

Health States of Exception: unsafe non-care and the (inadvertent) production of 'bare life' in complex care transitions

[Accepted for Sociology of Health and Illness]

Professor Justin Waring

Professor of Medical Sociology and Healthcare Organisation

Health Services Management Centre

University of Birmingham

Dr Simon Bishop

Associate Professor in Organisational Behaviour

Nottingham University Business School

University of Nottingham

## **Abstract**

This paper draws on the work of Giorgio Agamben to understand how the social organisation of care transitions can reduce people to their 'bare' life thereby making harmful and degrading treatment seemingly legitimate. The findings of a two-year ethnographic study show how some people experience hospital discharge as undignified, inhumane and unsafe process, expressed through their lack of involvement in care planning, delayed discharge from hospital, and poorly coordinated care. Our analysis explores how these experiences stem from the way patients are constituted as 'unknown' and 'ineligible' subjects and, in turn, how professionals become 'not responsible' for their care. In effect the person is reduced to their 'bare' life with limited value within the care system. We suggest the social production

of 'bare life' is an inadvertent consequence of reconciling and aligning multiple disciplines within a complex care system.

## Introduction

It is a terrible irony that health and care systems intended to care for people when they are at their most vulnerable, are also sites where degrading and harmful treatment is all too common (Mandelstam 2011). This has been powerfully demonstrated by high-profile reports into unsafe, abusive and undignified care within the English care system (Department of Health 2012; Francis 2013; Kirkup 2015). These reveal systemic failures due, in part, to shortcomings in professional regulation; cultures that foster unsafe practice; and managers that place operational priorities ahead of patient safety. And whilst these might be extreme cases, research suggests that patient safety remains an intractable problem for all healthcare systems (Dixon-Woods and Pronovost 2016).

In turn, quality and safety improvements have focused on modernising professional regulation (Walshe and Shortell 2004), creating a more compassionate 'safety culture' (Morello et al. 2013), and introducing more proactive risk management (Waring 2005). And yet, such efforts often involve techno-managerialist solutions that miss the point that culture change rarely occurs as 'planned' or that (mis-) management and (over-) regulation might be part of the problem (Waring et al. 2016a). In short, they can remake the practices and cultures that foster degrading and harmful treatment.

We suggest the experiences of harmful and degrading care described in reports indicate a mode of social organisation in which people's lives, under certain circumstances, can hold little meaning or value within the care system (Mandelstam 2011). Sociologists have long recognised the harmful and dehumanising effects of bureaucracy (Ritzer 2006) and whilst professions are sometimes portrayed as moral guardians for society (Durkheim 1992), they

have also been shown to prioritise collegial self-interest ahead of their clients' needs (Rosenthal 1995). We suggest the systemic devaluation of human life is brought about, not only by instrumental rationality or professional cultures, but by more fundamental socio-cultural and organisational arrangements in which certain lives are constituted as less valuable and, therefore, amenable to neglectful or harmful treatment. In seeking to develop new sociological understanding of this phenomena we turn to the ideas of Italian philosopher Giorgio Agamben. Agamben's work deals with how political-judicial systems can render life as 'devoid of value', thereby making suffering, degradation and death entirely legitimate (Agamben 1998). His work builds upon Foucault's (1998) concept of 'bio-power' by arguing that the contemporary 'politics of life' is rooted in classical thresholds of citizenship that are ultimately determined through sovereign authority (Agamben 2005). We draw upon Agamben's ideas in our ethnographic study of hospital discharge.

Hospital discharge denotes the stage where inpatient care ends and continuing care is provided in community settings. International research shows this can be a challenging and unsafe stage in the care pathway (Aase et al. 2017; Hesselink et al. 2012; Laugaland et al. 2014; Waring et al. 2016b), with patients often feeling abandoned and stigmatised as they leave hospital (Healthwatch 2015). Although some people involved in our study experienced well-organised discharge, others received unsafe and inhumane (*non-care*). Foreshadowing our findings, some had little influence on their care plans; some were discharged at night, alone to unfamiliar locations; and many arrived home with limited support for eating, sleeping or toileting. We wanted to understand why people experience unsafe and undignified hospital discharge; despite the commitment and good intentions of care professionals. Existing sociological research highlights, for instance, how professional

boundaries and financial pressures create obstacles to integrated care (Allen 2014).

Agamben's ideas help us understand how the social organisation of discharge can reduce people to a 'bare' life with limited value or meaning, which in turn normalises unsafe and undignified care. Unlike Agamben, we suggest this arises less from sovereign (political-legal) power and more from the incompatibilities of multiple decentred systems that inadvertently render certain people 'unknown', 'ineligible' and 'unvalued'.

### **Agamben's Homo Sacer and States of Exception**

Agamben's work considers how political-judicial (sovereign) systems (re-)define what it means to be human (Genel 2006). His work attends to the ways sovereign systems can deprive people of legal rights and protections, thereby making their suffering, degradation and death entirely legitimate. The Holocaust provides the backdrop to his thinking, but rather than explaining totalitarianism, dictatorships and death camps as the exclusive phenomena of the Nazi state, he locates these possibilities in the history of Western political-legal thought, arguing that similar processes of dehumanisation persist in contemporary society (Agamben 2005). His ideas engage, in particular, with Foucault's work on 'bio-power'. In his later works, Foucault invoked this concept to describe how the optimisation of productive human life had become the primary object of modern government (Foucault 1998). Although sovereign power can still determine 'life and death', Foucault saw 'bio-power' as realised through a decentred assemblage of discursively constituted institutions, calculations and technologies. Agamben's work can be seen as correcting and completing Foucault's ideas in two areas (Colebrook and Maxwell 2016). The first is to re-emphasise the fundamental

significance of sovereign power in relation to bio-power, and the second is to suggest that (sovereign) bio-power is not only a feature of modern government, but is an enduring feature of Western legal-political systems.

