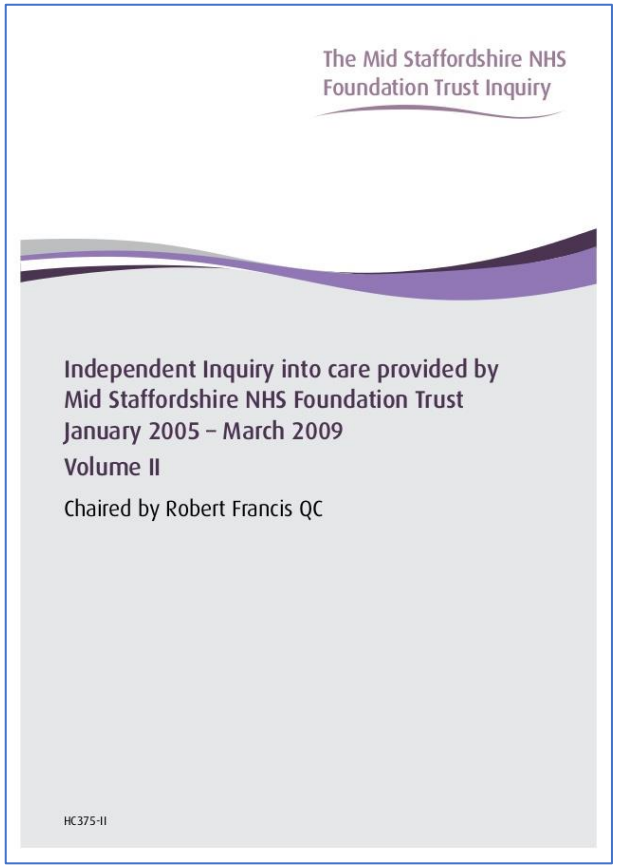
The ‘Health States’ of Exception: the (inadvertent) production of ‘bare life’ in complex care transitions

Professor Justin Waring

Degrading and Harmful (non-) Care

- Vulnerable patients can easily become the victims of abusive, undignified and neglectful care
- The Francis Report showed how older patients were subject to neglectful and degrading treatment
- Report shows residents of care homes and other long-stay settings can be the hidden victims of abuse
- Research in mental health settings shows patients are stripped of their identity and subject to abuse



Unsafe and degrading care transitions

- During hospital discharge, the *HealthWatch* and *Red Cross r*eports showed that, all too often, people….
- Have limited influence on their care
- Leave hospital with delayed or inadequate care
- Feel abandoned & stigmatised

Persistent & Widespread Failures

- Inadequacies in professional practice and regulation
- Cultures that foster and tolerate unsafe practice
- Managers that put operational priorities ahead of safety
- Care systems that are so complex to enable integrated working

The question….

- Degrading and harmful care is **not only** a consequence of…
  - A person's complex care needs
  - Unsafe professional practice, ineffective teamwork or inadequate regulation
  - The problems of integrating health and social care

- Systemic ***non-care*** speaks to **something more fundamental** about how cultures **produce and accept degrading and harmful care**

- We arrived at this issues because we couldn't understand why so many people experience **hospital discharge** as degrading and harmful

The Sociological Questions

- The sociology of bureaucracy
  - Max Weber saw instrumental rationality and hierarchical delegation as depriving people of their humanity
  - Zygmunt Bauman interpreted the Holocaust as a product of bureaucratic efficiency and dehumanisation
- The sociology of the professional
  - Durkheim saw the professions as moral guardians for society, but the likes of Freidson have shown how they can put collegial self-interest ahead of their clients needs
- Turning to the ideas of Italian philosopher Giorgio Agamben

The work of Giorgio Agamben

- How political-judicial systems deprive people of their rights
- How the deprivation of rights makes legitimate suffering, degradation and death
- Not just historical problems of authorities states or Fascism

