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The use of restrictive practices in the everyday care of people living with dementia in hospital settings: an ethnographic study

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The use of restrictive practices in the everyday care of people living with dementia in hospital settings: an ethnographic study

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and Katie Featherstone*





Extended Research Article

The use of restrictive practices in the everyday care of people living with dementia in hospital settings: an ethnographic study

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Disclaimer: This report contains transcripts of interviews conducted in the course of the research, or similar, and contains language which may offend some readers.

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This article

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Abstract

Background: Inquiries, National Health Service serious incident reviews and media reports identify people living with dementia at significant risk of experiencing restrictive practices during an unscheduled acute hospital admission. However, to date, this has not been the true focus of substantive empirical research.

Objectives: To explore the use of restrictive practices in the care of people living with dementia during an unscheduled acute hospital admission. To identify evidence-based (and alternative) strategies in the care of people living with dementia that are achievable, safe and transferrable.

Design: An ethnographic study (observation, ethnographic interviews, documentary analysis) in the symbolic interactionist research tradition, with the goal to deliver an in-depth empirically driven analysis of everyday acute care.

Setting: This ethnography was carried out for 225 days over an 18-month period between 2023 and 2024. In total, nine wards were observed across six National Health Service trusts in England, covering six acute wards (assessment and older peoples care) and three mental health wards (specialist older people mental health). Sites were chosen for diversity of demographic, geographic and practice variables.

Participants: One hundred and sixty-eight individuals consented to participate directly in this study, also contributing to 1116 ethnographic interviews.

Results: Our analysis identified a culture of containment within acute wards. The use of restrictive practice in the care of people living with dementia was an embedded aspect of routine ward care, within all shifts observed within acute wards, regardless of the ward, time of day and day of the week. Raised bedside rails, ward furniture and verbal commands were most frequently used, often quickly escalating to the use of enhanced observation, typically carried out at pace, to contain and restrict movement to the bedside. Recordable methods included the use of physical force and sedation. Our analysis demonstrates these apparently diverse range of practices cannot be understood in isolation but were utilised multiply in the care of individuals and cohorts of people living with dementia. Because their use was embedded within timetabled care, ward staff found defining and identifying restrictive interventions in their routine practices challenging, meaning these forms of restrictive practices were typically unrecognised and unrecorded. Staff experienced significant emotional impacts from using restrictive practices in patient care.

We identified a range of practices to support the reduction of restrictive practice within the acute setting. These included engagement with people living with dementia, making full use of the activity resources available to the ward, and supporting people living with dementia to leave the bedside to walk within their bay or ward.

Limitations: The potential for the Hawthorne effect was considered within the study design with the duration of the observation period within each ward designed to minimise this. Post-admission follow-up interviews with people living with dementia and their family partners were not possible due to low number of family visitors across all ward settings during the observation period.

Conclusions: Cultures of containment were embedded within routine organisation and delivery of care within acute wards, viewed as necessary for care delivery, required to increase patient safety, minimise risk of falls, absconding, or violence. Staff felt unable to practise in other ways for fear of risks to people living with dementia and reprisal. De-escalation approaches to reduce distress, as observed in appropriately resourced specialist units, are recommended over containment.

Future work: Development and translation of findings into open access training and National Health Service organisational tools to support best practice and alternative approaches in the care of people living with dementia at ward level will be coproduced in collaboration with our patient and public involvement participants, Improvement Cymru, and Dementia UK.

Study registration: This study is registered as ISRCTN11797465.

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List of abbreviations

A&E	accident and emergency	LGBTQ	Lesbian, Gay, Bi, Trans and Queer
AMU	acute medical unit	MAU	Medical Assessment Unit
APPG	All-Party Parliamentary Group	MCA	Mental Capacity Act
BPSD	behavioural and psychological symptoms in dementia	MDT	multidisciplinary team
COTE	care of the elderly	MHA	Mental Health Act
COVID	coronavirus disease	NIHR	National Institute for Health and Care Research
COVID-19	coronavirus disease discovered in 2019	PI	principal investigator
CPA	Care Programme Approach	PLWD	person/people living with dementia
CQC	Care Quality Commission	PPE	personal protective equipment
DoLS	deprivation of liberty safeguards	PPI	patient and public involvement
ECHR	European Convention on Human Rights	PRN	'pro re nata,' which means 'as needed'
ECR	Early Career Research	RN	registered nurse
HCA	healthcare assistant	SHO	senior house officer
LPS	Liberty Protection Safeguards	UTI	urinary tract infection

Plain language summary

People living with dementia are one of the largest groups of patients in United Kingdom hospitals. They are highly vulnerable during an admission. Their health can worsen during an admission. Poor experiences are widely reported, and people living with dementia have highlighted the use of restrictive practice as a key issue. However, very little research has been carried out to identify or understand its use.

For 225 days, across 18 months, we observed care in nine wards in six hospitals across England. This included six acute medical wards and three mental health wards.

We identified that the use of restrictive practice was an everyday feature of care for people living with dementia within acute medical wards. Restrictive practice can take many forms. This includes raised bedside rails, blocking doors and pathways with furniture, verbal commands to sit down or go back to bed, close one to one supervision, physical interventions and sedation.

Our analysis identified these practices could all be used in the care of an individual and groups of people living with dementia. Because the use of these practices was routine and everyday, many ward staff did not see them as restrictive practices, and questioned how else they could care for this patient group to keep them safe without them harming themselves or others.

Within specialist mental health wards, we identified practices that supported patient and staff, allowing the reduction of restrictive practice. We also saw examples within hospital wards where engagement and activity were used in place of restriction and verbal commands. This included supported walking, helping patients with personal care, listening and engaging patients in conversation. We argue these supportive approaches can be used within wards to improve the quality of care for people living with dementia while in hospital.

Scientific summary

Research aims

To examine the use of restrictive practice in the care of people living with dementia (PLWD) during a hospital admission. To explore what forms these practices take, the rationales for their use, and the experience of these practices from the perspectives of PLWD, their families, and ward staff and identify alternative strategies that are achievable, safe and transferrable across hospital settings.

Background

The Department of Health and Social Care estimate that between 25% and 50% of all acute hospital admissions are patients who are also living with dementia, making them one of the largest patient populations by diagnostic category. PLWD are also a highly vulnerable group within the hospital, at increased risk of deterioration, physical and cognitive decline, avoidable harm and adverse outcomes, including delayed discharge and institutionalisation.

Recent UK government enquiries and reports have repeatedly identified institutional cultures of restrictive practices (containment, restriction and restraint) as key features of the care inequalities PLWD experience during a hospital admission. To date, no UK research has systematically examined the use of restrictive practices, the forms it takes, rationales for its use, and its impacts on PLWD, carers and staff within NHS hospital wards. While there is a range of guidance across the NHS to inform its use for other patient populations and care settings, there are no best practice guidelines for its appropriate use, or training to support acute staff in using alternative approaches in the care of patients admitted with a diagnosis of dementia.

Our public consultations identified that use of restrictive practices in hospitals as a pressing research priority and PLWD coproduced this research. Many have direct experience of these practices in their care.

Objectives

In response, this in-depth ethnographic study examined the everyday cultures of restrictive practices in the care of PLWD during a hospital admission, exploring what forms these practices take, the rationales for their use, and the experience of these practices from the perspectives of PLWD, their families and ward staff. With a goal to identify evidence-based (and alternative) strategies in the care of PLWD that are achievable, safe and transferrable across care settings. Our objectives were to:

1. Provide a detailed examination of the social and organisational context in influencing the everyday care of PLWD to understand the (a) nature of restrictive (and alternative) practices within wards, (b) circumstances and contexts of use, (c) care practices when PLWD are perceived as at risk, or when their behaviour is perceived as 'challenging', 'disruptive' or 'aggressive'.
2. Examine the recognition, understandings and experiences of restrictive (and alternative) practices during an admission from the perspectives of PLWD and their families.
3. Examine staff perspectives (a) their understandings and recognition of restrictive practices, (b) the formal frameworks and informal rationales drawn on to inform the care of PLWD.
4. Translate the findings into evidence-based strategies to support best practice and alternative approaches to feasibly improve the care of PLWD at ward level.

Methods

This ethnographic study drew on symbolic interactionist traditions to provide a detailed contextual interpretive understanding of the social world of the ward. This supported a detailed examination of how the organisational processes influence social actors within them to work in particular ways when caring for PLWD. It also allowed us to examine taken-for-granted practices that have over time become part of the everyday ward cultures and the consequences of these ways of working PLWD.

This study was carried out across nine NHS hospital wards (six acute and three specialist mental health settings) within six NHS trusts (working in dyads in three towns and cities) across England. Sites were purposefully selected to represent a variety of hospital types, geographical locations and socioeconomic catchments (we were not able to access proposed sites in Wales). We conducted 225 days of ethnographic observation fieldwork within general acute medical wards, Medical Assessment Units (and variants thereof), older people's medicine wards and specialist mental health settings. Overall, we collected approximately 500,000 words of observational fieldnotes, transcribed, cleaned and anonymised by the research team. To obtain contextual understanding of the events and practices with these settings, we conducted 1116 in-depth in situ interviews with healthcare professionals, PLWD and care partners.

Research Ethics Committee (REC) approval for the study was granted by the NHS Research Ethics Service via the London – Bromley REC (22/LO/0448) and given approval by the Health Research Authority on 15 July 2022 [Integrated Research Application System (IRAS) 313618]. The research project was approved for the purposes of the Mental Capacity Act 2005 (section 31).

Results

Analysis of data provides understandings of the complex social and organisational interactions that occur in these settings, revealing how the everyday use of restrictive practices occurs in a complex set of wider institutional relations, expectations and priorities with consequences for PLWD admitted to these settings. For purposes of this report and considering the scope of the study, our analysis revealed eight themes: (1) everyday routine use of restrictive practice; (2) cultures of containment; (3) patterns of intensification and 'tightening'; (4) low tolerance of risk; (5) deprivation of liberty and everyday rights; (6) legal frameworks; (7) the impacts and consequences of the use of restrictive practices in the care of PLWD and (8) good practice and de-escalation.

The nature of restrictive practice

We identified the use of restrictive practice in the care of PLWD was an embedded aspect of everyday routine ward care, within all shifts observed within the acute wards, regardless of the ward, time of the day and day of the week. The restrictive practices used within these ward settings took a wide range of forms, with use of raised bedside rails, ward furniture and verbal commands, the most frequently used. These practices were typically carried out swiftly, and at pace, to contain and restrict the movements of PLWD at the bedside. What is of significance is that their use was embedded within timetabled care and viewed by staff as routine; thus, these forms of restrictive practices were typically unrecognised and unrecorded. We identified that ward staff found defining and identifying what constituted restrictive interventions in their routine practices as challenging.

Cultures of containment

Reflecting the international literature, our conceptual framework for defining restrictive practice is expansive, taking in practices that appear very different in their application and impacts, from the routine use of bedside rails and verbal commands, through to the non-consensual sedation of a person living with dementia. Our analysis demonstrates how these apparently diverse range of practices cannot be understood in isolation, but, instead, were utilised multiply in the care of both individuals and cohorts of PLWD within acute wards. The pervasive use and acceptability of these practices meant that escalation to the use of other and multiple forms of restrictive practice became acceptable features of ward care. In turn, this also shaped and normalised wider ward cultures of control, becoming routine aspects of everyday care, informing what patient behaviour was viewed as acceptable and also legitimised staff routine practice in response

to perceived risk of falls and 'absconding', or behaviour understood by staff as 'wandering', non-compliance and resistance to care.

Patterns of intensification and 'tightening'

Concerns over safeguarding, staffing and patient safety meant PLWD were required to conform to the expectations of the ward, rather than receiving a formal assessment of risk and consideration of returning home. Should the patient become distressed, lash out, or try to leave the ward, over an admission, this could quickly intensify the restrictive practices used in the care of a patient in the moment and over time. We observed patterns of intensification in the use of restrictive practices, the routine use of raised bedside rails and furniture, escalating to the consideration and use of one-to-one enhanced care, to restricted movement to the bedside. In turn, these practices could generate further patient distress or responses that included attempts to leave the bedside and the ward, which were met by the ward with increased 'tightening' of restrictive practices in their care, and ultimately this could inform the use of sedation. A key impact was the further limiting of an individual's potential pathways from the ward and increasing risk of institutionalisation.

Low tolerance of risk

A key focus for staff in utilising these approaches to restrict patients' movement or contain them at the bedside was as an immediate solution to a key quality assessment metric (falls prevention, a legitimate concern in the care of PLWD) for these wards and the wider institution. Other key identified risks included PLWD 'wandering' within the ward or 'absconding' from the hospital. Ward staff routinely applied restrictive practice not just to increase safety and reduce risk, but also to eliminate these risks for the population of PLWD, without accompanying risk assessment practices, informing powerful ward cultures of containment and low tolerance of risk. Ward staff often explained their actions and applications of restrictive practice interventions as being in the best interest of the patient and as a means of safeguarding and protecting the patient rather than a form of restraint. Yet legally, protective duties do not confer unfettered authority or powers on staff to restrict patients. These approaches had significant impacts on the personhood, dignity and independence of this patient population.

Deprivation of liberty and everyday rights

People living with dementia within these acute wards were likely to be deprived of their liberty. As we have already seen, PLWD were often contained in bed for most of the day with the bedside rails raised. This had the effect of almost completely restricting the persons' liberty of movement. PLWD were not able to leave their beds at will. We did not see any patients successfully lowering the bed rails themselves (although some tried to climb over the raised bed rails, posing significant injury risk). We did not observe ward staff offering to lower them, nor regularly offering PLWD opportunities to leave their beds with support. The intention and impact of the bedrails were that PLWD were effectively *confined* to their beds. These 'informal' restrictions may not involve the kinds of hands-on contact and direct use of force associated with physical restraint, but these environmental restraints significantly impacted on people's well-being and their everyday rights and freedoms – interfering with Article 8 of the European Convention on Human Rights.

