & built environment of the hospital
- Expert patient ‘managers’ -charging patients with staying well
- Expert patients- acceptance of choices by clinicians?

Choice in circumstances of threat to ‘oncological’ security

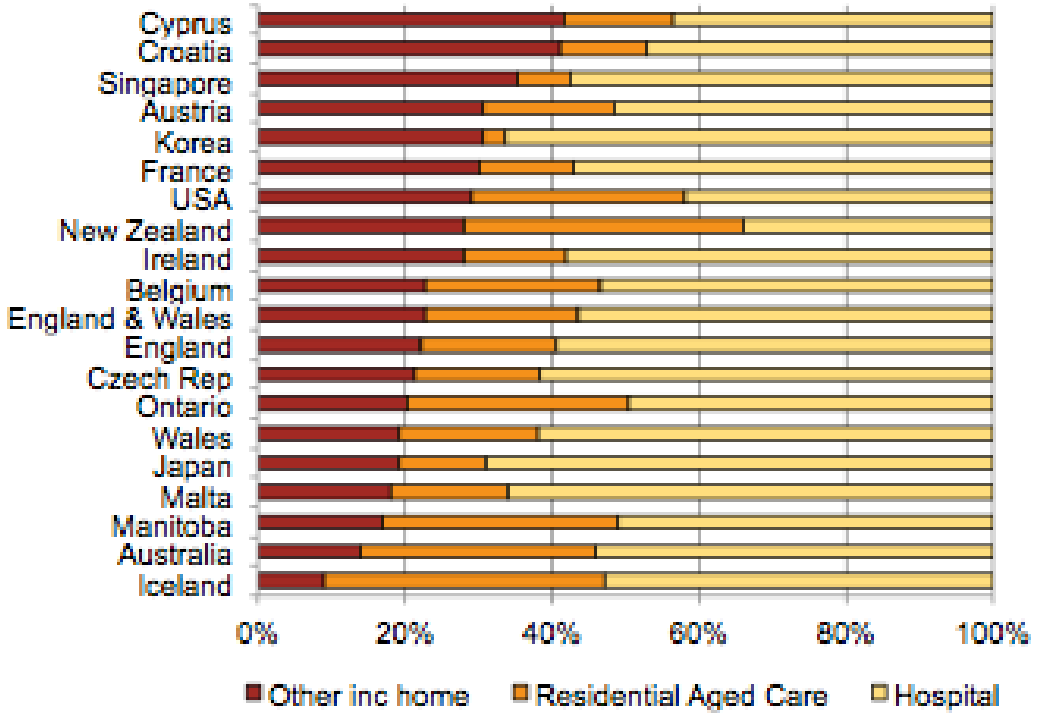
Ms Margaret Ambridge

Choices within the social complexity & built environment of the hospital

Expert patient ‘managers’-charging patients with staying well

Are patients choices accepted by clinicians? organisations?

Figure 1: Few Australians aged over 65 die at home
Location of deaths in selected OECD countries; per cent of deaths



Source: (Broad et al., 2013 (2013))

Has the pendulum swung too far in favour of patient autonomy?

New study questions whether doctors are not giving enough guidance to patients about end of life decisions.

> *A blind focus on autonomy might inadvertently undermine patient care by depriving patients and surrogates of the professional guidance needed to make critical end-of-life decisions.*
>
> — *Elizabeth Dzeng*

ww.cam.ac.uk/research/news/has-the-pendulum-swung-too-far-in-favour-of-patient-autonomy

Patient Safety at the End of life

Patient & Family Expertise + Clinician(s) (All disciplines) expertise = patient safety