Agamben's theoretical orientation

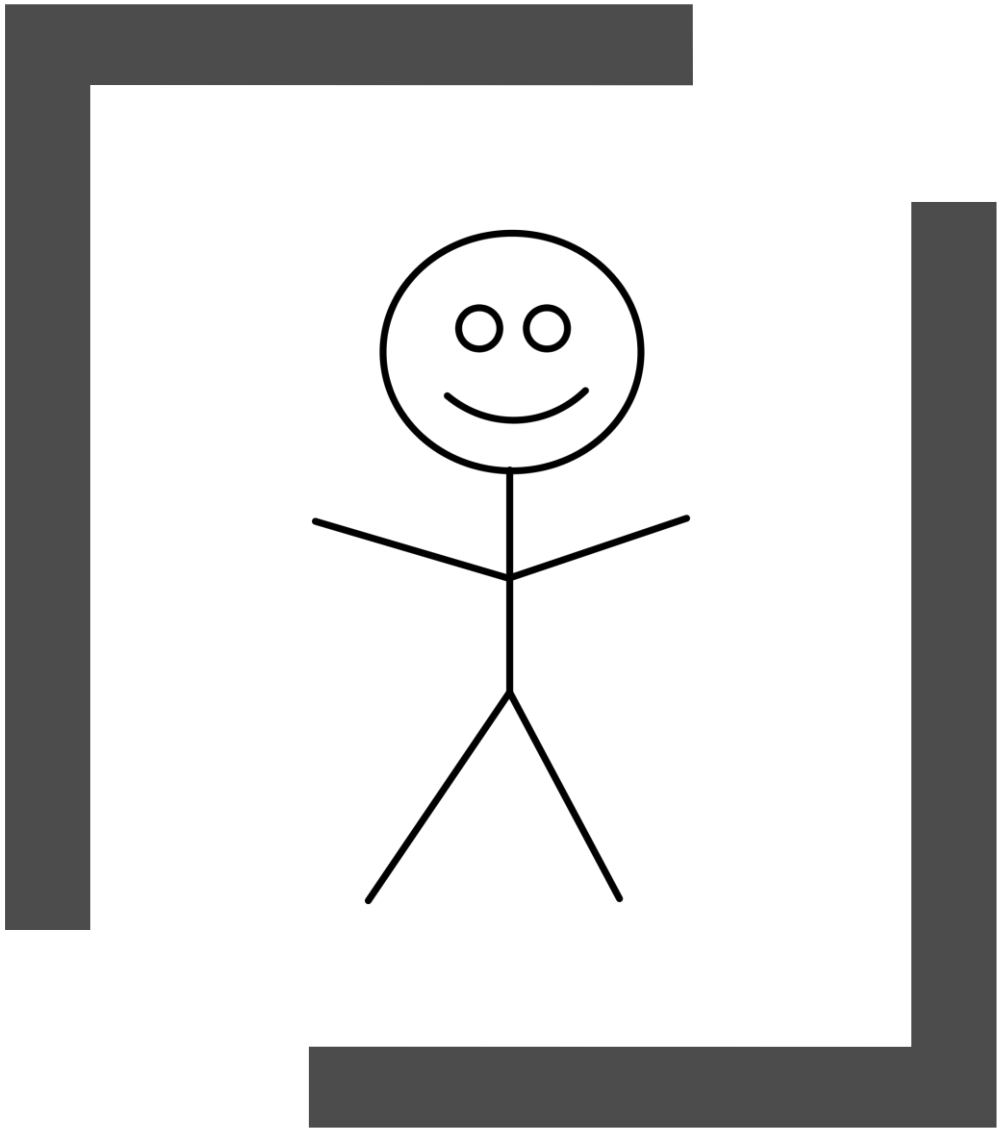
- Foucault described modern society in terms of '**bio-power**' – concerned with the ordering of productive human life

- Bio-power is realised through a complex arrangement of state and **non-state agencies** (non-sovereign)

- Agamben suggests bio-power is a historical foundation for society and that sovereign (statutory) power remains key

Key conceptual tools

- Bare life
- Homo Sacer
- State of exception



Zoe and *Bios*

- Zoe: The most basic, fundamental & biological parameters of life – or ‘bare life’ (could also be private life, not public)
- Bios: A life with social, legal and political significance – a ‘qualified’ life (to be a citizen with protections)
- The distinction between *qualified* and *bare* life is determined through **legal-sovereign authority** – to give and take rights