Drawing on Greek philosophy, Agamben (1998) highlights a distinction between 'bare' life (*zoe*) and 'qualified' life (*bios*). The former describes the most fundamental, biological parameters of life, and the latter a life with social, legal and political significance. For Agamben, the distinction between 'bare' and 'qualified' life structures social and political existence; with the boundary between the two determined through sovereign (political-judicial) authority (Agamben 1998). In ancient Greece, a 'qualified' life was the basis of meaningful citizenship and political participation. It is an act of political and legal inclusion, that is given and safeguarded through law; which by implication makes exclusion possible through removal of rights and return to 'bare life'. According to Agamben, the potential for sovereign power to define the value of human life is a constant feature of Western society (Colebrook and Maxwell 2016).

This distinction is elaborated in Agamben's (1998) writing on *homo sacer* – a concept derived from Roman law to designate someone who can be legitimately killed, but not sacrificed. The idea of 'sacred', in this sense, is different from contemporary use, describing someone who is accursed or outside of the law. The sovereign determination of *homo sacer* means a person is confined to their 'bare' life and can therefore be killed within impunity. For Agamben, the *homo sacer* is significant because, although the individual might be outside of the law, they are still subject to its influence, in so much that the law determines their outside position.

This reveals a paradoxical position where the *homo sacer* is simultaneously inside and outside

political-judicial jurisdiction (much like a sovereign who is simultaneously the basis of and above the law).

Agamben (2005) uses these ideas to interpret the relationship between the state and the citizen, especially in his analysis of the Holocaust. Agamben cites Carl Schmitt's (1985) maxim that the '*sovereign is he who decides on the state of exception*'. A 'state of exception' is a situation in which established democratic processes, legal protections and citizenship rights are suspended and replaced by forms of executive or dictatorial power, such as a State of Emergency or Marshall Law. This 'legalised lawlessness' (Humphreys 2006) is typically premised on the need to safeguard social order, i.e. civil liberties are temporarily curtailed to protect civil liberties. Significantly, a state of exception can remove legal protections for entire social groups, limiting them to a 'bare life' and making possible inhumane treatment. The extermination camps of the Nazi regime exemplify this, but it can be found in other situations, such as Guantanamo Bay (Agamben, 2005). A state of exception is not a place or mode of governance, rather it is the threshold that defines the boundary between 'qualified' life and 'bare' life. This threshold is not a hidden or subverted feature of the modern state rather it is a foundation of political-judicial authority or 'sovereign bio-power' (Fiskesjo 2012).

### **States of exception in health and healthcare**

Whilst Foucault's ideas have had enormous influence in medical sociology, Agamben's (1998) have been more limited. In his writings, he talks of 'overcoma' and 'neomort' (equivalent to permanent vegetative states) as situations in which human life is reduced to its most basic biological functions (Lemke 2011). In such situations, scientists and ethicists debate the bio-

political threshold of life and death as an expression of sovereign authority (Norris 2000). Agamben's ideas can be applied to other aspects of contemporary healthcare where 'pathways' to death are made possible through the legitimate curtailment of legal protections. The controversial Liverpool Care Pathway, for example, was established to support dignified end-of-life care, but the drive towards standardisation and rationalisation (Neuberger et al. 2013) might suggest it functioned as a procedural 'threshold' for establishing a person's 'bare life' and depriving care. Institutions for people with mental health problems, learning disabilities, dementia or other long-term conditions have also been shown to harbour harmful, abusive and degrading treatment (e.g. Department of Health 2012; Mandelstam 2011). Ethnographies of care homes further show how staff are unable to care when expected to comply with standardised procedures, government regulations and corporate pressures (DeForge et al. 2011). Although such cases reveal how economic and political pressures condition or exacerbate undignified and harmful treatment (e.g. Francis 2013), Agamben's ideas draw attention to the way life itself is (de-) valued in these social and political systems.

We draw upon Agamben's ideas to develop new thinking about the thresholds of life that are experienced during hospital discharge. As noted above, this care transition can be distressing, degrading and harmful (Healthwatch 2015; Waring et al. 2016b). Research tends to emphasise the micro-level dynamics of inter-professional communication and coordination as complicating care transitions (Kripalani et al. 2007; Waring et al. 2015), or the influence of macro-level resource constraints as undermining continuity of care (Glasby 2003). Accordingly, improvement interventions tend to focus on technical solutions for better communication, discharge planning, or resource sharing (Aase et al. 2017). As in other areas



of patient safety, there is limited consideration of how people are (de-) valued through these processes.

Drawing upon Agamben's ideas, hospital discharge can be interpreted as crossing various social, cultural and political *thresholds* – hospital/home, inpatient/outpatient, unwell/well. When inside the hospital it might be suggested that, to some extent, a person's 'bare' life comes to the fore of bio-medical attention; with their 'qualified' life temporarily limited. Discharge might then appear to be a return to a more 'qualified' life, but for many this is complicated by on-going illness and long-term care. Agamben's idea help us think about how professional expertise and scientific evidence, alongside organisational-legal bureaucracies, contribute to these processes as a delegated function of sovereign power, for example where criteria of discharge planning establish the threshold of 'bare' life. As elaborated below, this is not necessarily the consequence of any individual decision or legal determination, but an inadvertent consequence of incompatible decisions and determinations.