Legal frameworks

There was significant variation across and within the acute wards in the application and assessments of the legal frameworks deprivation of liberty safeguards (DoLS) and the Mental Capacity Act. We found that PLWD classified as at risk of falls, 'wandering' or absconding, were more likely to have DoLS instituted. The use of these legal frameworks in a patient's care was recognised as a sign that patient was, or could be, restrained, particularly allowing for the use of sedative medication such as lorazepam or haloperidol. It was common for these interventions, once put in place, to remain in place for the duration of the person's admission, rather than for the specific period of review. We identified that these measures were often used despite patients' repeated requests to be released from these wards.

The impacts and consequences for people living with dementia and ward staff

The use of restrictive practice had significant impacts on PLWD and staff in these settings. For PLWD, we identified increased emotional impacts including verbal and physical expressions of fear and distress. The use of restrictive practice meant some patients described their admission as a form of imprisonment or being held hostage. Cumulatively, the use of restrictive practice across an admission was usually accompanied by increasing the person's emotional

distress and their visible physical and cognitive deterioration. The use of restrictive practices also informed impacts on ward cultures, fostering the experience of an admission as one of loneliness, isolation and disconnection and increased the inequalities in care experienced by PLWD within these wards. The use of restrictive practice during admission was also highly distressing for care partners and families.

Ward staff were aware that the strategies they were institutionally expected to draw on and use neither reflected the needs or desires of the patient, nor how they wished to engage with and care for their patients. The lack of agency felt by ward and hospital staff meant these cultures of containment also meant high levels of distress and isolation for all within them. Ward staff often described feeling inadequate by not being able to provide appropriate care and recognised they lacked the skills to support distressed PLWD, also experiencing significant emotional impacts from using restrictive practices in patient care.

Good practice and de-escalation

Our analysis of mental health wards identified good practice potentially transferable to the acute setting. They all fostered cultures of care that minimised the use of restrictive practice in the care of PLWD through (1) the promotion of flexibility in the organisation and delivery of routine care; (2) supported staff in approaches to care that prevented and reduced patient distress by recognising and responding to individual need; (3) staff attuned to relational ways of working and to the emotional needs of their patients living with dementia; (4) ethos of promoting 'positive risks' to support mobility and independence; and (5) the legal frameworks governing patients and their admissions were explicitly discussed and recorded. Examples of individual good practices were also seen within the acute sites. Good practice focused on engagement with the patient's needs, including supporting patients' mobility, utilising ward resources such as day rooms and tablets, using YouTube (YouTube, LLC, San Bruno, CA, USA) to provide tailored entertainment, and supporting patients with hair and beauty treatments.

Conclusion

Our findings demonstrate that, while there was significant variation between sites in the types of restrictive practice most commonly employed and the use of legal frameworks within them, cultures of containment were in operation in the care of PLWD across these settings. Containment (in bed, at the bedside, within the bay) was both a requirement and expectation as part of the organisation and delivery of care. Any challenge to containment was met with restrictive practice, starting with raised bedside bars, placement of furniture, supervision, and escalating should the person continue to challenge containment practices. These cultures were driven by genuine staff fears over personal and professional reprisals, and enabled by a culture in which family visitors, volunteers and engagement have disappeared from ward settings, creating challenging environments of ennui and isolation.

Study registration

This study is registered as ISRCTN11797465.

Funding

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Chapter 1 Introduction and background

It is widely recognised across both policy and practice spheres that people living with dementia (PLWD) have poor experiences of care during a hospital admission.¹⁻³ Reports and inquiries³⁻⁶ have identified that PLWD are likely to experience poor care at some point during an acute hospital admission. A large body of policy reports and public inquiries all call for action to improve care provision for PLWD during a hospital admission.

Context

People living with dementia are one of the largest populations (25–50%) within our acute hospitals,⁷⁻¹⁰ representing a significant proportion of unscheduled and emergency admissions (77%), typically with potentially preventable conditions such as pneumonia, sepsis, urinary system disorders, frailty and long bone fractures.¹¹ However, their hospitalisation is associated with increased risk of deterioration,¹² institutionalisation¹³ and death,^{14,15} in comparison to similar patients without a diagnosis of dementia.

Evidence exploring restrictive practice for people living with dementia in hospital setting

People living with dementia are at significant risk of experiencing some form of restraint or restrictive practices during an unscheduled acute hospital admission.^{2,3} While there is variance in the literature as to what comprises restrictive practice, PLWD are identified as a patient group likely to experience this during an acute hospital admission.¹⁶ Living with cognitive and physical impairments,¹⁷ being older,^{18,19} being 'care dependant',¹⁹ and living with mental health and behavioural conditions¹⁹ are all highly predictive of the use of restrictive practices.

Despite the growing awareness internationally of the use of restrictive practices across care settings, their application continues, remaining excessive, intractable and resistant to change.²⁰ Globally, the use of restrictive practices across care settings is associated with adverse impacts for PLWD,^{21,22} with primarily further functional and cognitive decline.²³⁻²⁸ This is a significant concern given the long-standing recognition that immediate action is required to improve experiences and outcomes for PLWD during a hospital admission.^{10,29-31}

In the UK, a series of public inquiries,^{2,15,32-34} NHS serious incident reviews and media reports³⁵ have all identified institutional cultures of restraint in the care of PLWD during acute hospital care in England and Wales. The lack of policy action following these reports, of any inquiries since 2015, and evidence from the literature suggesting these restrictive practices continue, all provide the basis for this study, and why we need an empirical foundation of how restrictive practice is currently applied in the care of PLWD.

Research evidence of restrictive practice has repeatedly been identified as part of wider acute hospital organisational cultures of care,^{24,36} ward-level cultures of control³⁷ and cultures of nursing care.³⁸ Restrictive practice emerges within these wider studies of care cultures, but it has rarely been the true focus of any substantive rigorous research, with no studies exploring these practices within NHS post-coronavirus disease (COVID) hospital organisational cultures and practices. Importantly, these cultures obstruct the ability of both organisations and ward staff to recognise and understand what constitutes the use of restraint and appropriate practice, within these settings. As such, restrictive practices can become a feature of standard care due to 'custom and practice'.³⁹ A recent study identified high levels of restraint in the care of highly dependent and vulnerable patients across all medical specialties within acute hospitals.¹⁹ Nursing staff report feeling that the use of restraint is a requirement in the care of older patients;³⁶ however, their routine use is associated with high levels of staff sickness and low morale.⁴⁰ Reviews suggest that there is limited and poor-quality evidence to support strategies to achieve the reduction in the use of physical restraints among hospitalised older adults⁴¹ and within acute hospitals.⁴²

Defining restrictive practices for people living with dementia within hospital settings

When referring to restrictive practices within hospital setting, we refer to a collection of institutional cultures and approaches to care that go beyond formal legal regimes, encompassing a wider range of routine practices,^{3,26,39,41,43} staff attitudes and established approaches²⁰ during care. Internationally, restrictive practices identified include the use of the following:

- Bedrails or other means of containment to prevent someone from leaving the bed.^{18,19,37}
- Verbal commands and restrictions⁴⁴ including therapeutic lies, persuasion, pressure, offers and threats.⁴⁵
- Indirect approaches such as removing walking aids and moving them out of reach.^{39,46}
- Keeping people undressed⁴⁶ and the use of institutional clothing.⁴⁷
- Furniture including tray tables to restrict movement.^{39,48-50}
- Contenance products.⁵¹⁻⁵³
- Ward organisational approaches and interventions including one-to-one care (referred to by a variety of terms in the literature and in sites), often repurposed for isolation of a patient.^{54,55}
- The use of security guards.³⁷
- Seclusion and isolation of the patient.⁵⁶
- Chair and bed alarms, also described as 'electronic restraints'.^{19,37}
- Pharmacological restraint to control behaviour.⁵⁷⁻⁵⁹
- The built environment employed as a form of restrictive practice.⁶⁰

Within NHS, data records of restrictive practice vary (see [Data on the use of restrictive practice in National Health Service inpatient settings](#)) with recording variable and largely limited to mental health settings, and recording focused on incidents of pharmacological and legal intervention. Within this report, we use a broad definition of restrictive practice, covering any intervention delivered with the intention to keep the patient contained or restricted in their movements, including raised bed rails, the use of ward furniture, verbal commands, and locked doors alongside more overt forms of restrictive practice such as sedation. A detailed description of the restrictive practices observed can be found in [Results](#).

Frequency or application restrictive practice in the care of people living with dementia

Internationally, across care settings, the widespread use of restraint in the care of PLWD has been identified, including the USA,^{61,62} Singapore,⁶³ Germany,⁶⁴ Australia⁶⁵ and the Netherlands.⁶⁶ Rates of reported restraint of PLWD in the acute hospital setting are particularly high, ranging from 27% in one study in the USA⁶² up to 44.5% in one Japanese study.⁶⁷ More widely, there are high rates of restraint within hospital settings across patient groups, to the extent that, in Germany, this is described as 'standard care' with older people (80–99 years) the group most likely to experience restraint during an admission.¹⁸

Restrictive practices in the care of PLWD have not been the true focus of any substantive rigorous research and remain an unexamined but potentially routine practice in the NHS. A longitudinal study of 230 PLWD within 2 UK acute hospitals identified that 22%, or 50 of these patients, experienced restraint during their admission, either via antipsychotic medication or containment through the use of raised bed rails.⁵⁹ Similarly, a service evaluation of patient incident and adverse event reports from inpatient wards (6) across 1 (UK) hospital over a 6-month period identified 424 incidents of physical intervention and 184 incidents of seclusion, with the majority (67%) involving PLWD.⁵⁶ A 5-day observational study of two UK acute wards identified high usage of restrictive practice, particularly the use of 'indirect practices' identified as the removal of mobility aids, sitting with a patient to prevent movement, or not responding to calls from PLWD.³⁹

The use of restrictive practice in the care of PLWD in the UK has been predominantly reported as a side issue within research and reviews examining the acute setting. A National Institute for Health and Care Research (NIHR) ethnographic study examining continence care identified the use of continence pads as a form of restrictive practice, allowing the patient to be contained within the bed or bedside,⁵³ while another ethnographic study from the same team noted restrictive practice as a routine response to refusal of food and medication.⁶⁸ Restrictive practice is also embedded within reviews of research examining the organisation and delivery of acute hospital care for PLWD within the international literature (c.f.).^{17,37,38,69,70} Wang and Moyle in their review identified restraint used by nurses in the context of maintaining peace and harmony within care settings.¹⁷ A qualitative synthesis examining staff experiences

and perceptions of caring for PLWD in acute wards further identified that cultures of nursing care were associated with the use of restraint.^{36,38} Hughes³⁷ concludes that PLWD may experience restraint when they are viewed as disturbing others or exhibit behaviour which is believed to require significant support. The cultures of care that prioritise routine timetabled care mean that PLWD may be subject to restraint when they are viewed by staff as 'bothering' others or when their clinical needs or behaviour is assessed as requiring intensive forms of support.³⁷ The routine use of restrictive practice is also alluded to within a review of research exploring the social and organisational context of acute care influencing front-line delivery within acute hospital wards.⁷¹

Justifications of safety and risk

Nursing staff working in the UK acute setting report differing views on what restraint use is, but largely conclude it is a justifiable and legitimate practice based on environmental considerations,¹⁷ also described as a 'necessary evil' to 'maintain a duty of care'.^{39,72} Safety concerns in particular are identified both as a trigger and justification for the use of restraint.³⁷ The difficulties ward staff experience in balancing patient safety, minimising risk and supporting liberty means it can become 'ordinary' and 'standard care',²⁴ used 'subconsciously'³⁹ by staff as part of everyday cultures of care.²⁴

These justifications are echoed within international literature. Within their review of the acute setting, De Bellis *et al.*²² identified the management of behaviour, prevention of falls, resistance towards oral hygiene, and preventing a patients from removing cannula and medical devices as key justifications provided to validate the use of restraint. With a previous review also concluding that the key justification for the high levels of physical restraint in the care of older people (acute and long-term care) was 'patient safety'.⁷³ A meta-synthesis of qualitative studies of nurses' perspectives of the use of restraint across settings identified that, while complex, the key justification used was safety including preventing falls⁷⁴ and harm to the patient,⁷⁵ with Canadian nurses describing the use of restraint with PLWD as coming from a place of desperation.⁷⁶

Experiences of people living with dementia

People living with dementia who had experienced restraint reported negative experiences, including loss of freedom, restriction, anger and discomfort⁷⁷ and described the practice as 'like jail'⁷⁸ and feeling like a prisoner and an outsider.⁷⁹ Older people in long-term care in Finland reported fear and loneliness and mistrusting staff, but also their resignation and acceptance of this practice.⁴⁶

Our ethnographic approach was accompanied throughout the study by a fully embedded programme of coproduction and patient and public involvement (PPI). PPI began with our study oversight group, including PLWD and those with lived experience of caring for and supporting them. As the study progressed so did the scope of our PPI programme, representing the diverse groups we observed on the wards to ensure these experiences were included in our analysis and findings (see [Chapter 6](#) and [Table 1](#)). Across these groups, participants clearly identified a range of restrictive practices they had experienced, while some raised concerns from their experiences of caring for a PLWD across a hospital admission. Many participants had direct personal experience of either being restrained or observing a family member being subject to restraint during a hospital admission. Information derived from these events and discussions guided this study from its inception through to writing up and dissemination and will continue to guide its impact.

Restrictive practice and adverse outcomes for patients

Reviews conclude that the use of physical restraint is a dangerous practice²⁶ in both acute and long-term care, and is associated with poor care quality^{37,80} and adverse outcomes for older people⁸¹ and PLWD.²² A systematic review concluded that the use of restraint for older people in long-term care led to further dependence, falls and incontinence.⁸² An increased risk of iatrogenesis,⁸³ falls,⁸⁴ exacerbation of behavioural and psychological symptoms in dementia (BPSD),⁵⁹ mobility problems,²⁶ injuries⁸³ and increased length of hospital admissions.²⁶

Importantly, the use of physical restraint has been recognised at a policy level as 'a negative, traumatic and potentially dangerous experience for both service users and staff' (p. 1),⁴⁰ detrimental to the well-being of all involved in the delivery of care. Restraint practices are associated with high levels of staff sickness, low morale and impacts on safety

and quality of care,⁴⁰ meaning restraint impacts negatively not only on patients and staff, but also on healthcare organisations and providers.