Homo Sacer

- In Roman Law – a significant form of punishment was the removal of citizenship rights – a non-person
- *Homo Sacer:* someone who can be killed with impunity, but not sacrificed
- Symbolically, worse than slavery because slaves had protections under property rights
- The *homo sacer* is outside the law but still governed by the law (insider/outsider)

State of Exception

- These ideas frame Agamben's analysis of the Holocaust: how human life is legitimately deprived of its legal significance
- *State of exception*: where democratic processes, legal protections and citizenship rights are suspended
- Legalised lawlessness – safeguards suspended often on the premise of protecting these safeguards
- In the state of exception, people are reduced to their bare life through statutory (sovereign) instrument

The ‘Health States’ of Exception

- Overcoma and neomort – when human life is reduced to its most basic biological functions

- The *Liverpool care pathway* – a technical-legal instrument for managing the end-of-life care – procedure for allocating ‘bare life’

- Other institutions for those with long-term conditions, learning disabilities, and mental health problems have been shown to promote harmful and degrading (non-) care

Our study

- Ethnographic study of the social organisation of hospital discharge

- **The settings**:
  - Two ‘care systems’ in two contrasting localities
    - One large acute NHS Trust (multiple sites)
    - Community NHS care providers
    - Primary care providers
    - Local authority social services (and care)
    - Mixed economy of social care

  - Comparison of stroke and hip fracture patients

Our study

- **Data collection:**
  - 10 Months of non-participant observations:
    - System mapping, Key situations and interaction, Shadowing people
  - Tracking patients across discharge pathway (inc. diaries):
    - 32 recruited prior to discharge, 27 interviewed within 10 days of returning to community, 17 interviewed at 3 weeks, and 9 interviews at 6 weeks
  - Interviews with 213 individuals

Our study

- **Data analysis:**
  - Interpretative qualitative data analysis
  - Elaboration and categorisation of participants' experiences of hospital discharge
- Arrived at the question: '*why does this happen*'
- Looked for explanations that related professional practices and modes of social organisation to underlying cultural issues

The experiences of ‘bare life’

- Hospital discharge as a ‘spatial-temporal’ threshold – ‘in’ and ‘out’
- A symbolic boundary between a (temporary) bare life subject to hospital order and a returned ‘qualified’ life (if aspirational)
- But where a person’s ‘bare life’ can become institutionalised

Readiness
Influence of care plan
Scheduling and Timing

Continuity & Quality of Care
Abandonment
Burden

Readiness for discharge

- Not feeling ready or ‘fit’ for discharge – still physically weak, in need of care, dependent
- Examples of needing help to toilet or dress, still requiring therapy or care from specialists
- Being forced to leave hospital – underpinning feelings of vulnerability, and abandonment

‘I am not sure I feel ready to leave. I still feel very poorly, and I can’t get around like they expect me to. I still need help with, you know, personal things. But I am told it won’t be long’ (Sandra, Fieldnote)

Influence on Decision-making

- Being spoken ‘over’ or ‘about’ (not to or with) – common during ward rounds
- Patients anxious about living arrangements and levels of support – the desire to go ‘home’
- Feelings of anxiety and frustration – especially family collusion with medical staff

‘Doctor visited ward round. Did not speak to me on his ward round. No discussion about discharge. Feel like I’m invisible.’ (Flo)

‘I’m not sure my view really counts anymore. No one seems to listen to me. They have just put me here to rot’ (Barbara)

Scheduling and timing

- Moving the goalpost – the estimated date or discharge - building and dashing hopes
- Frustration with being ‘kept’ in hospital
- And, the feeling of being ‘thrown-out’ of hospital - moved to the Discharge Lounge
- Transfers to community hospitals late at night with no family or support

‘It’s like the goal-post get moved and moved and moved. Just when you think about getting out and going home, they take it away from you.’ (Bob)

‘It’s a holding area. Some wards send patients down there at half-past eight and they’re there till four o’clock and they’ve not had a hot meal.’ (Nurse, Site 1).