## **The study**

### *Study setting*

Our ethnographic study was carried out between 2011 and 2014 in two 'care systems' in the English National Health Services (NHS). The term 'care system' describes the configuration of inter-connected organisations involved in the delivery of health and care at the municipal level. Each system comprised a single NHS Trust providing specialist care, around which community health and social care services were configured, including general practitioners

(GPs), community hospitals, rehabilitation services, local authority social services, and nursing homes. To focus our enquiries, the study investigated the discharge of stroke and hip fracture patients, because these patients typically have complex care needs and present a particular challenge to discharge planning. As discussed below, it might be assumed that younger or less complex patients would not receive the types of care observed.

### *Data collection*

Ethnographic fieldwork was carried out by the authors for 10 months in each system. We collaborated, in the first instance, with clinical leaders to gain access to the stroke and orthopaedic services; and to identify and recruit relevant staff groups in hospital and community settings. Observations were carried out over multiple stages to refine our understanding of hospital discharge. Initially, we 'mapped' care processes through observing daily routines, followed by in-depth observations of key situations and activities, such as planning meetings and referral processes, and then we 'shadowed' key individuals, such as discharge coordinators, ward nurses, and doctors. Observations were recorded in hand-written field journals.

The study also 'shadowed' 30 patients over the course of their care transition. Patients were recruited in collaboration with medical staff who identified those who were soon to be discharged, and who could speak English or had family members to assist with communication. The designated clinician for each patient introduced a researcher to the patient at the bedside, whereupon the study was described, and a participant information sheet provided. Patients (with their relatives) were then re-approached by a researcher 24-48 hours later to answer questions and seek consent. Sampling intended to reflect

differences in age, gender, ethnicity and residence, but recruitment needed to be opportunistic because of the challenges of recruiting and retaining patients, who were often very unwell and confused. Given these challenges, it was not always possible to obtain comprehensive socio-demographic data, especially age, ethnicity and residence. 30 participants were recruited and interviewed in hospital within 72 hours of discharge; 27 interviewed within 2 weeks of discharge, and then 17 and 9 participants at four- and six-weeks, respectively. The reduction in participation reflected the challenges of recruitment, e.g. 4 were re-admitted, 3 left the area, 5 were unable to participate due to ill health, and 6 passed away. Patients and/or relatives were invited to keep a reflective diary that asked participants to '*describe daily activities following discharge, especially contact with health and social care workers*' (8 completed). Patient advisors suggested a paper-based, minimally structured diary was preferable because participants would likely be elderly, with low IT literacy and with possible cognitive impairments.

Semi-structured interviews were carried out with 213 individuals across the study sites (Table 1). Participants were purposively sampled during fieldwork on the basis of their observed involvement in discharge processes. The interviews explored: career biographies, roles and responsibilities in discharge, communication processes, and perceptions of risk. Interviews were recorded with the consent of participants. Four focus groups were undertaken with community-based professionals, including GPs (n:4 & 7), ambulance services (n:3), and community rehabilitation specialists (n:12). These asked participants to individually describe (or draw) their understanding of a 'typical' discharge, followed by a group exercise to deliberate and 'map out' the discharge processes. All names have been changed to assure

the confidentiality and anonymity of participants. The study received favourable ethical approach through standard NHS research governance arrangements.

**Table 1:** Interview Participants

Group	System 1	System 2	Total
Medical (hospital)	10	8	18
Nursing	18	15	33
HCA's	5	2	7
Occupational Therapists	10	10	20
Physiotherapists	16	8	24
Other therapists (speech, dieticians)	2	3	5
Pharmacists	1	2	3
Ambulance manager	1	1	2
Administrative	2	2	4
Hospital/Ward Management	3	3	6
Social Work	9	5	14
Social Care	2	2	4
Community Nursing	2	7	9
General Practitioners	1	2	3
GP/CCG administration	2	0	2
Support group/voluntary	4	2	6
Patients	16	14	30
Carers/Family	12	11	23
<b>Total</b>	<b>116</b>	<b>97</b>	<b>213</b>

### *Analysis*

Data analysis aimed to develop a rich descriptive and interpretative understanding of discharge processes. Following Corbin and Strauss (2014), this involved an iterative process of open coding; constant comparison; elaboration of cross-cutting themes; and engagement with wider literature. We initially open-coded our observed and participants' reported experiences of discharge, which were categorised around different settings, activities and events. These were further analysed as second-order codes; for example, the category of 'harms and safety' formed part of a broader theme of 'Follow-on care', and these were

further analysed as higher-order themes. Tables 2 and 3 illustrate our coding process with additional extracts of data. We acknowledge that from the standpoint of the academic researcher, interpretations of clinical appropriateness and in/humane care are shaped by our own position and moral sensibilities. To be more confident in our interpretations we discussed interpretations with study advisors. As thematic analysis progressed, candidate theories were considered to explain the social organisation of discharge, including sociological accounts of bureaucracy and professional cultures. Through this iterative process, the work of Agamben was used to help interpret findings and inform thematic analysis. We present our findings along three lines. First, we describe how, for some patients, hospital discharge is experienced as degrading and unsafe; second, we describe how these experiences are shaped by the social organisation of hospital discharge; finally, we discuss our findings through the ideas of Agamben.

## **Findings**

### *The experiences of 'bare' life in hospital discharge*

Almost all participants described discharge as an important symbolic spatial-temporal 'threshold' between hospital and community that represented aspirations for recovery, wellbeing and dignity - a return to a more 'qualified' life. For some, this threshold was experienced as undignified and distressing, or in ways that appeared to precipitate a more enduring 'bare' life. Participants talked of these negative experiences in terms of their limited influence in care planning, scheduling of discharge, and provision of follow-on care.