Cognitive decline and restrictive practice

A review²⁵ concludes that the use of restraint for PLWD causes stress, further damaging areas of the brain already impacted by their dementia. Restraint is associated with an increased risk of functional dependence,²³ cognitive decline,^{27,85} delirium,⁸⁶⁻⁸⁸ high levels of patient distress,⁴⁶ increased 'agitation' and anxiety.⁸³ For PLWD with past experience of trauma, particular care is needed with the use restraint to avoid triggering past memories.⁸⁹

Injuries and death

Within the international literature, the use of physical restraint is associated not only with increased risk of falls but in some cases serious injury.^{26,83} An international review examining the extent, nature and impact of restraint practices on the mortality of older people in long-term care settings identified 174 deaths across 8 studies associated with the use of restraint, most commonly from neck compression and subsequent asphyxiation.⁹⁰

Legal frameworks governing restrictive practices in the acute setting

As we have seen, research examining restrictive practices highlights the cultures of care in which restraint operates, but, importantly, must take into account the legal frameworks which, in the UK, is complex and raises questions which are as yet not adequately answered.

Restraint of PLWD within hospital settings is governed by interlocking and complex legal regimes. The starting point is that unless there is lawful authority or a defence for the use of restraint, it will be unlawful. However, the law also contains countervailing obligations to protect from harms that might arise if a person were not restrained in some circumstances. Thus, the legal frameworks provide a tightrope that healthcare providers must walk between different potential sources of liability concerning restraint. These include the Mental Capacity Act 2005 (MCA), which provides a defence for restraint in cases where there is need to prevent harm to the individual. This includes the deprivation of liberty safeguards (DoLS) [replaced by the Liberty Protection Safeguards (LPS) since 2022], which can authorise restrictions amounting to a deprivation of liberty in settings including hospitals. Following the Supreme Court's ruling in *Cheshire West*,⁹¹ the majority of the estimated 300,000 who will need a LPS authorisation for a health or social care setting are PLWD,^{92,93} with as many as one in every 15 adults over 85 years subject to a DoLS authorisation.⁹⁴

The intent behind DoLS/LPS was to 'shine a light' on, and reduce, restrictive practices in care settings (p. 29).⁹⁵ However, some commentators on the MCA suggest that the massive expansion of the legal regulation of deprivation of liberty following the *Cheshire West* ruling may, paradoxically, actually more deeply embed 'institutionalising' practices such as restraint because it normalises and legitimises restrictions.⁹⁶⁻⁹⁸ To date, no empirical research has explored how these regulatory frameworks interact with the use of restrictive practices within healthcare settings.

Where PLWD are admitted to hospital for treatment for a mental disorder, they may be there voluntarily (i.e. they have 'mental capacity' and have given consent), or if they are deprived of their liberty, this can be authorised under either the DoLS/LPS or the Mental Health Act 1983 (MHA). The interface between the MCA and the MHA is notoriously complex, but in summary, if the purpose of detention is treatment for mental disorder and if the person is objecting, then the DoLS/LPS cannot be used and the MHA must be used instead to authorise their detention. A recent report found that there has been a significant increase (37%) in the use of the MHA between 2010 and 2016⁹⁹ to detain people, which is partly associated with its disproportionate use for people from minority ethnic communities, older people and PLWD,⁶ suggesting that clinicians may be applying the criteria for detention differently for specific populations and conditions such as dementia.⁶ However, we do not know the significance of intersectionality and the ways in which diagnostic and identity categories (e.g. gender, race, ethnicity and religion) may interact in its application.¹⁰⁰

During COVID, restrictive practices became governed by new public health powers of detention to reduce infection risk for the person and others, which are complex to apply for PLWD.¹⁰¹ In practice, many PLWD were possibly unlawfully deprived of their liberty by restrictions imposed in relation to COVID. Research internationally reported higher uses

of restrictive practices as a result of COVID.¹⁰² The resulting widespread restrictions were seen to 'place further strain on therapeutic relationships and the delicate balance between nursing care and restrictive practice' (p. 2743)¹⁰³ and meant such practices became increasingly normalised¹⁰⁴ even after the resolution of the pandemic. This gives particular urgency to the examination of contemporary cultures of restrictive practices.

These complex legal frameworks governing the restraint of PLWD aim to ensure it is only used in the last resort after consideration of less restrictive alternatives, supporting the difficult balance between promoting autonomy and protecting from harm. However, they have been criticised as complex, costly, bureaucratic and failing to adequately protect human rights.^{105,106} They are also increasingly contested, particularly in connection with contemporary disability rights perspectives, which advocate against the use of coercion and for approaches based on equality and respecting the 'will and preferences' of the person (c.f.).¹⁰⁷

There is a significant body of research examining the impacts of the MCA and the MHA, spanning a number of disciplinary approaches and methodologies (c.f.).¹⁰⁸ However, this has predominantly focused on the experiences of younger patients, and although there is a small body of research examining the impact of the MCA on the experiences of PLWD and those caring for them,¹⁰⁹⁻¹¹³ none have specifically focused on restrictive practices. A small body of ethnographic studies have examined the MCA focusing on the assessment of capacity and discharge practices in the acute setting,^{114,115} and adult safeguarding,¹¹⁶ but have not examined the care of PLWD and restrictive practices.

Poorly recognised and under-reported practices

Importantly, healthcare staff and ward cultures may not recognise certain practices as restraint (c.f.).¹¹⁷ In response to the Andrews Report,³⁴ a programme of spot checks in hospitals wards across Wales identified that staff understandings and use of restraint was highly variable.² In addition, the institutional practice of re-categorising ward interventions as 'safety measures' and 'positional aids',¹¹⁸ the low levels of recorded complaints in the use of restrictive practices, reflecting patient and family under-reporting,¹ and fears among older people of making complaints (Article 8),⁴ all potentially contribute to under-reporting. This means recorded estimates are likely to be low,^{26,43,119} with limited evidence to establish the scale of use within the acute setting,²⁶ the impacts for individuals, or ward cultures.

Indeed, the established variations in the reported incidence of restrictive practice across hospitals³ indicate potential variations in both the accuracy of reporting and definitions being used therein.¹ One review concludes that there are likely to be high levels of under-reporting of injuries associated with the use of restraint.²⁶ This poor documentation in the acute setting is reflected internationally.¹⁹ The absence of robust systems to assess and monitor the quality of services was a key finding in the Winterbourne View review.¹²⁰

Data on the use of restrictive practice in National Health Service inpatient settings

In response to the shortcomings in data recording and reporting, within this study, we also set out to demonstrate the extent to which restrictive practices in the care of PLWD are currently recorded and defined within NHS hospitals. To do this, we sought quantitative data from NHS Digital on the recorded use of restrictive practice in acute medical settings.

The process of accessing data revealed several significant issues. There is no routine national data collected from acute NHS trusts providing the scale of the use of restrictive practice in the care of PLWD. This is because the use of restraints or other restrictive interventions for older patients with dementia is categorised as a 'nontreatment intervention' and thus not recorded in Hospital Episodic Statistics. Therefore, it is not possible to conduct a quantitative analysis. The only data available came from trusts delivering mental health services.

We were able to collect data catalogued annually by Mental Health Trust, with data included providing that either the start or end date of the use of restraint occurred after April 2019, with data for previous years considered 'Invalid' due to previous criteria around collection and classification. Within the post-2019 data, there were still significant issues as to whether 'dementia' as a diagnostic category was recorded within the data, rather than another mental health issue or simply not classified.

Poor and differentiated reporting practices across sites created significant variance throughout the data, rendering any detailed analysis meaningless. Some trusts and sites reported restrictive practice incredibly frequently, whereas other sites known to admit a large number of PLWD recorded no to little use of restraint at all, distorting the data set. Where restraint was recorded, it was most commonly at the extremes, specifically the use of physical restraint of a patient only, and to a lesser extent the use of sedation, which again is not always conceptualised as restraint in and of itself.

While there are data on the gender of the patients and their ethnicity, the lack of data collection over long periods made any meaningful analysis impossible. There are also no data on the impact of these interventions on patients, for example on patient outcomes, routes of discharge, or if they experienced further restrictive interventions during an admission.

These data were however crucial for this study in confirming the findings of our literature review, namely that restraint is a poorly defined, under-conceptualised, and under-recorded practice. This provides the basis of our research aim to create an empirical foundation understanding how restrictive practice is applied to PLWD across a spectrum of NHS hospital settings, and to explore how it can be improved.

Calls for transformation

A key goal of the NHS long-term plan is reductions in the use of restrictive practices for all patients,¹²¹ with Department of Health guidance emphasising the use of preventive approaches and de-escalation for managing behaviour that services may find challenging (*Positive and Proactive Care* <https://cutt.ly/3jb8wgb>). Key recommendations include the development of UK national standards (p. 4)^{1,122} and practice guidelines.¹²³ In response, a key focus has been developing best practice to support younger adults in mental health, learning disability and autism settings.^{9,124-129} Acute hospital settings have so far been overlooked, and although best practice guidelines have been developed for emergency departments, a recognised site where restrictive practices feature within acute clinical work,¹⁰⁹ there is no UK guidance or Code of Practice^{130,131} on its use in the care of PLWD within acute ward settings¹³² to where PLWD are typically transferred to. In addition, although the MHA code of practice includes 'restrictive interventions', this is not dementia specific,⁹⁹ with the current MCA codes of practice containing no detailed guidance on the use of restrictive practices.^{130,133}

A large number of reports highlight that in order to deliver significant improvements in care for PLWD, there is a need for specialist training to improve staff knowledge, skills and attitudes, within the acute setting.^{30,134-136} Government inquiries,³⁴ reports¹²² and professional bodies⁷ all call for training in the use of restrictive practices for all healthcare staff caring for PLWD. Training is recognised as key to improve cultures of dignity and respect for older people in hospital.^{4,99} However, there is currently no evidence base to inform training to reduce its inappropriate use, identifying good practice and alternative approaches to improve care within the acute setting.

In order to reduce the inappropriate use of restrictive practices within the distinctive organisational cultures of the acute setting, evidence-based rigorous research^{22,26,37} must inform education and training for ward staff that reflects the interactional expertise involved in the care of PLWD during an acute admission,^{49,137} that can provide tailored strategies,¹³⁸ relevant to everyday practice,¹³⁹ and responds to the everyday challenges staff face in supporting PLWD rights, ensuring safety, and managing risk, within fast-paced, pressured acute care environments.³⁷ This present study aims to create the empirical foundations to enable a shift in organisational culture in which tailored training around reducing restrictive practice can be effective.

Aim and objectives

In sum, there is widespread agreement that restrictive practices, while affecting any patient group, may be especially widespread among PLWD, that they may cause more harm than good, and their use should be minimised if possible. Yet such practices are variably understood, data are poor and their deployment may be unrecognised within the cultures of ward practice, with insufficient detailed research about their use to provide the foundations for staff training and other changes to practice needed to bring about the long-called-for transformations in practice. PLWD are a large and

vulnerable group in NHS hospitals, and it is already known that their experiences within the wards may differ from those of other groups of patients, often leading to poorer outcomes, meaning that they may be especially vulnerable to the deleterious impacts of restrictive practices.

This in-depth ethnographic study aimed to respond to the research gap by examining the everyday cultures of restrictive practices in the care of PLWD during a hospital admission, exploring what forms these practices take, the rationales for their use, and the experience of these practices from the perspectives of PLWD, their families and ward staff. To identify evidence-based (and alternative) strategies in the care of PLWD that are achievable, safe and transferrable across care settings.

Our objectives were to:

1. Provide a detailed examination of the social and organisational context in influencing the everyday care of PLWD to understand the (a) nature of restrictive (and alternative) practices within wards, (b) circumstances and contexts of use, (c) care practices when PLWD are perceived as at risk, or when their behaviour is perceived as 'challenging', 'disruptive' or 'aggressive'.
2. Examine the recognition, understandings and experiences of restrictive (and alternative) practices during an admission from the perspectives of PLWD and their families.
3. Examine staff perspectives (a) their understandings and recognition of restrictive practices, (b) the formal frameworks and informal rationales drawn on to inform the care of PLWD.
4. Translate the findings into evidence-based strategies to support best practice and alternative approaches to feasibly improve the care of PLWD at ward level.

Chapter 2 Methods

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Methodology

An ethnographic design

An ethnographic approach involves the in-depth study of people's everyday actions and accounts, by collecting relatively 'unstructured' data from a range of sources (observation, ethnographic interviews, document analysis).¹⁴⁰ It can provide sophisticated tools for understanding the complexities of everyday life within an organisational setting,¹⁴¹ by examining the routines and behaviours of groups and individuals, both within and across multidisciplinary teams (MDTs) and sites of care,¹⁴² and by including the perspectives of patients, families and healthcare staff.¹⁴³ Ethnography allows us to examine all these elements, and, importantly, the interplay between them.¹⁴⁴

Ethnography is particularly useful to examine topics and answer research questions where measurement is either not easy, inappropriate or may be organisationally invisible work,¹⁴⁵ involve populations and settings where the issues are sensitive and multifaceted, where our aim is to access the unspoken and tacitly understood,¹⁴⁶ and to understand complex social relations, routines and institutional forces as they influence everyday cultures¹⁴⁷ of care. As we have set out in the chapter above, inquiries, reports, reviews and research have consistently identified variations in both the accuracy and definitions of restrictive practices being used, emphasising this as a significant obstacle in examining NHS routine data or using quantitative methods to establish the nature or scale of its use across care,^{1,3,26,120} and NHS^{3,109,132,148,149} settings.