‘From half-past five in the morning to strip my bed and I was sitting on a chair from that time till I got home. It had gone eight o’clock at night. I felt like I wanted to cry because, you know, I felt they just didn’t care. (Bill, Interview)

Continuity and Quality of Care

- Incomplete care plans – hinder decision-making and care delivery
- Misaligned or inaccurate care plans – provision of inappropriate care
- Reliance upon ’generic’ care, rather than personalised care
- Rapid period of re-assessment, re-ordering tests, chasing-up information
- Missing home adaptions, devices, medicines or support

We see patients when they get home and we look for their care plan, and its nothing, it's just a few notes about mobilisation or medicines. There is nothing detailed about what level of care they need. We spend a lot of time re-assessing the patient and devising new care plans (Social care)

'Norman did not have his insulin this morning because the district nurse thought he did not have to have it. He went to the hospital for his appointment' (Norman's spouse, Diary)

'Heart nurse said BP was low. Increased Furosemide to two tabs. [But] Furosemide did not arrive! Rang [pharmacy] about Furo tabs. No prescriptive received from surgery' (William, Diary)

Abandoned

- Left to fed for self with out expected level of care
- Care plans gradually reduced with the expectation that someone else will do the work – cliff edge
- People often don't want to do the more personal tasks related to personal hygiene – or do them badly

'it's being slowly phased out. I had somebody come this morning. I don't think anyone's coming at lunchtime or this evening anymore. I think they're being phased out…' (Arijit, Interview)

‘We needed a hospital bed downstairs, so it arrived last Saturday, but it will not do. The chap said … I thought it could go in the hall, but even if we move furniture it blocks the stairs… If you bring it forwards so that we could then get out of the front door you couldn’t get in here. So now we help him upstairs, you only go up once and down. Down’s a bit tricky but I help him and we’re managing.’ (Jenny, Spouse)

Burden and Work

- Friends, family and neighbours routinely do the work of care
- Need to ‘work’ the system
- Feeling like a physical, emotional and financial burden on others
- Feelings of despair

‘it was is a different matter to when she was in hospital and she goes to sleep and you can go and have your little break, and now at home there’s no break. It’s full-on twenty-four hours’ (Zoe’s spouse, Interview)

The social production of ‘bare’ life

- Health and care professionals in no way wanted to treat patients this way, everyone tried their hardest
- The demands of care were seen as too great, the problems of integration insurmountable and the system too complex
- But, the social organisation of care (in this context) was key to the production of the ‘bare’ life

‘Not known'

- Each professional had a different definition or understanding of the patient at the point of discharge - a component of the person

- In discharge planning, these views were often brought together to create a more ‘holistic picture’ – but in many cases this was difficult to achieve

- The patient is not a stable ‘thing’ but a constantly changing set of meaning that are often difficult to reconcile

‘Day after day we go through the same people waiting for the same assessments. Mental health, OT, physio, and you can go back the next day and [it’s like] you’ve talked to a brick wall the day before’. (Social work)

‘We *should* be working all together, and we should all attend that MDT so that everybody knows. Once it’s identified, that’s when we should go in and say get all your evidence, get your risk assessments, plan it properly, and then get the discharge right. But…we don’t have the time for that’. (Senior nurses)

Instances & Examples

- In discharge planning, there was often a debate about the patients' 'readiness' for discharge
  - Doctors can have narrow bio-medical definition of being 'fit'
  - Therapists have different views about wellbeing and functional ability

- Reliance upon assessment tools and checklists could exacerbate the problem
  - Patient assessments of cooking or mobility carried out in 'controlled' settings
  - Checks for continuing care set so high to avoid cost

- Positional power is unclear – the patient is **neither health or social care** – links to the issues of responsibility

‘The lines of responsibility are opaque. We might have clear ideas around who completes continuing healthcare or financial eligibility, but it is less clear about how we put these together as a care plan.’ (Social work)

‘You think it’s a medical decision, at the end of the day I suppose it is, but the docs are so little involved in the process that it’s usually us that deals with it and makes the decision’ (Nurse)

‘Not eligible’