A key stage in discharge planning is determining a patient's 'readiness' for discharge according to their reduced need for hospital care and suitability for care in the community. Participants described having little influence on these decisions and reported feeling frustrated that their wishes and important aspects of their personal circumstances were not sufficiently considered.

*'Ward round: consultant introduces herself to the patient, asks 'how are you doing today'. She then says they are thinking about when 'you might go home'. The consultant then talks to a junior doctor about some results and the nurse about the patient's mobility and confusion, but without really talking to the patient directly... they talk over and about the patient.'* (Fieldnote)

*'Doctor visited ward round. Did not speak to me on his ward round. No discussion about discharge. Feel like I'm invisible. I am getting agitated with staff. They just stand about taking no notice.'* (Flo, Hip fracture, White British)

A prominent anxiety for patients related to the plans for their future living arrangements with many describing a sense of apprehension, even fear about what *'will happen next'*. Most wished to return 'home', but some felt clinicians and social workers, often in collusion with relatives, were planning a move to a residential facility. Too often, it seemed patients were easily treated as passive subjects, rather than active participants in care planning.

A further concern was the scheduling of discharge, especially where discharge was delayed. Many participants were given an 'estimated date of discharge' to which great symbolic

importance was attached, and yet, this date was regularly revised due to deteriorating health or difficulties in arranging community care. These delays were deeply frustrating for patients, with some alluding to the idea that being *'kept in hospital'* curtailed their liberty.

*'It's like the goal-post get moved and moved and moved. Just when you think about getting going home, they take it away from you.'* (Bob, Stroke, White British, Field journal)

By turns, patients described being told about their discharge only shortly before it occurred. This led to an intensive period in which they needed to dress, contact family, and confirm arrangements. Some talked of being *'thrown out of hospital'*. A highly distressing occurrence was when patients were discharged to community hospital or care homes late at night, usually alone and with little information about where they were going and for how long.

*'From half-past in the morning...to strip my bed, and I sitting on a chair from that time till I got home. It had done eight o'clock at night. I felt like I wanted t cry because, you know, I felt they just didn't care'.* (Thelma, Hip Fracture, 79, White British)

On the day of discharge some patients were moved to a 'discharge lounge' whilst arrangements for their medicines and transportation was finalised; which released the hospital bed for the next inpatient. Although intended for short-term use, we observed how patients spent many hours waiting here, in unsuitable seating and without specialist care. Even nurses described it as a *'holding pen'* with obvious parallels with animal transportation.

*'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).

Once in the community, patients experienced common problems with care quality. Some described having limited or no contact with their GP following discharge and others described how their GP would know little about the care received in hospital or plans for on-going recovery. We were informed by both patients and GPs that discharge letters were often delayed and could lack important information.

*'Researcher: Have you seen your GP?*

*Patient: No. I'll tell you why. Because the last I went, I've been passing out and I'd just been in the hospital. And her exact words to me were, 'Fred, I don't know how to treat you because haven't heard anything from the hospital'*

Patients also talked of being sent home with incomplete or incorrect medicines, or with limited understanding of how to take them. They described finding it difficult to book community nurses to treat wounds, change dressing or give injections, and that often relatives were required to carry out such tasks.

*'[I was] given bag of medications but no instructions. No idea what they are for.'*

*(Maurice, Hip Fracture, White British, 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, Stroke, White British, diary)

In other ways, community health and social care workers described how it was usual for care plans, devised by hospital staff, to neglect important information related to ongoing needs, such as when to arrange out-patient appointments or what types of physical therapy were needed. This meant patients' initial encounters with community services were often poorly specified and required rapid revision.

*'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)

In such circumstances, participants talked of the difficulties of managing basic tasks, such as dressing, cooking and personal hygiene. For some, this was exacerbated by the failure to provide required aides, such as grab-rails, steps, or toilet seats. Two patients returned home requiring a special bed, but one found that it did not fit in their house, whilst another was provided with the bedframe but no mattress.

*'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, Stroke)

Patients also had anxieties about when their care package would end, and their longer-term care needs. Given pressures on the care system, care was often sporadic and partial, with late or missed activities. It was also clear that most participants relied upon relatives and friends to help with basic personal care and to 'manage' the care system by coordinating social care visits, chasing-up prescriptions and arranging appointments. Many of our patients described themselves as a burden on their family and as abandoned by the care system.

*'The nurse was supposed to come back again. She didn't say exactly when she was coming but nobody's been since. So, nobody's really checked me over.'* (Ralph, Stroke, 73, White British)

*'Sunday: No carer, I managed on my own, but I feel tired.*

*Monday: No carer again. Trouble with too frequent visits to the toilet'* (Sidney, Stroke, White British, Diary)

*The social production of 'bare life'*

We next describe how the experiences outlined above were made possible, even acceptable through the social organisation of hospital discharge. Our analysis highlights three themes that account for why, for some people, discharge can precipitate a 'bare' life. An important contextual observation was that both care systems were experiencing severe financial constraints, which created an environment of pressured working and exacerbated tensions between professionals; allowing thresholds of exclusion to be more readily enacted.