Theoretical framework

In response, our ethnographic approach was informed by the symbolic interactionist research tradition, which aims to provide an interpretive understanding of the social world, with an emphasis on examining interaction.¹⁵⁰ The aim of this ethnography was to provide detailed understandings of ward organisational cultures, social processes and the inter-relationships between different elements of these organisations.^{143,151} Observational methods are a key approach to examine the interactional aspects of care delivery at the bedside,⁴⁹ workplace cultures of care,^{20,51,86,152} and the largely invisible work of restrictive practices as part of the everyday routine care for PLWD within acute settings. This approach has enabled us to provide a detailed examination of the social and institutional forces that shape and influence this work and to provide understandings of the rationales and uses of restrictive practices,¹⁸ and the impacts on both PLWD^{26,43,119,153} and ward staff. Our ethnographic approach enabled us to examine and understand how staff respond to the care needs of PLWD, the role of restrictive practices, and to follow the consequences of their actions during shifts and over an admission on PLWD and their families. Importantly, we were also able to examine how staff account for and make sense of their responses to the care needs of PLWD in these contexts and the impacts of the organisational pressures and the use of restrictive practices on individual staff members and ward teams.

Our approach draws on a body of research^{24,48,83} and reviews²² concluding that to develop interventions in order to reduce the use of restrictive practices in the care of PLWD, research must deliver understandings of NHS organisational cultures that can inform interventions that 'address the person, the environment and the interaction between the two' (pp. 9–10).¹²³ Ethnography is able to provide these understandings, what contributes to cultures of restrictive practices, but also crucially the ways in which the organisational cultures can be modified and what alternatives could inform care. The goal is to provide depth of understanding and theory generation, with transferability a key objective.¹⁵⁴

Ethnographic approach to data collection and analysis

Our ethnographic approach to data collection and analysis is in the tradition of grounded theory and we employed the constant comparative method and theoretical sampling whereby data collection and analysis are inter-related^{155,156} and carried out concurrently.^{157,158} The flexible nature of this approach was important, because it allowed us to increase the 'analytic incisiveness' (p. 160)¹⁵⁹ of the ethnography: as data were collected in one site, preliminary analysis of this proceeded in parallel, with this preliminary analysis informing the focus of later data collection within the next site and the further stages of analysis.

Grounded theory¹⁵⁵ is a practical and flexible analytic approach for ethnographic research.¹⁵⁹ It reinforces the ethnographic aims of achieving a theoretical interpretation of the data, while the ethnographic approach prevents grounded theory from being applied in a mechanistic and rigid way.¹⁵⁹ A common concern with ethnography is that it can treat everything within a setting as 'data', which can lead to the collection of large volumes of unconnected data, producing a heavily descriptive analysis.¹⁶⁰ Instead, grounded theory provided the ethnographic team with focused data collection strategies for studying key social processes. This approach provides a middle ground in which the ethnographic team, often seen as passive observers of the social world, used grounded theory to provide a systematic approach to data collection that can support the generation and development of theory to understand the interpretive realities of the wide range of actors within these ward settings.¹⁵⁹

Coproduction and patient involvement

To ensure inclusion of diverse voices and experiences, the study included a detailed and systematic continuous programme of coproduction and PPI. PPI involved engaging people with lived experience in our study oversight committee through to community events. To achieve this, we utilised a synergy of ethnographic^{140,143} and arts-based methodologies^{161,162} to examine and obtain experiences of restrictive practice in the care of PLWD. Arts-based ethnographic research approaches are an established approach within healthcare research.^{161,162} Predicated on the multisensory nature of reality, and experiences of both participants and researcher, art-based ethnography aims to provide space via active engagement in creative processes, for the appreciation and examination non-verbal,¹⁶³ and often embodied experiences of everyday life. Obtaining these requires an appreciation that experiences cannot always be verbally articulated but require creative methods to elicit people's accounts,¹⁶³ especially if the phenomenon of interest has affective and potentially traumatic impacts.¹⁶⁴ This helps to bring about an in-depth and new understandings of people's experiences.^{162,165} This is particularly pertinent for participants for whom verbal communication may be a challenge.¹⁶⁶ Employed in this way the approach enabled an in-depth examination of the physical and material experiences, as well as tacit knowledge¹⁶⁷ and embodied knowledge and practice¹⁶⁸ imbued in hospital admissions and the experiences of restrictive practices for PLWD.

Utilising art-based approaches¹⁶⁹ facilitated for a deeper depth and understanding of the experiences and impacts of restrictive practices. We conducted a series of PPI events ($n = 22$ events) across England and Wales for the duration of the study (see [Chapter 6](#) for full details). These events involved diverse communities including PLWD of African and Caribbean background and their carers, PLWD an area of socioeconomic deprived area and their carers (one event), PLWD of Asian background and their carers, PLWD with complex needs, those requiring one-to-one support and carers among others. Together these events led to collation of significant amounts of data on experiences of restrictive practice in healthcare settings.

Data collection: ethnographic fieldwork

Our approach to ethnographic fieldwork centred on the significance of the 'busy intersections' (p. 28)¹⁷⁰ within each setting, of seeking out sites of tension where a large number of interactions, interests and identities coalesce. It is at these points that we could observe the everyday ward practices and the ways in which they were articulated and expressed. Our goal was to provide detailed understandings of the clinical and social processes that influence ward teams, the interactional work, and the rationales for the use of restrictive practice in the care of PLWD, the impacts

on PLWD, carers, families and staff, and the organisation and application of restrictive practice across shifts, rotas and admissions.

Thus, at each acute hospital ($n = 3$), we conducted 30 days of observation within each ward ($n = 2$) over a period of 8 weeks of detailed fieldwork. At each mental health hospital ($n = 3$), we conducted 15 days of observation within each ward ($n = 1$) over a period of 6 weeks of detailed fieldwork. Care was observed within and across day and night shifts, weekdays, weekends, and where possible also public holidays. Observations ranged in duration from 2 to 6 hours and were reactive to events within the wards during these periods of observation. Observations took place from the many 'public' areas of the wards (corridors, nursing stations, day rooms) and at no point did the researchers go behind screens or curtains or observe intimate care. Patients were only observed at the bedside or in single occupancy rooms with written informed consent to do so.

We recognised that within these wards no team or individual operates within a vacuum. In response, as well as observing the ward teams, where possible, we also observed and explored the work of other clinical staff (specialist registrars, consultants, liaison psychiatry, allied health professionals and staff with managerial responsibilities), administrative and bureaucratic teams (discharge co-ordinators, flow managers and ward clerks) and auxiliary staff (porters, domestic services, security staff and chaplaincy teams) alongside the work of nurses and healthcare assistants (HCAs) within these wards. We observed their actions and accounts to explore how individuals, teams and institutions responded to the care needs of PLWD, and how they recognised, communicated and organised the use of restrictive practices within these wards, alongside the organisational cultures that are both produced and maintained by them.

We acknowledge the potential for the Hawthorne effect or 'participant reactivity' and that the use of observational methods may mean behaviour within these wards may have been altered by the researcher's presence in the wards. Based on our prior research within acute wards,⁵¹ we chose the extended time frame within each acute ward to allow the development of close ties with participants (those being observed), minimising its potential to impact on our data collection and analysis. A strength of an ethnographic approach is that any performances we observed, however staged or influenced by the researcher presence (typically during early data collection), can reveal critical insights by displaying how people see themselves and how they want to be seen.^{171,172}

Ethnographic observations

Observations were undertaken by three of the authors of this paper (AN, SM, KF). Each is an experienced ethnographer with between 5 and 20 years' experience of conducting ethnographic research in clinical settings. Two of the team draw on 10 years of experience of conducting ethnographic research examining the care of PLWD. Within the team there is a mix of ethnicity, socioeconomic, gender, age and cultural backgrounds. No data collectors external to the study team were utilised within this study. Each ethnographic researcher holds a PhD. None of the researchers have previously or currently had any clinical registrations.

Each team member observed a single ward, embedded with the everyday routine of care throughout the 30-day period. Observations included recoding meetings, such as handovers, MDT meetings and discharge discussion, shadowing individual staff members or teams, speaking to administrative staff at their stations and talking to individual patients and their care partners about their experiences. For the most part, the role of the observer was to stand in the corridor of each ward observing the routine minutiae of the delivery of care within it. At no point did the team directly observe care behind the privacy curtain or closed doors. Conversations from behind curtains and privacy screens that could be heard from the corridor were recorded as fieldnotes only where the researchers had appropriate consent.

The goal of our observational strategy was to provide an in-depth evidence-based analysis of the organisation rationales, methods and impacts of restrictive practices within these wards and to provide directly observed examples of the ways in which restrictive (and alternative) practices manifest during the timetabled routine work of these wards and during everyday patient bedside care. Our observations focused on the everyday organisational context and delivery of care, capturing the 'incidents, events, and happenings that denote the work that they do, the conditions that facilitate, interrupt, or prevent their work, the action/interaction by which it is expressed and the consequences that result' (p. 421).¹⁵⁶ Thus, data collection within each site focused on:

- Shadowing (observation, ethnographic interviews) healthcare staff and teams as they organised and delivered care for PLWD, to understand their practices and rationales.
- Observing wider care practices within and across shifts (am/pm) and different staffing structures (weekends/nights) to include high demand periods, to understand the impacts of the timetable and ward routines, everyday cultures of care for PLWD, and the role of restrictive (and alternative) practices.
- Observing clinical assessment (handover, board rounds, MDT meetings, and where possible 'patient flow' and transfer meetings) to examine understandings of dementia, the assessment of risk, beliefs about safety and the visibility of restrictive practices in decision-making for PLWD during and across an admission.
- Document analysis (from ward managers, clerks, patient records) of staffing, work allocation, bed occupancy, patient acuity, turnover and physical space (layout, visibility, signage, locked entrance, 'dementia friendly' resources and design). To support understandings of the formal and informal ways restrictive (and alternative) practices manifest within wards.

Working within acute wards required the researchers to adopt a range of observational practices and strategies. Observation time was spent standing, rarely sitting, reflecting the pace of work of the ward teams and the wider hospital staff within them. Our practice involved standing in ward corridors, usually close to an alcove, sink, trolley, or equipment that was already blocking part of the walkway, where there was space to stand out of the way of the team, and from where areas of the ward and the events within them were visible. We also shadowed and walked with individual members of ward staff and teams as they worked within the wards. The built environment of the observed wards was highly variable, ranging from a central hub with satellite bays, to long corridors, sometimes with windows onto bays and rooms, other times without. The researchers positioned themselves accordingly in the corridors to maximise visibility while minimising obstruction.

Our data collection strategy was of comprehensive note-taking during these periods of observation with fieldnotes written up as more detailed accounts. The researchers wrote extensively during these periods of observation, using digital tablets. Data collection was typically carried out with the tablet in hand, writing as we were standing or walking. The recorded fieldnotes took the form of a running record of events and incidents including details and near verbatim text of conversations and interactions. Note-taking was clearly visible to all within the wards (staff and patients) who had natural opportunities (as well as routinely being offered opportunities by the research team) to ask questions about our notes. Staff were granted access to look at the fieldnotes taken if they expressed interest in seeing them and were encouraged to respond to what they had read.

Ethnographic in situ interviews with people living with dementia, care partners and families

We draw on a range of literature that demonstrates people at all stages of their dementia diagnosis, can participate in qualitative and ethnographic research, including during a hospital admission,^{79,173} and that contributing to research and discussing their care and experiences can promote well-being and social inclusion.^{174,175}

Ethnographic in situ interviews with ward staff

To provide a detailed understanding of the influences, rationales and responses to restrictive practice, ethnographic (during observation) in situ interviews focused on and were predominantly carried out with nursing (across all grades) and HCAs within these wards. We also including clinical staff, from a range of disciplines (including foundation year doctors, junior doctors, registrars, consultants, physiotherapists, occupational therapists, liaison psychiatrists, pharmacists and specialist dementia teams), staff with co-ordinating responsibilities (ward clerk and discharge co-ordinators) and auxiliary staff (including domestic services and security staff) where appropriate. These interviews with ward staff over multiple occasions during and across shifts as staff cared for PLWD within each ward, had a broad focus on the organisation and delivery of everyday care and continence care. These ethnographic interviews allowed us to question routine practices, rationales and decision-making, to understand what staff were doing and why:

- What was their articulation work within those settings, how did staff account for and make sense of their actions?
- What were their experiences and training of working with PLWD and restrictive practice, what informed their practices?
- What aspects of caring were defined as difficult, demanding or rewarding and what was their confidence in caring for this patient group?

- What were the barriers and enablers to supporting PLWD?
- What was the recognition and rewards of providing care for this group from patients, relatives, colleagues, managers?

In total, we conducted 1116 short in situ interviews as part of our observations, as broken down in [Tables 1](#) and [2](#).

Case studies

In our original protocol, we set out to recruit a series of case study participants ($n = 10$) with the intention of following PLWD and their family carers on their journey from initial admission to the acute ward through to discharge (home, long-term care) and to follow their short-term care pathways. The goal of our case study approach was to support PLWD and their families to share their experiences of an admission and the impacts of restrictive practices in their care. This design was based on the research team's experience of recruiting participants within the acute setting prior to the pandemic (2020–2).

However, we found this approach was no longer viable and was not suited to the way these wards operated. Our design and recruitment strategies relied on care partners and family members to be regular visitors on these wards to support recruitment of the person and their family network, an approach we had successfully utilised multiple times in the past.^{49,52} However, during our observations for this study, these wards had very few, if any, family visitors, with few able or allowed to stay for any length of time at the patient's bedside. As a cohort, PLWD experiencing restrictions on their movement are also at a high risk of being judged by the clinical teams as not having the capacity to consent to research participation.

In response, to ensure the inclusion of the experiences of PLWD within the study, we extended our outreach, engagement and coproduction programmes to include semistructured interviews with PLWD who had experienced a recent hospital admission outside the catchment areas of our participating sites. The findings from this sample are summarised in the final chapter of this report.

TABLE 1 In situ interviews in acute settings

	Interviews	Doctor ^a	Senior nurse ^b	Nurse	HCA	Patient	Other ^c
Site B	333	35	27	61	83	35	93
Site D	311	37	18	118	74	26	38
Site F	404	13	27	140	126	59	38
Total	1048	85	72	319	283	120	169

a Includes junior doctors, consultants, registrars and senior house officers.

b Includes matrons, ward sisters and nurse in charge.

c Includes anybody on the wards outside of main categories including clerks, specialist teams, admin staff and visitors.