- Difficult to determine patients needs – often linked to their ineligibility certain types of care
- Financial and domestic factors often complicated care planning
- Continuing healthcare assessments set so high to limit risk
- Re-ablement or rehab service not available in certain areas or localities
- Constrained by the bureaucracy

“There’s a lot of pressure there where people are trying to follow the right pathway, using the right checks, but they’ve also got that pressure there to say no we need the bed, get them out’. (Nurse)

‘We try our best to take into account their wider personal circumstances, and we do speak with patients and their families, but there is only so much we can include in the assessment’ (Occupational Therapist)

‘Not responsible’

- Bounded jurisdictions – professional see certain needs and issues outside of their realm of expertise

- Work prioritisation – discharge not see as clinical priority in the hospital and the need to deal with more pressing urgent cases (admission over discharge)

- Common to find staff pass the buck for discharge planning – low status task for low grade professionals

‘It’s quite clearly a job for the district nurse, not us. We can’t be interfering with these dressing when the stitches and wound area are so infected.’ (Social care)

The night shift are supposed to complete the assessment and referral forms, but they never get round it! So, it ends up back with the day team, who are just as busy’ (Ward manager)

its not always that easy to focus on the discharge bit of the process because you still need to be looking at the patients that have just been admitted and are in a bad way or have complex needs’ (Nurse, Fieldnote)

Discussion (i)

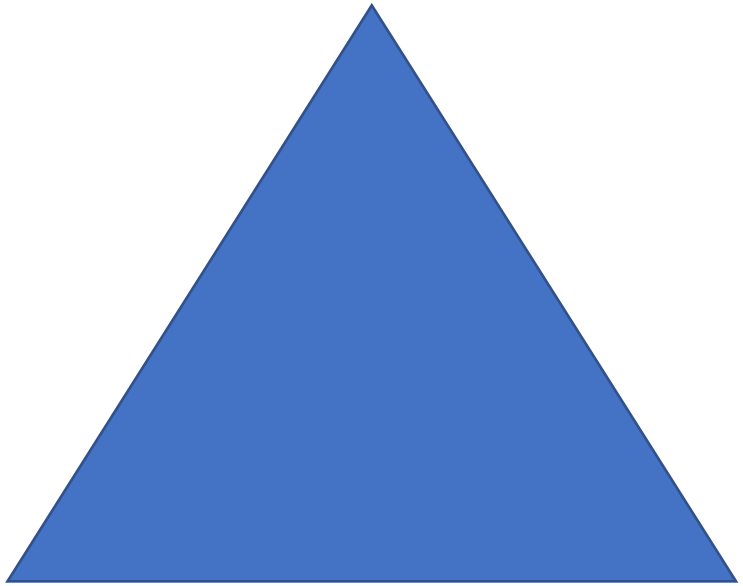
- The findings reinforce a large body of evidence on human suffering and harm during and after hospital discharge (HealthWatch etc)

- Three common explanations:
  1. Clinical complexity and co-morbidities
  2. Dehumanisation of bureaucracy
  3. Influence of professional boundaries on integration

- Although discharge might be seen as ‘a return’ or ‘liberation’ it can be the ‘stepping stone’ to ‘social death’

Discussion (ii)

- Problem of not knowing:
  - Patients are given multiple segmented meanings
- Problem of eligibility:
  - Multiple and competing procedures formalise the lack of responsibility
- Legitimate non-responsibility
  - Discharge happens between care settings and no-one really takes responsibility for it



Discussion (iii)

- ‘Health state’ of exception - where substandard non-care becomes both normal and acceptable –

- But this happens by accident, not design - it is not produced by statutory instrument (although these can play a role)

- Rather the patient falls between the gaps of care systems - they become inadvertent non-people

Implications & Recommendations

- Patient and family involvement throughout
- Community teams work earlier with hospital staff in formulating care plans
- Facilitate more open dialogue and exchange of views in multi-disciplinary decision-making
- Try not to become a ‘slave’ to the checklist – see the person not the number
- Encourage hospital clinicians to value discharge not simply for operational (flow) benefits but for the longer term health of the patient
- Someone needs to take responsibility for the discharge patient – GP?