Our first theme describes how at the point of discharge certain patients are seemingly '*not known*'. We observed how each professional-practice group ascribed a different meaning onto the 'patient', 'client' or 'service user' and how these rendered different 'parts' of the patient visible and amenable to intervention (Foucault 1994). For example, specialist medical staff were usually concerned with determining 'readiness' for discharge based on core bio-physiological assessments; ward nurses were concerned with measures of health and well-being; and therapists with different aspects of mobility, speech or diet. Yet, these did not always come together into a coherent or shared understanding of care. For example, we repeatedly observed in multi-disciplinary team meetings how specialists took turns to present their assessment of the patient, each adhering to the evidence-based guidelines of their own practice, but where they often talked past one another and rarely reached a holistic understanding:

*'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 worker)*

‘At the MDT, his case was again reviewed in a very sequential way with staff taking turns. The OT described the progress made in his mobility, and the SaLT indicated that he no longer needed the nasogastric tube ... the ward nurse informed the group that his wife had left the country for a short period and there was limited family support at home.’ (Fieldnote)

Such multi-disciplinary team meetings revealed incompatibilities amongst professionals. This included, for example, regular discrepancies between doctors and therapists about whether a patient was ‘fit’ for discharge, as well as disagreements amongst occupational therapists and social workers about patients’ on-going needs.

*‘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’.* (Nurse)

These types of interactions illustrate how professional groups tend to operate within *bounded* jurisdictions, which are often poorly integrated and not always well-aligned to the needs of patients. Such boundaries between professionals were especially pronounced in the relationship between health and social care professionals where divisions centred on categorisation of needs as ‘medical’ or ‘social’; which had implications for the allocation of caring and funding responsibilities. The stringent criteria for ‘continuing healthcare’ (NHS funded) meant that seemingly very frail and dependent patients were categorised as having ‘social’ rather than ‘medical’ needs.

*'It was quite clear that she was very poorly and shouldn't have been discharged home, even with the care package...we have to make the patient stable....but there is only so much we can do on the medical-side of things.'* (Social care)

*'We get a lot of flak for it because obviously we refuse a patient, it's our fault, you know, it's not because the ward have done something and haven't done... their assessment is proper. It's because we're not accepting this patient'.* (Community Team)

It seemed therefore, people were allocated multiple, often incompatible meanings across the discharge process, and it was difficult to establish a sufficiently complete or stable definition of 'what' (or 'who') the patient is. The problem is exacerbated because at the point of discharge the patient is in a relatively liminal space as they transition across multiple professional boundaries. As such, the person becomes them 'not known' or a non-subject., creating consequent problems for determining and coordinating care, and which also makes it difficult to allocate professional 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)

Our second theme considers how people experiencing discharge could easily and legitimately be rendered '*ineligible*' for care, especially through the use of formulaic and standardised

assessment procedures. We found that the problems of 'knowing' the person, were intensified by the reliance upon planning guidelines and assessment criteria that related to discrete and bounded areas of professional practice and which reinforced a highly segmented and abstract view of the person. More significantly, the widespread use of prescriptive assessments and criteria were often ignorant of the complex needs and personal circumstances of patients, leading to highly abstract and depersonalised measures, e.g. of mobility, falls-risk or cognitive ability. For example, assessments of a cooking abilities were completed in 'mock kitchens' that rarely resembled the patient's home, and mobility assessments were carried out in controlled environments devoid of real-world hazards. Moreover, staff themselves reported feeling under pressure to use assessments to 'sign-off' patients and meet operational demands, rather than identify the needs of the patient.

*"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)*

More significant, was the way formulaic assessment processes enabled professionals to determine people as ineligible or unsuitable for certain care services. A prominent example was social workers' assessment of ongoing needs, which took into account a person's personal and domestic arrangements, including finances and home ownership. Unlike healthcare, which is free at the point of need, social care in England is means-tested, and many patients were surprised to find that relatively modest savings and/or home ownership would make them ineligible for funded care. Also confusing for staff and patients were the eligibility criteria for 're-ablement' and rehabilitation services, where some patients were

deemed ineligible because they were assessed as too complex, too old or too frail. It seemed that such assessments were often geared towards depriving people of services, primarily to cope with excessive demand and resource constraints. As described below, community services could decline referrals, often citing obscure eligibility criteria. Importantly, people deemed ineligible for care typically left hospital with a patchwork of services.

‘[N]urse initiated external referrals for social care using a computer-based referral system. Social services reviewed and declined the request for social care on the grounds that he was not formally registered as a local resident and did not have appropriate legal status.... The social care referral stalled at this point and remained unresolved.’(Fieldnote)

‘OT went to the sister’s office to discuss a problematic discharge. She had found a curt note fastened in his patient records from a social worker, saying unless a capacity test is done on the gentleman today, his discharge would be further delayed.’

(Fieldnote)

Our third theme relates to how professionals saw themselves as not responsible for care. As described above, professional cultures were relatively bounded in terms of their areas of expert work. Such jurisdictions can complicate task sharing and coordination (Nancarrow and Borthwick 2005) and, in our study, seemed to make the coordination of care at the point of discharge difficult. That is, hospital discharge complicates the allocation of professional responsibility because it is experienced as a liminal spatial-temporal threshold where no one professional holds unambiguous responsibility for care.