TABLE 2 In situ interviews in mental health setting

	Interviews	Nurse in charge	Nurse	Ward clerk	HCA	Activities co-ord
Site A	23	7	10	1	5	0
Site C	21	7	12	0	0	2
Site E	24	9	8	0	7	0
Total	68	23	30	1	12	2

Sampling

Probability sampling is not appropriate for ethnography; instead, non-probability sampling (theoretical sampling) provided analytically rather than statistically generalisable findings.¹⁷⁶ This is a flexible, pragmatic approach, with research sites, clinical settings and participants (and sample size), selected by identifying a range of variables that may influence the phenomena (purposive sampling). It emphasises the importance of comparisons across sites¹⁷⁷ allowing for and optimising the generalisability of our findings¹⁷⁸ and enhancing the ability for our findings to have an impact on policy and practice.¹⁴³

Sampling of hospitals and ward sites

Hospital settings are well suited to an ethnographic approach,^{51,52,68} and we identified a range of variables in our review of the literature that could influence the phenomena. We used purposive and maximum variation sampling to include three dyads of sites that represented hospital types, geographical location, expertise and interventions. All sites were reported in recent Care Quality Commission (CQC) assessments as 'good' or 'requires improvement' in order to ensure study observations were of 'average sites' rather than exemplars of 'outstanding' or 'inadequate' practice.

Within each dyad of trusts ($n = 3$), we observed everyday care involving PLWD within two acute wards and one allied dementia specialist mental health inpatient ward. In total, we examined 9 wards: 6 acute wards ($3 \times$ general medicine and $3 \times$ older person's care = 6) and 3 specialist inpatient mental health wards within three dyads of hospital trusts, partnerships covering acute and mental health care in single geographic regions.

We have particularly chosen these sites for the populations they serve, with significant minority ethnic communities (10–38%). Within these hospitals, we included sites of care which received a significant volume of patients living with dementia with a wide range of complex care needs.

Detailed descriptions of these hospital sites and profiles of participating wards can be found in [Appendix 1](#) and [Appendix 2](#).

Sampling within regional dyads

While our data collection sites (acute and mental health hospitals and wards) were standardised, with sequential and systematic data collection, variation was required within each site. Consistency within data collection is important, however, and we used theoretical sampling *within* sites to ensure representativeness, and consistency of concepts and events was achieved within the study, rather than sites and people. Informed by grounded theory, new knowledge emerging from the ongoing analysis informed the following stage of data collection to expand the research process, and to capture all relevant aspects as they emerged, into the ongoing analysis. The focus was on 'discovery' to ensure the grounding of emerging concepts within data and reflected the reality of these ward settings.¹⁵⁵

Sampling and recruitment of people living with dementia and their families for interview and observation

It was not possible to predict the type of patients admitted within acute hospital wards during the fieldwork period. However, we were confident from our previous research,^{49–53} that PLWD would represent a significant population within them, and this proved to be the case. We acknowledge that the presence or absence of a formal diagnosis of dementia in these wards was not always straightforward to establish, with many older patients often obtaining a provisional diagnosis or query '?dementia' diagnosis during admission. However, our patient group were well represented within these acute wards and (where possible) were identified early in the admissions process as individuals with unplanned admission and an accompanying comorbid diagnosis of dementia formally recorded in their acute medical records.

The hospital sites all served diverse populations; however, this was not always reflected in their inpatient population. During our periods of observations, sites 1 and 2 rarely had minority ethnic patients within them, while site 3 had a more diverse inpatient population. Thus, over the course of data collection, we had fewer opportunities to include further maximum variation sampling to ensure our recruitment also reflects groups of PLWD often under-represented within research but are admitted to hospital wards, and who may be at increased risk of experiencing restrictive practices; this included PLWD and families from ethnic minority communities, and PLWD who are homeless.

The acute hospital ward is a setting where a dementia diagnosis could fluctuate; it could be applied, removed and denied for a person.

Handover notes and records regularly have notes such as 'Dementia' or 'Query Dementia', alongside specific diagnosis such as 'delirium' and broad undefined categories such as 'confusion' and 'decline'.⁵¹ Our approach to inclusion and exclusion of PLWD built on previous ethnographic studies in hospital settings.^{49,52} At the beginning of each period of observations within the wards, we approached the nurse in charge of the ward and asked which of their patients had dementia. If ward staff identified that they were caring for PLWD, and if those patients required any form of restrictive practice, then approaches to care for this identified cohort would be observed regardless of whether they had a formal diagnosis within their medical records.

If a person was to be directly involved in the research, such as participating in an interview or direct observations of their care requiring consent from the person living with dementia, a review of the persons medical records, conducted by a member of staff responsible for that patient, would be requested, alongside a professional review of that patient's capacity to consent and ability to participate in observations or interviews. Patients without a formal diagnosis would be excluded at this stage, alongside any patients that medical staff perceived to lack capacity to consent or were at risk of a negative response or increased distress if approached.

Ethical approvals

Ethics Committee approval for the study was provided by the NHS Research Ethics Service via Bromley Research Ethics Committee 16 June 2022 (22/LO/0448) with approval from the Health Research Authority and Health and Care Research Wales granted on 15 July 2022 (IRAS 313816/Protocol 1.0). The research project was approved for the purposes of the MCA 2005, confirming that it met the requirements of section 31 of the Act in relation to research carried out as part of this project on, or in relation to, a person who lacks capacity to consent to taking part in the project. Recruitment for the study was managed and recorded through the Central Portfolio Management System. One hundred and sixty-eight participants were recruited to the study.

The safety of all participants was a key priority at all stages of the study. Before commencement, the ethics of observing care, and of reporting where necessary what was observed, were frequently discussed with the hospital sites and ward teams. Prior to commencement, all three researchers in the field (AN, SM, KF), all experienced in both hospital ethnography and conducting research with PLWD, renewed their Good Clinical Practice certification and superseded their existing Protection of Vulnerable Adults level 1 certification by completing Level 1 and 2 Safeguarding Adults certification. They were made aware of safeguarding and whistleblowing procedures at each site and had a named member of staff [the site principal investigator (PI) or senior nurse on shift] to contact if malpractice or behaviour putting vulnerable patients at risk was observed. All researchers underwent full occupational health checks, held honorary contracts with the NHS Health Boards and trusts, and had up-to-date Enhanced Disclosure and Barring Service certification and NHS research passports.

Over the course of the observations, the researchers saw many aspects of everyday practice which would not be considered 'best practice', or in the interests of the individual patient. However, the examples presented within this report were not isolated but formed part of systemic and established everyday routine practice within every ward at each hospital site. We never observed individual malicious behaviour, or isolated incidents of deviance placing a vulnerable adult at risk. Instead, we observed how the everyday routine organisation and delivery of care itself often placed the vulnerable person living with dementia at risk, as a part of the routine and established cultures of these hospitals and the wards within them.

The data and emergent analysis were regularly presented to nurses, clinicians and trust leads, PLWD and family carers, and while it was agreed that the care observed could be detrimental or distressing to a person living with dementia, it was also recognisable as the everyday practice of ward staff. We also ensured we shared with ward teams examples of good practice observed on their wards and identified organisational obstacles that influenced certain types of care while preventing other, often more compassionate approaches.

Modes of analysis and interpretation

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Analysis

We applied an inductive approach to our analysis, a widely used approach, which means developing our hypothesis from the data, rather than a priori¹⁷⁹ and is closely linked with the delivery of our objectives. We also applied 'ethnographic abduction'¹⁸⁰ as part of our analytic process, which supports the aim of doing justice to (rather than reducing) the complexity of everyday life.

Ethnographic data collection produced observational fieldnotes (> 500,000 words) and in situ interviews with healthcare staff, PLWD and families ($n = 1116$). Fieldnotes of observation, experience and in situ conversations were written up near verbatim into word files.^{181,182} All sites, individuals and data collected were anonymised and sorted in line with the UK General Data Protection Regulations as part of the Data Protection Act (2018), and the NHS England Data Protection Policy (2014). Storage of the data is managed by the University of West London. Qualitative Analysis Software [NVivo (QSR International, Warrington, UK)] was used for both analysis and to ensure password protected encryption of data to assist the secure management of anonymous data, facilitating team access.¹⁸³

Analysis involved the development and testing of analytic concepts and categories, and strategies for their development include careful reading of the data, looking for patterns and relationships, noting anything surprising and inconsistencies and contradictions across the range of perspectives gathered. Initially this produced a collection of 'sensitizing concepts'¹⁸⁴ and analytic memos, which informed the development of more refined and stable analytic concepts. Line-by-line coding is not appropriate for fieldnotes, where coding is selective and involves whole events or scenarios.¹⁵⁹ The constant comparative method (grounded theory) means that the coding of data into categories was a recurrent process. The data were examined in the context of previous fieldwork, and the analytic memos generated informed further data collection within the next site and the next, more focused, stages of analysis.¹⁵⁹ The analytic concepts that emerged from this process were tested and refined to develop stable concepts transcending local contexts to identify broader structural conditions¹⁵⁶ influencing the care of PLWD.

A number of approaches were utilised to support validity. After each period of observation, the researchers had a debrief with another member of the research team to discuss what they had recorded that day and supported the search for negative cases. During data collection, fieldnotes were made available to ward staff to inform discussions about the events recorded in fieldnotes to support respondent validation and ensure accuracy and validity. The research team also routinely shared data and emerging analysis with appropriate specialists within the wider study team to support reflexivity. Within the analysis, thick description has been utilised to ensure sufficient detail is provided so that the reader can assess whether the examples provided reflect and are transferrable to other settings and contexts of care for PLWD. Throughout the period of data collection and analysis, we have also carried out a series of public consultation events with PLWD and family carers. During these events, we discovered that our findings strongly resonated. This represents a form of member checking or respondent validation and their recognition of the analysis we present, supports the reliability and validity of our fieldwork and analysis.

Chapter 3 Results

The everyday use of restrictive practice within acute wards

The use of restrictive practice in the care of PLWD was an embedded aspect of everyday routine ward care. The restrictive practice used within these ward settings took a wide range of forms. What is of significance is that restrictive practices were present as part of routine care during all shifts observed with PLWD across all of these acute wards. There was some variance in the type of restraint most frequently used within individual wards, for example some older people's wards were more likely to sedate patients (site F), while other sites predominantly utilised outsourced one-to-one enhanced observation utilising security guards (site B); however, the everyday application of restrictive practices as part of routine care was consistent across wards and sites.

We identified how cultures of containment were present throughout these wards, with everyday routine use of restrictive practices, exacerbated by low tolerance of risks and deprivation of everyday rights, all fed into patterns of intensification and tightening of restrictive practice across a person's admission. We explore the impacts this has on the person living with dementia during an admission, and we also highlight where good practice was able to break these cycles of containment and tightening (see [Figure 1](#)).

Everyday routine use of restrictive practice

We observed ward staff using a wide range of approaches and methods to contain and restrict the movements of PLWD at the bedside. During prolonged periods of observations during shifts and across a series of days and weeks within these wards, we were able to observe that these practices were employed to restrict the movements of PLWD and to contain them at the bed or bedside; however, these practices were typically unrecognised as restrictive practice by staff or by the wider institutions and remained unrecorded. These restrictive practices were typically carried out as part of routine everyday practice, swiftly, and at pace, embedded within and as part of the organisation and delivery of timetabled care at the bedside, without reflection on the impact for the person.

The focus for staff in utilising these approaches to restrict patients' movement or contain them in place was an immediate solution to a key metric and a legitimate concern for this patient population (falls prevention) for these wards and the wider institution, to increase patient safety and minimise the risk of falls. It was also routinely utilised by staff to support the delivery of timetabled routine bedside care (typically during personal care, medication and observation rounds), containing PLWD at the bedside enabled ward staff to complete task-based care and to move on to the next person/bedside. This strategy responded to a universal anxiety for all ward staff, that the ward timetables could be slipping, and the ever-present fear of 'falling behind' and failing to meet the expectations of the timetable within a shift.

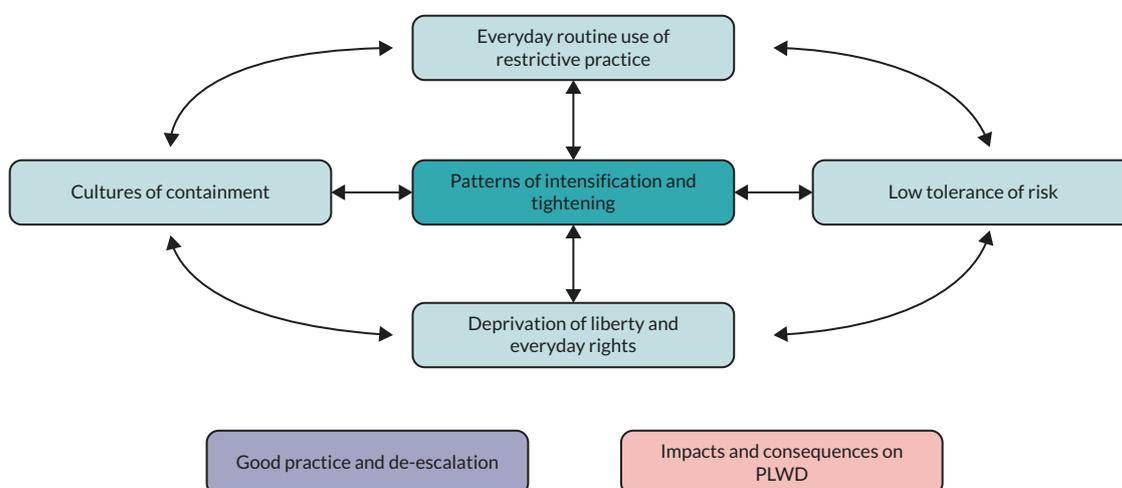


FIGURE 1 Relationships between themes.

Falling behind was viewed by staff as a significant personal shortcoming, visible to their team (and to the following team taking over the next shift) and the wider organisation.

Importantly, our observations of the use of restrictive practices identified were represented within our data as routine practice across all hospital sites, regardless of the ward, time of the day and day of the week. By spending extended time within these ward settings, the research team were able to observe how routine restrictive practice occurred as embedded within everyday care. We were also able to observe the triggers and rationales for their use.