For many hospital-based professionals, discharge planning was a major task, but it was also regarded as low-status and low-priority, diverting clinicians from more acute duties. For doctors, in particular, their clinical attention was on the urgent needs of newly admitted patients; with discharge seen as a low-status task for *'finishing off'* and *'handing over'* care. As such, tasks related to discharge were often devalued and delegated. This was seen, for example, with reduced surgical involvement in discharge planning and where doctors delegate responsibility for discharge planning to junior staff. The withdrawal of involvement might account for the problems in the continuity of medical care, as described above:

'The surgeon's involvement...reduced dramatically. In board rounds he only acknowledged that [patient] care was progressing and that no significant changes had occurred. It seemed that the responsibility for care had been transferred to the rehabilitation team.' (Fieldnote)

*'The discharge summer that goes out...it's filled by the junior doctor. Its quite a cursory document at time and it doesn't necessarily reflect what's happen'* (Care of the elderly doctor)

Social workers and occupational therapists usually had more direct responsibility for discharge planning, but again with a view to determining what 'could' (not what 'should') be provided. Moreover, there were tensions amongst specialists about determining the levels of need, and in turn the allocation of responsibilities (and funding). For example, discharge



could be delayed whilst determining who should order and fund home-adaptions with responsibility for ordering equipment passed from one professional to another.

*'we'll fight over who orders what, who's budget it's going to come out of? 'No. It's a social commode.' What on earth is a social commode?'* (Social Worker)

*'People are happy to say there's nothing we can do and pass it on to the next staff member and the next.'* (Healthcare assistant).

In the community, we observed how responsibility for care was dispersed across health and social care providers, who rarely worked together. This meant that patients could receive parallel or contradictory care packages. Overall, people's care often fell through gaps between organisational and professional silos. Discharge was seen by many in the hospital as the end point of responsibility, whilst in the community the diffuse nature of care provision meant that no one took responsible (Heavey et al. 2019).

*'I think there just somehow seems to be a void between hospital and community where things sort of fall down. Almost like a bit of a hurdle'.* (Nurse)

## **Discussion**

Our ethnographic study echoes research that describes hospital discharge as a potentially undignified, degrading and harmful process (Healthwatch 2015. Waring et al. 2016b). We show how patients, and their relatives, routinely experience discharge as disempowering and dehumanising, which for some could be a 'stepping-stone' towards more sustained forms of

exclusion, even 'social death' (Bauman 1992). Moreover, it finds that all too often those working within the care system accept this potential, possibly because they are pressured to focus on their discrete part of the care process, and because operational pressures require staff to 'push' people through the system. We are in no way suggesting that professionals intended to treat patients in this way, and it is important to state that the vast majority of the staff we interviewed expressed a deep commitment to patient care and were dismayed at elements of the wider system. Instead, we argue that people's (and professionals') negative experiences of care are rooted in the social organisation of hospital discharge, combined with the enduring pressures of increased demand and reduced resources.

Three explanations are commonly invoked to explain how hospital discharge can result in experiences of degradation and harm. The first relates to the complexity of a person's health conditions that renders their care difficult and costly. However, it does not (nor should it) necessarily follow that these lives hold no value. The second explanation sees the process of dehumanisation as a consequence of 'bureaucracy', where the strict division of labour, coupled with standardised procedures inevitably promote operational efficiency ahead of human dignity (Francis 2013). The third, and linking the above two viewpoints, emphasises the role of 'professional boundaries' in complicated efforts to provide safe and integrated care at the point of discharge (Waring et al. 2015). Although these lines of analysis provide important insights, they do not necessarily account for how harmful and degrading treatment is deeply rooted within the social and cultural systems of care. We draw upon Agamben's ideas to develop a complementary, but also radical interpretation of hospital discharge that explores how patients are reduced to a 'bare' life thereby making permissible harmful and degrading (non-) care.

Our participants' accounts suggest hospital discharge is a significant symbolic threshold between hospital/home or ill/well. A preliminary reflection is that patients might accepted a relatively passive role in hospital, with echoes of Parson's (1975) 'sick role'. One interpretation is that being in hospital involves a temporary suspension of a 'qualified' life - where a 'bare' life of bio-medical care comes to the fore. This makes hospital discharge a significant threshold for a return to a more 'qualified' existence; if only as an aspiration. And yet for some people, discharge is experienced as a 'stepping-stone' or 'passage point' to more fundamental and sustained exclusion and abandonment: a deepening of their 'bare' life. We are not suggesting that patients acquire the status of *homo sacer* in the sense that they can be killed with impunity, but discharge can be a threshold for rendering harm and degradations more likely *and* acceptable through the removal of care and diffusion of responsibility. For Agamben (2005), the 'state of exception' is a threshold of inclusion and exclusion, between 'qualified' and 'bare' life. For our study, this might be interpreted as 'health-state of exception' in which certain types of patients are more easily excluded and reduced to their 'bare' life. Although it might be argued these 'health-states' reflect the nature of a patient's health conditions or 'health state', especially where they are older with complex comorbidities. However, we argue that the production of a person's 'bare' life stems from the way people become 'un-known', deemed 'in-eligible', and where professionals take no 'responsibility' for their care.

Our study finds that professionals struggle to agree upon 'what' (not 'who') the patient is; not because of their complex needs, but because of the persistence of multiple, competing professional discourses. As such, the definition of 'the patient' remains elusive and outside

the bounds of professional practice. With parallels to the work of Mol (2002), each professional group 'knows' the patient through particular bio-medical or psycho-social criteria, with 'disease' and by implication 'the patient' redefined across the pathway. At the threshold of discharge, these multiple perspectives struggle and compete to define the patient, because they are simultaneously inside/outside the hospital/community. Put another way, there is a tendency to 'segment' the patient according to different ontologies (Mol 2002), but at the liminal point of discharge where these segments are brought together to develop a coordinated care plan, they all too often fail to establish a holistic understanding of the 'qualified' person. Returning to Foucault's (1994) concept of the 'gaze', the patient is both known *and* unknown rendering them an un-governable 'non-subject'. This occurs not through sovereign (politico-legal) decision-making (Agamben 1998), but because of the complex eco-system of competing jurisdictions.

The use of formal assessment criteria to determine eligibility further renders people as 'unknown' and makes legitimate the deprivation of care. With closer alignment with Agamben's work (1998), these technical instruments illustrate the type of depersonalised legal-bureaucratic processes that deprive people of their humanity or reduce them to their 'bare life', especially through transforming complex needs into a segmented abstraction that can be managed within the parameters of bounded professional responsibility. Interestingly, these bureaucratic procedures are often realised through delegated forms of authority to low-grade professionals, whilst high-grade experts focus on other more specialist tasks (Nancarrow and Borthwick 2005). Where professionals disagree about their specialist assessments it further renders the person unknown, but now in a more formal and technical sense, creating an indeterminate site or 'zone of exclusion'.

The dilemmas of 'knowing' the person and determining 'eligibility' sets the parameters for establishing professional 'non-responsibility' for care; i.e. the inability to define an eligible subject makes the responsibility for care diffuse (Heavey et al. 2019). This is similar to the 'problem of many hands' where the distribution of responsibility amongst multiple actors can mean that no one actor ultimately takes responsibility for care (Dixon-Woods and Provonost 2016). This is heightening at the liminal point of discharge, where the person is in transition across multiple boundaries (Waring et al. 2015). When combined, the problems of knowing the person, determining eligibility and allocating responsibility might be seen as a self-reinforcing triangular relationship that determines the threshold of inclusion/exclusion or bare/qualified life.

Although our paper focuses on the dehumanising experiences of discharge, many patients in our study experienced a more positive transition, and as noted above, these were often younger with less complex needs. Considering these more positive experiences in the context of the above analysis, enables us to offer tentative suggestions for how degrading and unsafe non-care might be avoided. First, we think it important to remember that at the centre of all care system are vulnerable people with rich complex lives, and rather than using labels such as 'patient', 'service user' or 'client', care providers could more readily rehumanise people by calling them by their name. Second, our study supports the idea that patients and their relatives are generally the only source of continuity across a multi-professional pathway (Waring et al. 2015). They have a unique understanding, not only of their own care needs, but how multiple care providers can work together. As such patients and their relatives should, where possible, be involved in care planning to help 'scaffold' the system (O'Hara et

al. 2019). Third, health and care providers need to establish a common frame of reference and shared understanding of respective work routines and pressures in order to facilitate coordination (Waring et al. 2015). This might not necessarily involve expensive digital technologies, but more opportunities for face-to-face working and shared decision-making. Improving patient safety during hospital discharge will certainly rely upon better inter-professional communication and coordination (Aase et al 2017); especially as these are important for developing a shared understanding of and responsibility for the person. However, over-reliance on standardised communication or decision-making procedures could further dehumanise people. Instead, improvements in hospital discharge, and other aspects of the care system, need to better recognise the potential for complex systems to exclude people because they *'fall between the gaps'* of disciplinary sub-systems or technologies.

In this paper, we are not suggesting that hospital discharge is in anyway equivalent to the Holocaust or other such atrocities; but the harms and degradations experienced by patient speak to similar thresholds of exclusion rooted in the modern state. Agamben (2005) associates these processes with socio-legal systems that are rooted in antiquity and systematically deprive people of their rights (i.e. sovereign bio-power). In the case of hospital discharge, and care systems more broadly, we suggest the production of 'bare life' is only partially a product of sovereign authority, for example, in the delegated legal powers of professionals to determine levels of care. Rather, we suggest patients can be reduced to their bare life *inadvertently* as result of the incompatibility of different disciplinary calculations and technologies within a broader state apparatus of care. Specifically, the 'health-state of exception' arises when the difficulties of knowing the patient, determining eligibility and

allocating responsible are manifest within a complex system of interdependent specialists interacting in dynamic and non-linear ways (author). Whereas Agamben's work focuses primarily on political-legal systems, closer attention to the specific contexts and social practices through which exclusion and degradation occurs reveals a more complex form of decentred bio-power (Lemke 2002).

By way of a provocative conclusion, we therefore return to Foucault's (1998) observation that bio-power is concerned with the optimisation of the productive health of a given population. What we see in the case of hospital discharge, and other instances of sub-standard care, is apparatus of bio-power that consistently fail, i.e. they harm the subjects they are intended to care for. This might therefore be interpreted as a problematic or failed apparatus. And yet, following Agamben (1998) and Bauman (1992) the 'politics of death' and the purification of society remain a primary function of bio-power; where, for example, it might be viewed by state actors as more expedient (and acceptable) to exclude those people that are beyond saving or unable to contribute to society. Our study suggests this is not a consequence of disciplinary design or sovereign power, but rather the inadvertent consequence of the incompatibility of disciplinary technologies, apparatus and calculations which result in a flawed mode of governance.

## References

Aase, K., Waring, J. and Schibevaag, L. (2017) 'Crossing boundaries: quality in care transitions' in Aase, et al. (Eds). *Research quality in Care transitions*, London: Palgrave.

Agamben, G. (1998) *Homo Sacer: sovereign power and bare life*, Standford: Stanford University Press.

Agamben, G. (2005) *State of Exception*, London: University of Chicago Press.

Allen, D. (2014) *The Invisible work of Nurses*, London: Taylor-Francis

Bauman, Z. (1992) *Mortality, immortality and other life strategies*, London: Stanford University Press.

Cuthill, F. (2017) 'Repositioning of 'self': social recognition as a path to resilience for destitute asylum seekers in the United Kingdom', *Social Theory and Health*, vol.15:117-137.

Colebrook, C. and Maxwell, J. (2016) *Agamben*, Cambridge: Polity.