The use of ward furniture

We observed ward staff using a variety of ward furniture including mobile tray tables, hospital beds, raised bedrails and verbal commands to contain and restrict the movements of PLWD at the bedside. These practices were viewed by staff as a routine part of everyday care and thus were typically unrecognised and unrecorded forms of restrictive practice.

Mobile tray tables

It was routine practice for ward staff across all sites to place mobile tray tables in front of patients living with dementia sitting in bedside chairs. This was not to support independence but placed close to the body as a way of limiting the patients' movements. Tray tables tended to be used to both restrict a person's ability to move or stand up and were also used as a means of preventing patients from leaving the bedside and walking (to remove the risk of falls). This practice allowed staff to walk away from the patient and to attend to other duties, knowing the person living with dementia would remain in place with their risk of falls removed, as in the example of a 96-year-old woman below:

11:30 22 is about to stand. HCA asks her where she is going. Asks patient to lift her feet and HCA pushes table back in front of her, preventing 22 from standing up. 22 is not pleased. She protests she has been waiting for too long. HCA walks away. The whole incident sets 22 to start talking to herself about a whole lot of grievances she has. 22 is considered at risk of falls and malnutrition. The HCA's action seems to irritate the patient as she turns to look away. HCA walks away does not check what 22 wanted or needs. 22 Sits in her chair staring ahead hand on cheek.

Site D, Day 7

People living with dementia who attempt to stand up, to walk unauthorised within the ward, were typically discouraged through the use of bedside furniture to keep the person contained in position and through repetitive verbal commands to 'sit down'. These approaches were routine for PLWD, particularly if they were viewed by the ward team as a person who is 'mobile' and at risk of leaving the bedside. Where a tray table did not work to contain the person, other pieces of ward furniture were often placed in front of their bedside chair, creating a small zone of containment around the patient's bedside. A common practice across all sites for ward staff to place their workstation (a computer or laptop on a wheeled standing desk, sometimes referred to as a Computer on Wheels or COW) and/or their chair across a bedside walkway or bay door, completing ward administration while passively creating an obstruction to contain mobile patients.

Hospital beds

Hospital beds were also used as a discrete but common form of restrictive practice. Staff utilised the ability to adjust and raise or lower beds for patients living with dementia. Lowering beds was described by ward staff as a measure to remove the risk of falls; however, these adjustments were routinely used as a means of preventing patients from being able to get out of the bed unaided by standing and leaving the bedside.

Bed 5 has bed lower than most, as usual. HCA tells me it's because he stands up a lot, he is unsteady on his feet, he has walking frame rarely uses it and at risk of falls. The low bed doubles as both a deterrent for standing up and reduces risk of injury if he falls down. Nurses' notes show this is recorded as part of their risk assessment.

Site F, Day 19

Of note in the example above, this person does not have the bedside bars raised. For most patients with dementia on these wards, across all acute settings, the ability to move from their bed was restricted at all times by the raising of side bars on each side of the bed, as we discuss below.

Raised bedrails

The most common form of routine restrictive practice as part of bedside care was the use of raised bed side rails (we use the terms side rails and side bars in our fieldnotes, both commonly used on the wards). The everyday, ordinary and commonplace technique of raising the bedside rails may have originally been designed to prevent people from falling out of the bed but has transformed into a routine method of containing people within it.

While rationalised by ward staff as a key risk reduction measure (preventing people from falling out of bed), it was routine across all the sites to observe staff keeping the bedside rails raised for the entire time PLWD (this also extended to older patients within the ward) remained in bed, which for many patients observed could mean the entire shift or day and could extend across many days and continue for their entire admission. A key focus for ward staff was patient safety which meant that the constant presence of raised bedside bars removed the risk of patient falls. In addition, the number of falls is a key metric wards are required to report on and reducing the incidence of falls also protects the performance of the ward.

Bed 4 is shouting out in a distressed tone, RN and HCA are trying to administer meds to him. he screams 'Too much of it! Leave me alone' as the two staff are towering over his bed. He is laid flat on his back with both side bars raised ... There are three patients on the bay who all have both side bars raised on their beds. HCA says to me they 'they are all at risk of falls so in case they slide to the side I don't want them to fall. It's for their safety really'.

Site F, Day 11

The use of raised bedside rails was often justified by staff as required as a safety measure to prevent falls (a legitimate concern for this patient population); however, the protection these bars offer to staff is viewed by PLWD as a form of restraint. As in the example below, which comes from a bay that is informally referred to as a 'falls bay', a typical feature of these wards where patients deemed or diagnosed to need supervision are cohorted in one place with a single HCA watching over them instead of multiple members of staff. Rather than compliance and remaining in bed as required by the ward team, this person living with dementia below sees the raised side bars as an obstacle, and spent the day attempting to pull his body around and over the bars, creating more risk of harm, and the need for constant monitoring by the ward team who continue to contain him within the bed.

Four male patients on the bay. 19 laying down and has both rails raised. Notes suggest he is one-to-one and his risk of falling. HCA goes to check and asks 22 'What do you want?' 'Where do you want to go?' Side rails are raised. Patient has moved his legs out of bed and is sitting between the foot of the bed and end of side rails. HCA helps him back into bed. He lays down briefly, but still tries to get out of bed. Patient is attempting to get out of bed, HCA holds his hand and taps on his shoulder to indicate the direction he should move - back into bed.

Site B, Day 13

We observed these routines of raised bedrails and patient resistance to them during every shift/day of our observations. Raised bedrails typically led to patients living with dementia feeling trapped and frustrated, subsequently leading to more frequent attempts to free themselves from the perceived containment, and to get out of bed. Some patients living with dementia attempted to get out of bed by jumping over the bedrails, which in turn led to staff becoming more forceful in their instructions and to intensify their efforts to keep them contained within the bed, tightening the restrictions on their movements with the additional verbal commands requiring them to also 'sit still' within the bed.

Verbal commands

Across these wards, we found the rehearsal and duplication of remarkably stable patterns of interactional performance that were forms of restrictive practice, and also accompanied the implementation of other forms of restrictive practice. Of course, it is not unexpected that interactions during the fast-paced work of these wards feature well-rehearsed and repeated scripts; however, we found these to be particularly reductive in the care of PLWD. We observed increased prescription and rigidity of talk, often characterised by repetition of phrases and instructions directed at PLWD, and extending to include older patients, who are not always able to recognise or follow these commands. Across these encounters, ward staff appeared less able to pay attention to the potential underlying care needs of the individual in the moment (e.g. continence, pain, hunger, thirst or distress), focusing on communicating and reinforcing the expectations of the ward, rather than recognising the needs of the person.

Across all sites, the various forms of restraint we observed were usually accompanied by verbal commands, with the cycles of tightening of restraint always beginning with an instruction taken from a limited repertoire of highly contracted and simplified commands ('No', 'Sit down', 'wait there', 'don't get up', 'back to your bed', 'Stop', 'you will fall', 'lie down'). These verbal commands follow the rationales of patient safety, risk management, and containment, preventing falls and allowing staff to monitor where patients are located. However, they also established authority over the person and provided a framework for the patient to fail a command or to challenge the authority of ward staff. When this happened, other forms of restraint presented in this chapter were then utilised, often rapidly escalating from verbal commands leading to enhanced observation, through to sedation and restrictions on the person's legal autonomy.

Often the requirements within these verbal commands were required to protect the dignity and safety of the person or others. However, the interactional approaches utilised highlighted the limited toolkit available to ward staff in the care of patients who challenge the organisational requirements of the ward. For example, there are limited options for ward staff within this fast-paced Medical Assessment Unit (MAU):

I speak to the Nurse in Charge. Tells me that restraint is not something they can do here, just one-to-one if needed and then transfer

Site D, MAU, Day 40

This results in situations such as that outlined below, where the pace of organisation and delivery of care at the bedside and the reduced staff numbers (only one HCA within this bay), leads to staff only having recourse to repeated verbal commands:

The lady in bed 13 is sat with her coat on, sat by the window looking out across the city outside. In the background 'Don't leave me this way' by Harold Melvin & the Blue Notes plays quietly. There are curtains around the neighbouring bed [14]. A HCA is assisting the patient to change her continence pad and clothes. 13 has stuck her head through the curtain to see what is happening and refuses to leave. The HCA pleads with her 'this is not nice' ... 'she needs some privacy' but 13 disagrees and only relents after a few minutes of constant verbal admonishment. She remains in a seat next to the curtain, her back now to it.

Site B, care of the elderly (COTE), Day 21

We also have examples where verbal commands were delivered in a more lighthearted and relational approach, delivered as a form of engagement and de-escalation, reducing the prospect of the use of more overt forms of restraint, such as the use of security guards, a bay under enhanced care protocols and the use of side bars:

17 steps into corridor, she warmly greets two passing HCAs

HCA 1: 'how are you doing'

17: 'Terrible, I've got dementia!' (smiles all around).

17: 'I am sick of this man following me around' [refers to the security guard assigned to watch her]. 17 then goes into a side room and begins to talk to another patient. The security guard verbally encourages her to go back to her own bed, suggesting she can watch TV there. The HCA also comes over 'Come on you, back here... oh, you're being invited this time'.

17 comes out of the other patient's side room and follows the nurse back to her bedside.

Site B, COTE, Day 27

However, the example above was rare in our data and limited to staff that were individually exceptional in their engagement with patients living with dementia. More often, verbal commands lacked engagement and instead were borne of exasperation and frustration with the person, a form of restrictive admonishment with real consequences for patients.

In the example below, an 89-year-old man admitted with delirium has been assigned to a single occupancy room and already has a one-to-one HCA providing enhanced care in his room. However, even in this small and secluded space, away from other patients, he was not allowed to do anything independently. His attempts to stand up and walk using his walking frame, to use the toilet, to walk out the side room to stretch his legs, were all perceived by staff to be concerning behaviour that needed to be managed and contained. The HCA constantly commands him to 'STOP' and 'SIT', reprimanding this person living with dementia for his behaviour and actions. In this example, the HCA's tone is sharp and cutting, with her communications accompanied by eye rolls. The tension between them increases as she further tightens her attempts to contain him and he resists. The HCA increases her delivery of verbal commands, telling him repeatedly to 'Sit down' 'Where are you going?' 'Come back in here!' used to discipline and establish authority over the patient. This is illustrated in the quote below:

1310 [...] I'm not sure what happened with the SRJ. He was calm while the Dementia Support Team were visiting with him earlier, but he is now standing in the middle of the room, the HCA is telling him off repeatedly for moving around and removing clothes. The tension between them is getting palpable. The man decides to leave the room... gripping his walking aid tight as he shuffles towards the door and front of the side room in the corridor, where there are two chairs.

1315. The patient comes out of his side room door. The HCA follows him, telling him repeatedly to 'Sit down. Where are you going? Come back in here!!'

*SRJ: 'I ****ing hate you!!!'*

HCA: [taking offence] 'You are old enough to be my father, how can you speak to me like that?'

SRJ: 'Cause you never stop nagging me'

As in the example above, PLWD typically responded to these repeated verbal commands by becoming more distressed, expressed either verbally or physically, particularly when they could observe other patients within the ward who enjoyed more freedoms within the ward. Many PLWD verbally responded to these commands, making it clear that they found these instructions anything from an irritation to being experienced as a form of imprisonment or kidnapping. In these situations, it was routine for these interactions to quickly escalate, and to lead to further forms of restrictive practice being used in their care. As in the example below, where a patient's dismissal of verbal commands leads quickly to their direct supervision and a legal assessment of her mental capacity (DoLS):

I arrive on the ward and a lady, dressed in her own clothes, who is being shadowed by a HCA and a nurse, goes for the ward door as it closes behind me, the staff panic and reach for her. [...] I speak to the discharge nurse, she tells me that the lady in the corridor is one to watch, very aggressive, staff have stopped talking to her, apparently, she gets angry when they talk to her, just shouts about her rights and going home. [...] The lady is at reception. She is angry & talking about wanting to contact her solicitor, she wants to go home. [...] The HCA is telling her to go to back to her bed so that the HCA can go and help another patient [bed 10]. The patient responds angrily, stood in the middle of the bay, continuing to demand that she can go home. I check the handover notes - the lady in the corridor is awaiting DoLS (or was at time the notes were last updated, doesn't say when but at some time today). Ward is acting as if it's already in place, although allowing the lady to move around with a one-to-one shadowing her, giving instruction on where to go.

Site B, COTE, Day 11

To ward staff, PLWD were often viewed as not responding to their verbal commands in the appropriate and correct way, demonstrating they did not understand the requirement of the ward or were in some way wilfully disregarding them.

SRH 'I want to go out. Make a phone call'

HCA 'No you can't go out. Do you have a number you want to call I will call her for you?'

Her response and tone is a little tense and noticeably high pitched.

SRH *'No I told you I don't, please stop making me panic. Stop panicking stop it now.'*

HCA: *'Okay the doctor will come and see you?'*

SRH *Stands up. He is wearing a hospital gown and hospital socks red with anti-slip stripes underfoot.*

SRH *'I just want to go out and sort the mess out'*

HCA: *'You won't go out, sit down'*

SRH: *'Of course I can! what do you mean I can't?'*

HCA *moves a computer on wheels to block SRH's way out and says firmly to him*

'You won't go outside'

SRH: *'I didn't say I want to go outside! I want to leave the room and make a phone call'*

Site F, Day 78

Despite attempts by this person living with dementia to explain their intentions, it instead resulted in intensified and contracted verbal commands to comply. The staff members focus on minimising patient movement with short commands, followed by calls to the needs of the institution and 'the doctor', and use of ward furniture (the computer stand) to block the way out of the room. For many patients living with dementia, the experience of constant verbal commands and instructions intensified their feelings of distress and contributed to their experience of their admission within the ward as being imprisoned.

This is illustrated in the account of a 77-year-old man living with dementia. He has been on the ward for over 3 months now, despite being classed as medically optimised for discharge, with his discharge dependent on finding an appropriate social care placement. He does not know why he is on this ward, and he spends his time constantly looking for a way out. He is worried about his car, which he believes has been left outside, and also worried about his partner. On this shift he is again in some distress searching for a way out and worrying about his car. In response, ward staff constantly tell him to 'sit down' 'move away from the door' or 'don't enter', all verbal commands which make him feel he is 'being held prisoner'. His experience of this admission is imprisonment, all intensified and made worse by the manner in which all the staff within this ward speak to him.

I ask what he thinks about being on the ward. 'I feel I am being held prisoner the way they talk to me in here... "come back" "don't do that they say"... I want to go home but I worry if I run out of here someone will complain. No one has explained to me why I am being held here.'

Site B, Day 22

The impact of these patterns of repetitive verbal admonishment and instruction, without clear explanation as in the extract above, can create a powerful sense of not only institutionalisation, but of incarceration, highlighting the lack of autonomy patients living with dementia experience not only in staying in the hospital, and in the ward, but also the intensification of these commands requiring how they must behave and where they can be during their admission.

These patients living with dementia were often able to clearly verbalise their unhappiness at these verbal commands; however, staff were not able to adapt their communication style. PLWD clearly verbalised their feelings of being held captive, being imprisoned or being kidnapped. Many of these PLWD were medically well, living with their dementia, and ready for discharge, but instead were required to remain on the ward, experiencing these cultures of containment and restrictive practice for days, weeks and months (in many ways the hospital itself become an instrument of restriction, as we will discuss later), in a way that is not possible for other patient groups, or those whose admission is protected by the legal frameworks previously discussed.

The porter opens the ward doors, transporting a patient on a bed. The lady from bed 2 jumps for the door [She is living with dementia but is a social admission, found lost by the police and now under a safeguarding order despite family wishes for her to go home. She has been on the ward for over a week]. The porter uses his body to block the door, and the patient begins to hit him, flailing her arms. The senior nurse comes over with a nurse, they take her by each arm and march back on to bay. The senior nurse is firm: 'You cannot leave today you cannot leave today, you can't go home today'. When this fails to have an effect she repeats other well practiced verbal cues, she appeals to the bed and chair by the window but the patient does not respond.

Site B, COTE, Day 19

Importantly, these approaches also indicated, to us, to PLWD, and to the wider ward, staff understandings of 'dementia' as a condition, that the often-compulsive repetition of verbal commands, of single words and phrases, would aid comprehension and result in compliance. In turn, these approaches also demonstrate the status of PLWD within these wards and shaped and reinforced the cultures of containment within these wards.

In this section, we have looked at the often invisible, indirect and unrecorded nature of everyday restrictive practice such as furniture placement, bed side bars and verbal commands. They reflect the methods that introduce the patient to the routine use of restrictive practice within these wards. In the following section, we explore what happens when further direct and overt restriction is applied to patients.

Quantifiable and recorded restrictive practice

We observed instances where patients living with dementia assessed by ward staff as being disruptive to the routine work of the ward were routinely referred for psychiatric review and subsequently prescribed antipsychotic or sedative medication. While the administration of such medication to PLWD typically involved oral administration, intramuscular administration was also observed. The intramuscular administration of antipsychotic or sedative medication often involved physically restraining the person, with doses administered multiple times, until the required effect was achieved. During our observations of this practice, we did not once observe ward staff informing patients about these medications or taking their consent during the administration of these medications. Their administration usually took the form of a team stealing up on the patient, and using deception in their description and presentation of the medication.

The patient is just standing in the corridor now. All interaction stopped for a moment, the silence broken by a porter arriving with a chair to transfer the patient in bed 1.

A HCA offers 6 a fresh cup of tea and goes to get it. HCA tells me it keeps him happy if they keep bringing him tea.

The nurse lies and tells the man in bed 6 that his blood sugar is too high, need to give a jab of insulin (actually this is the powerful sedative). The patient disagrees, tells him that the doctor told him not to take any more insulin. The nurse uses the brand name of the drug, but says it is for diabetes. The patient sees through this:

Put it in you then... PUT IT IN YOU FIRST THEN... I'm not even diabetic

You are, you told me earlier

The patient will not allow the injection to take place, making this clear verbally and physically:

That is not what that bloody bastards for, you are trying to control me with your pricks'... going to fill me up with that muck!

The patient swings at the nurse with his two walking sticks. A male HCA steps in and takes the sticks, together the nurse and HCA hold the patient and deliver the sedative. The patient has one last moment of rebellion, pulling off the nurse's lanyard and tossing it across the bay, but the drugs have been delivered. The staff immediately clear the area around the

patient's bed of chairs and obstacles (fall risk). The nurse who delivered the jab (not the assigned one-to-one nurse), says they used Haloperidol, tried it yesterday and it didn't work but that is what is prescribed so they are limited to it.

Site D, Day 59

These approaches resulted in PLWD experienced high levels of distrust in ward staff, particularly during medication rounds and this informed non-compliance with medications during an admission. These patterns of encounters and approaches to administering antipsychotic and sedative medications could continue during an admission, and in turn, intensify the person's distress over time.

The built environment

The locked ward as a restrictive practice

All wards observed operated a locked door system. For two sites (B and D), this took the form of a swipe card system for both entry and exit of the ward. One site (F) utilised a swipe system for entry only, pressing a door release button by the door to exit. Both systems ensured that only staff with permission to enter the wards were allowed entry and exit. Visitors were only admitted to the ward by pressing a doorbell and waiting to be admitted. To avoid unauthorised exits one ward one site F covered the door release button with paper to hide it from patient view.

While some staff suggested to us that they explained to patients the ward operated a locked door system, during the period of this study we did not once observe staff having this conversation with patients. Instead, we observed staff providing PLWD with a wide range of explanations for the locked ward or using distraction or further restrictive methods in their attempts to reduce or prevent them from focusing on the exit doors. Patients living with dementia who walked towards or attempted to open the exit doors were a significant focus of anxiety for staff, who described their intense fear a patient would 'abscond' from the ward. Our conversations with ward staff were replete with stories, anecdotes, moral tales and atrocity stories of PLWD who had 'absconded' from the ward, providing accounts of near misses, patients who had 'escaped' and found in various locations miles away. Versions of these scenarios do happen, but they feature heavily in staff accounts justifying these practices.

The locked door policy contributed to PLWD's increased experiences and feeling of imprisonment. This was powerfully felt, and many were observed describing being within the ward as a form of incarceration. Many wanted to leave and repeatedly had conversations with others and pronounced to the ward in general, their powerfully felt need to go home, of escaping, or of contacting the authorities (the police) or somebody (passersby or other visitors within the ward) to help them, as in the example below:

The lady from bay one is shouting now, standing in the corridor outside the day room, calling out, pleading, to anyone passing her:

'I have done nothing wrong... there is no reason why I'm here... I don't want to be here'. The one-to-one carer with her is no longer responding to this, he is just staying close to her. She continues to shout, demanding to go home, she questions the legality, she calls for witnesses, asks for somebody to call the police for her.

Site B

The inability of PLWD to find their way out of the ward, and their recognition that they were imprisoned within it, increased their distress, and in turn, they became even more desperate to leave, leading to continued and escalated attempts to leave the ward. This would typically be viewed by ward staff as behaviour to be managed, aggression and understood a feature of their dementia:

The ward co-ordinator looks exasperated. She begins to tell me about the man in bed B1. He is currently asleep, sedated on a 'heavy dose' of Lorazepam after three acts of aggression overnight. Security called each time but they refused to engage and admonished the nurses for time wasting. Aggression included twisting the arm of a nurse and verbal racism towards one of the cleaners. Big issue is for the unit shouldn't here, he had already been transferred to care of the elderly on a higher floor, but tried to jump out of the window of his side room after breaking the glass with a chair. They cannot

get mental health support as a medical admission so the ward team is stuck, limited to assigning a male one-to-one due to strength of the patient, and terrified he will try to jump or abscond again.

Site F, MAU, Day 85

In response, as in the example above, staff continued to increase and intensify the restrictions placed on and experienced by these patients living with dementia. However, these cycles of restrictive interventions focused on the locked doors at the exit, resulting in further restrictive measures being implemented by staff, and a further tightening of restrictions for these patients within the ward. This typically included the increased use of verbal commands, deception, persuasion and offers, which in turn, escalated to the use of security guards and chemical restraint used in the care of these PLWD.

For staff, the locked door policy was considered to be a central and essential feature of the ward environment that ensured the safety of patients living with dementia on the wards. Some staff described the idea of allowing older patients and those living with dementia to walk around or in and out of the ward as a safety and safeguarding concern, expressing palpable concerns and fear that they would be personally liable if the patient fell, walked out into the road, or got lost having absconded from the ward.

Seclusion

A routine practice within all the wards was to transfer patients who were assessed as 'challenging' to within single occupancy rooms or side rooms, with the exception of MAUs, where clinical need for infection control over-rode the practice:

The lady from side room 12 is stood in the doorway of her room. She is very smart looking with neat hair, despite the hospital robe. A security guard is with her, a stout man in all black uniform and a face mask. He is stood across the door facing inwards, both arms pinned across the door frame to block 12 from exiting. She is stood close to him looking out. She points forlornly and says she wants to go out the door. Fleetwood Mac's 'Go Your own way' plays in the corridor.

Site B, Day 21

While single occupancy rooms were described by ward staff as being predominantly used to 'house' patients with an infectious condition or at end of life, we observed many occasions where patients without an infection but considered to be a disruption to the everyday work and routines of the wards were moved into such rooms. Generally, staff explained the use of side rooms, which were all single occupancy in this study, as being 'in the patient's or other patients' interest. Moving PLWD who were considered a disruption into side rooms was focused on containment, restoring much desired order to the ward and allowing staff to 'get on' with the everyday routine timetabled work of the wards, as in the discussion below:

RN describes changes on the ward and rationales for the: 'Side room B was on Bay E previously, but moved into a Side room because of perceived psychiatric problems. She has not been aggressive to staff but disruptive to other patients on the bay. She is incredibly loud. Has been going round talking to other patients and initiating arguments ... she was disturbing other patients shouting or trying to wake them up to talk to them. It means we had to keep a close eye on her. In here though, she is likely to be easier to look after gives other patients peace and we can get on with work.'

Site F, Day 75

Outsourcing of restrictive practice

Within site B, we observed a high use of external, outsourced, security guards in the care of PLWD, as opposed to other sites where one-to-one enhanced observation was predominantly sourced through existing rotas or through bank and agency care staff. The rationale for the practice at site B was a lack of available agency care workers in the region.

Because these outsourced security guards were typically a solution to support ward teams, it was usual for the application for security for that person to continue across an admission, even where the need was reduced or may not be required. In part, this was organisational, the security guards worked on 12-hour shifts, so there was an element of the team getting the value of an extra pair of hands and eyes on the ward during that shift. As in the example below, returning to the woman living with dementia from the previous section, who was isolated in a side room:

I speak to the discharge nurse to ask why the lady in side room 12 has security [name of company] but other more active patients don't. She checks the notes and says that she has DoLS in place as she is prone to wandering, but so do bed 2 and bed 13 and they are not being guarded. She says the lady had issues repeatedly removing her fluid drip but is settled now. She says there is no clinical reason for the lady in side-room 12 to have different care to others, she suspects the guard was assigned by the previous ward before she was transferred here, whereas the other patients came straight here, and this ward is less likely to call for [name of company].

Site F, Day 21

In the example above, one of the other patients (without a security guard) went on to pose a risk to the other patients on her bay, knocking over furniture and shouting at other patients. While she was eventually moved to a side room this took considerable time, and no hospital or agency security was used.

The nature of the organisation of care within these wards was routine staff shortages (both perceived by staff and reflected in actual staffing) and staff distress due to workloads within these wards. In these contexts, the request for security guards became used as an extension of the routine care that staff carried out on the ward. For example, some security guards, in addition to being imposing figures within the ward, took it upon themselves to direct patients to drink or eat while nurses looked on or moved on to other routine timetabled tasks within the ward, as in the example below:

23 has a one-to-one Security guard assigned, both currently sitting at nurses' station as well. Two nurses on duty. They are short staffed. A nurse is expected to come in from another ward, but they don't know when. All staff look tired already.

Security guard asks 23 to go to bed as he was nodding off at the station. He refuses 'I don't need to and I don't want to.' 'He must be tired for sure', the staff say among themselves. A few minutes later 23 gets up and tells the Security guard that

'he is ready to go to his bed now.'

Security guard follows him.

[...] The security guard asks 23 if he wants to have breakfast. After a few exchanges 23 agrees to have cornflakes. When trolley approaches the guard asks 23 to go to his bedside for breakfast.

Site B, Day 26

The use of security guards, whether outsourced or from within the hospital, often exacerbated the distress of the person living with dementia. It could lead to the escalation and use of other restrictive practices (seclusion, sedation) in the care of the person, which, could in turn, be distressing for the person and for other patients to observe.

In the example below, the patient, 19, a man in his 80s has been admitted for over 5 weeks, but his distress only begins after week 3 with the presence of security guards allocated to supervise another patient within the bay (23) from the previous extract:

The security guard is holding 19 by the arm and pulling him back telling him to go to back to his bed side or use the nearest toilet. 19 is undeterred he walks on ahead and makes his way eventually to nurses' station. He says he wants to go outside the building. He turns to security guard to ask him 'Are you some kind of police officer?' Standing up to walk away he shouts 'leave me be!' His hospital gown is undone at the back, his back is exposed, revealing a pad and the netting underwear that is now nearly down to his knees. The security guard is concerned 19 may fall. Says to me 'that's why I have been holding onto him from the bay. He is unsteady on his feet'.[...] 19 walks towards the nurses' station waves his walking stick at security guard. [...] He shouts 'help please! I want the police! I want to be freed!'

Site B, Day 27

These practices could also routinely lead to contagion within the wards, with the assessment that further restrictive intervention, including security and or sedation, was required for patients distressed by witnessing the restraint of other

patients. The man, bed 19, in the example above was not under restraint, but the presence of the guard assigned to another patient meant this restrictive practice extended to him witnessing and experiencing this restraint. His distress informed staff judgements that he too required restrictive practice. In this way, the use of security increased distress within the wards, creating a need for further security.