Corbin, J. and Strauss, A. (2014) *Basics of Qualitative Research*, London: Sage.

DeForge, R., VanWyk, P., Hall, J. and Salmoni, A. (2011) Afraid to care; unable to care: A critical ethnography within a long-term care home. *Journal of Aging Studies*, vol.25(4):415-426.

Department of Health (2012) *Transforming Care: national response to Winterbourne View Hospital*, London: Department of Health.



Dixon-Woods, M. and Pronovost, P. (2016). Patient safety and the problem of many hands. *BMJ Quality and Safety* vol.25(7):485-488.

Durkheim, E. (1992) *Professional Ethics and Civic Morals*, London: Routledge.

Ferlie, E., Fitzgerald, L., McGivern, G., Dopson, S., and Bennett, C. (2013). *Making Wicked Problems Governable?* Oxford: OUP.

Fiskesjö, M. (2012). Outlaws, barbarians, slaves: Critical reflections on Agamben's homo sacer. *HAU: Journal of Ethnographic Theory*, vol.2(1):161-180.

Foucault, M. (1994) *The Birth of the Clinic*, London: Vintage Books.

Foucault's (1998) *History of Sexuality vol.1: The Will to Knowledge*, London: Penguin

Francis, R. (Chair) (2013). *Report of the Mid Staffordshire NHS Foundation Trust public inquiry*, London: TSO.

Genel, K. (2006). The question of biopower: Foucault and Agamben. *Rethinking Marxism*, vol.18(1):43-62.

Glasby, J (2003) *Hospital Discharge*, Oxford: Radcliffe.

Healthwatch (2015) *Safely Home*, London: Healthwatch.

Heavey, E., Waring, J. De Brun, A., Dawson, P. and Scott, J. (2019) 'Patients' conceptualisation of responsibility for healthcare: a typology for understand differing attributions in the context of patient safety' *Journal of Health and Social Behavior*, vol.60(2):188-203.

Hesselink, G., Schoonhoven, L., Plas, M., Wollersheim, H., and Vernooij-Dassen, M. (2012) Quality and safety of hospital discharge: a study on experiences and perceptions of patients, relatives and care providers. *International Journal for Quality in Health Care*, vol.25(1):66-74.

Humphreys, S. (2006). Legalizing lawlessness: On Giorgio Agamben's state of exception. *European journal of international law*, vol.17(3):677-687.

Kirkup, B. (2015) *The Report of the Morecombe Bay Investigation*, Morecombe Bay: Morecombe Bay Investigation.

Kripalani, S., Jackson, A., Schnipper, J. and Coleman, E. (2007). Promoting effective transitions of care at hospital discharge: a review of key issues for hospitalists. *Journal of hospital medicine*, vol.2(5):314-323.

Laugaland, K., Aase, K., & Waring, J. (2014). Hospital discharge of the elderly-an observational case study of functions, variability and performance-shaping factors. *BMC health services research*, 14(1), 365.

Lemke, T. (2011) *Bio-politics*, London: New York University Press.

Mandelstam, M. (2011) *How we treat the sick*, London: JKP Publishers

Mol, A. (2002). *The body multiple*. London: Duke University Press.

Morello, R., Lowthian, J., Barker, A., McGinnes, R., Dunt, D., and Brand, C. (2013) Strategies for improving patient safety culture in hospitals. *BMJ Quality and Safety*, vol22(1):11-18.

Nancarrow, S. A., & Borthwick, A. M. (2005). Dynamic professional boundaries in the healthcare workforce. *Sociology of health & illness*, vol.27(7):897-919.

Neuberger, J. (Chair) (2013) *More care, less pathway: review of the Liverpool Care Pathway*, London: Independent Review of the Liverpool Care Pathway.

Norris, A. (2000). Giorgio Agamben and the politics of the living dead. *Diacritics*, 3

O'Hara, J., Aase, K. and Waring, J. (2019) Scaffolding our systems? Patients and families 'reaching in' as a source of healthcare resilience' *BMJ Quality and Safety*, vol.28,pp.3-6.

Parsons, T. (1975). The sick role and the role of the physician reconsidered. *Milbank Quarterly*, vol.53(3):257-278.

Ritzer, G. (2006) 'Precursors: Bureaucracy and Max Weber's Theory of Rationality, Irrationality and the Iron Cage' in Ritzer (Ed.) *McDonaldization: The Reader*, London: Pine Forge.

Rose, N. (2007) *The Politics of Life Itself*, Oxford: Princeton University Press.

Rosenthal, M. (1995) *The Incompetent Doctor*, Milton Keynes: Open University Press.

Schmitt, C. (1985) *Political Theology*, Cambridge: MIT Press.

Walshe, K., and Shortell, S. (2004). When things go wrong: how health care organizations deal with major failures. *Health Affairs*, vol.23(3):103-111.

Waring, J. (2005). Patient safety: new directions in the management of health service quality. *Policy & Politics*, 33(4), 675-692.

Waring, J., Marshall, F., & Bishop, S. (2015). Understanding the occupational and organizational boundaries to safe hospital discharge. *Journal of health services research & policy*, 20(1\_suppl), 35-44.

Waring, J., Allen, D., Braithwaite, J., & Sandall, J. (2016a). Healthcare quality and safety: a review of policy, practice and research. *Sociology of Health & Illness*, 38(2), 198-215.

Waring, J., Bishop, S., & Marshall, F. (2016b). A qualitative study of professional and carer perceptions of the threats to safe hospital discharge for stroke and hip fracture patients in the English National Health Service. *BMC health services research*, 16(1), 297.