Legal frameworks

We identified that ward staff found defining and identifying what constituted restrictive interventions in their routine practices as challenging. However, the use of legal frameworks in a patient's care was recognised as a sign that patient was, or could be, restrained, particularly allowing for the use of sedative medication such as lorazepam or haloperidol. However, there was significant variation in the application of legal frameworks, such as DoLS or the MCA across these wards, varying from everyday usage (site B) to not at all (Assessment Units).

The use of DoLS was most typically observed to be instituted for PLWD who were described as at risk of leaving the wards (referred to within these settings as 'absconding') or a patient who routinely left the bedside and walked within the wards (referred to within these settings as 'wandering'). These behaviours were observed to be of immediate and significant concern for wards staff particularly when a patient walked towards the ward exit, walked away from the bedside and around the ward, or followed visitors as they exited the ward.

The application of DoLS places significant limitations on the autonomy of a person and requires assessment and periodic review once in place. For PLWD, however this review would often be overlooked, with the repercussions of the safeguarding order remaining in place across the person's admission. During our observations, the restrictions put in place by these orders were never explained to the PLWD at any site, which meant they were unable to object to their use in their care or to request reassessment. The example below was typical across the observed settings (except MAU at sites D and F where DoLS were not employed), with the exception that this man has been on the ward for 120 days:

SHO: 20 had DoLS Instituted [Date X (4 months prior)]. Records do not show if and when it was renewed. However, 20 is currently under care on DoLS. It may be best to speak to the safeguarding team to find out why this is still in place. I have not been asked to review any of the DoLS on this shift save for the standard bi-weekly patient reviews.

Site B, Day 15

The use of DoLS in practice led to generalised assumptions of a person's capacity and capabilities, with no recognition that this could or would change over their admission. Once a patient was under DoLS (or other framework), they were recognised as lacking capacity throughout their admission, with exceptions such as site B, where Mental Health Liaison teams could assess and reassess patients. In terms of everyday care, however, DoLS meant that even when patients living with dementia were clear about their wishes, how they wanted to be looked after, or expressed their needs, this could be dismissed or over-ruled. DoLS meant the patients' wishes could be over-ruled for what the ward considered the patients best interests, and an individual's objections to this could be ignored or dismissed due to diminished capacity.

In the following section, we look at this in more detail, exploring how the practices we observed intersect with the laws governing them.

Dementia, restrictive practices and the law

Healthcare practitioners must balance conflicting legal duties: providing care and treatment to PLWD, protecting them from harm, and respecting their rights to self-determination, bodily integrity and liberty. In English health law, the general rule is that care or treatment should only be provided with the person's informed consent, unless there is a legal reason to do otherwise. Without consent or a clear legal basis for providing care, treatment, or restricting a person's movement, practitioners and healthcare providers may be held liable for negligence, battery, false imprisonment, or breaches of human rights (under the Human Rights Act 1998).¹⁸⁵ If a patient's movement is so restricted that they are effectively deprived of their liberty, this could violate their human rights or amount to false imprisonment unless there is lawful authority for their confinement. At the same time, failing to provide necessary care or not taking reasonable steps to protect individuals from foreseeable harm could also breach the duty of care owed to the person (negligence) or violate their human rights.

Two main statutes help practitioners navigate this tightrope: the MCA 2005, which applies to care, treatment and restrictive practices in all health and care settings, and the MHA 1983, which applies specifically to care, treatment and restrictive practices linked to treatment for mental disorders. Both statutes provide a clear legal basis for care and treatment without consent, and protection against liability for restrictive practices. However, their principles and procedures must be followed properly; practitioners cannot simply claim that they were acting in good faith, intended to protect a person from harm or rely on the doctrine of ‘necessity’.¹⁸⁶

Both the MHA and the MCA DoLS can authorise deprivation of liberty linked to care and treatment. The MHA is mainly used in mental health settings, and the DoLS is mainly used in acute hospital settings. However, both statutes could potentially be used in either context. A very complex interface governs the rules on which regime should be used.¹⁸⁷ In 2014, the Supreme Court defined deprivation of liberty as being subject to ‘continuous supervision and control’ and ‘not free to leave’.⁹¹ Since then, the number of DoLS applications from acute hospitals increased dramatically, to over 100,000 in 2023–4 in England.¹⁸⁸ Although later case law narrowed the scope of this ruling for people receiving life-sustaining treatments (e.g. in intensive care),¹⁶⁷ most treatments in the settings that we observed would not fall within this category.

The next section analyses how hospital staff understand and apply these legal frameworks when caring for PLWD in acute hospital settings.

Consent on the acute wards

Consent is more than mere acquiescence – for example, being willing to take medication that one is given. In broad terms, informed consent means giving patients information about the treatments recommended by the medical team, discussing any risks to the patient, and providing information about alternative treatment options.¹⁸⁹ Professional guidance explains how doctors should support patients in understanding treatment, options and risks, *involving* them in the decision-making process.¹⁹⁰ Supported decision-making is also key to evaluating a person’s mental capacity to consent to particular treatments.^{136,191}

Although we observed healthcare practitioners – including medical and nursing staff – administering treatments, for example medication, we did not observe any practices that could recognisably be described as trying to support *informed consent* from PLWD. For example, within these acute wards, we observed several PLWD being given medication, including powerful antipsychotic medications such as lorazepam, haloperidol and risperidone. These medications are known to carry significant risks of morbidity and mortality to patients living with dementia; treatment decisions are finely balanced.¹⁹² However, although we observed PLWD being told they needed to take their medicine or to have a diagnostic test or assessment, we did not observe these treatment choices being discussed with patients, nor the attendant risks. It is possible that these discussions happened with PLWD when we were not present, but we note that we did not *once* observe an interaction that could recognisably be described as supporting their informed consent to treatment.

We note this at the outset, because without consent the administration of these medications, and the other restrictive practices outlined in this report, are potentially unlawful, *unless* there is an alternative legal basis for treatments without consent – such as the MCA or the MHA.

Negligence could arise if a patient suffered material harm because of a material risk that they were not informed about and therefore did not consent to.¹⁸⁹ Battery actions are rarer in medicine, but can arise in cases where the patient has not been informed about the treatment in even ‘broad’ terms such as *Chatterton v Gerson* (1981). Confinement on the ward can amount to false imprisonment without a clear legal basis. These acts could also unlawfully interfere with a person’s human rights, chiefly article 8 (the right to home, family and private life) and article 5 (the right to liberty) of the European Convention on Human Rights (ECHR). Acting in good faith, attempting to protect a person from harm, or believing that one is acting in the person’s best interests is not a defence to a charge of battery, negligence or false imprisonment *unless* the procedures of the MCA have been followed appropriately.¹⁸⁶

Restrictive practices in acute wards

On these acute wards we observed restrictive practices and restrictions on patients' liberty of movement, but only some of these seemed to be recognised by staff as possible 'restraints'. Restraint is defined under s6(4) MCA as either:

- using, or threatening to use, 'force to secure the doing of an act which P resists'; or
- restricting 'P's liberty of movement, whether or not P resists'.

Active physical resistance to care by PLWD was common in our own direct observations which reflects our previous findings,^{49,50} although the extent or impact of violence from PLWD and older people within these wards was often exaggerated. We witnessed a number of instances of the use of force which the person living with dementia resisted, and staff described instances of it to us in our conversations on the wards. For example, PLWD were often said to have attempted to 'abscond' or 'absconded' from the ward, meaning leaving without the permission of the staff. Usually, they would be brought back from the exit or returned to the ward by staff or security, often by holding a patient's arm, holding them by the arm or in rare circumstances held and lifted by both arms by multiple staff. One patient complained about the 'rough handling' they experienced during this. PLWD for whom there was a concern or who had previously tried to 'abscond' were typically allocated a healthcare auxiliary staff member, or security staff, to provide 'one-to-one' supervision of the patient at all times, often referred to as 'one-to-one' observation or 'enhanced care' repurposed to prevent them from leaving bedside and the ward.

More rarely, staff also reported instances of aggression from PLWD. Often, this was described as verbal aggression, but in one case nursing staff told us about a patient who had 'escaped' and punched a nurse twice when trying to bring them back to the ward. PLWD who were perceived to be verbally 'aggressive' to staff or other patients, or who resisted care, or whom staff said were 'agitated', 'unsettled' (e.g. shouting a lot), or viewed as likely to 'kick off' were more likely to be prescribed the sedating antipsychotic medications discussed above.

When we talked to staff on the acute wards about these measures, they often (although not always) recognised one-to-one supervision and sedating medication to be forms of restraint. One staff member described these as 'formal' restraints that might require a DoLS application (we return to deprivation of liberty below). Sometimes these measures might involve specialists, such as the liaison psychiatry team. When we spoke to the liaison psychiatrist, they expressed concern that once a measure such as being put on a one-to-one or being prescribed sedating antipsychotics was in place, it might not subsequently be reviewed and reduced. They contrasted this lack of regular review of restrictive practices in acute settings with practice on mental health wards, settings where we observed legal frameworks being used and recognised as requiring regular review.

We also observed several measures employed on these acute wards that restricted the person's 'liberty of movement'. These were typically not recognised by staff as forms of restraint, although they could be defined as such by section 6 of the MCA and could contribute towards a deprivation of liberty. These were environmental forms of containment, employing everyday furniture and healthcare devices that are not designed for restraint, but which were repurposed to contain and restrict the person living with dementia at the bedside.

As we have already seen, PLWD were often in bed for most of the day with the bedside rails raised up. This had the effect of almost completely restricting the person's liberty of movement. PLWD were not able to leave their beds at will. We did not see any patients successfully lowering the bed rails themselves (although some tried to climb over the raised bed rails, posing significant injury risk). We did not observe ward staff offering to lower them, nor regularly offering PLWD opportunities to leave their beds with support. The intention and impact of the bedrails were that patients living with dementia were effectively *confined* to their beds.

These 'informal' restrictions may not involve the kinds of hands-on contact and direct use of force associated with physical restraint, but these environmental restraints significantly impacted on people's everyday rights and freedoms – interfering with article 8 of the ECHR. The MCA provides a potential defence against liability for these restrictive practices, but that would require staff taking 'reasonable steps' to assess the person's mental capacity in relation to the matter, and then following the appropriate frameworks for making best interests decisions. This requires considering the person's wishes and feelings about the matter (e.g. how they feel about being confined to their bed, or a chair, or

the use of sedating medication), involving others who are interested in their welfare (e.g. family members or friends) in discussions about their best interests (MCA, s4), and considering whether there are 'less restrictive' courses of action [MCA s1(6)]. We did not observe these approaches or conversations while on these wards. Restrictive practices should also be 'necessary' and 'proportionate' to the likelihood and severity of the harm that might occur otherwise. Given the concerns of liaison psychiatry that acute wards did not review restraints, it is worth noting that if it were no longer necessary or proportionate, it would no longer meet criteria for lawful use under either the MCA or human rights law. Interferences with a person's bodily integrity (protected by article 8 ECHR) or right to liberty (article 5) must be in pursuit of a legitimate aim (e.g. health, safety or the protection of the rights of others), but they must also be *necessary* and *proportionate*.

Deprivation of liberty

Following *Cheshire West*, patients are considered 'deprived of their liberty' if they are subject to continuous supervision and control, are not free to leave, and have not given consent to their confinement. It is irrelevant whether the restrictions are intended to keep them safe, or 'normal' for someone with that condition. Mere acquiescence to confinement is not consent, particularly if patients lack mental capacity to give a valid consent to their confinement. The key question for determining whether a person is deprived of their liberty is subjunctive; not *whether* the person has actively tried to leave, nor whether they are physically capable of leaving without assistance, but *would they be prevented if they did?*^{193,194}

Freedom to leave

Many PLWD in these acute wards were effectively confined to the ward. A person living with dementia was only ever permitted to leave these acute wards for clinical need, such as diagnostic tests or treatment interventions. A family member was not able to take a person living with dementia for a walk outside of the ward (e.g. to the hospital coffee shop) or to leave the hospital (our only example is when a senior member of the hospital medical staff took their mother out of the ward for a birthday) and it was rare for a care worker or specialist to do so.

People living with dementia within these wards were therefore likely to be deprived of their liberty.

As outlined above, some patients were effectively confined for long periods of time to their beds or the area around their beds, through the use of environmental restraints. While very unwell patients may be physically unable to move around, many patients were often being deliberately contained within these areas by staff, to restrict their freedom of movement. Sensors designed to monitor patients identified as at risk of falls, and 'bay alarms', were repurposed to allow staff to supervise patients' movements. Patients who were considered at risk of 'absconding' were often given one-to-one care, often referred to as 'specialing', 'enhanced observation' or 'enhanced care' whose primary purpose was not to provide *care* as such, but rather to supervise patients to prevent them from leaving the bedside, or from disrupting other aspects of the workflow of the ward.

A variety of measures were used to supervise and control patients' freedom to come and go from the ward or other areas. All wards operated a locked door policy where staff had to buzz people in and out. In one ward, staff took it in turns to 'watch the door' to ensure patients did not leave and one ward adopted a swipe card system after a patient had 'absconded'. Some wards seemed to be operating a kind of pseudo-capacity assessment system for deciding whether to allow patients freedom of movement within the ward:

The bay also operates a strict bay tagging system. The bays are self-contained, therefore patients leaving them ward must have very good explanations or judged to be rational enough and not a risk to themselves or others to left to walk around the ward or 'wander'.

In themselves, locked doors, bed and chair sensors, bay alarms and so on do not constitute a deprivation of liberty; deprivation of liberty arises where staff use measures like these to supervise and control patients and prevent them from leaving. When PLWD actively attempted to leave, staff often referred to this as 'absconding' or 'escaping', terms that convey a belief that these patients were *not permitted* to leave. Yet for many of these PLWD, there was no legal

authority in place to require them to remain in the hospital, such as the DoLS or the MHA. Staff, however, appeared to believe that they nevertheless had the authority to decide whether patients should be *allowed* to go home. For example, we saw one senior nurse telling a member of the ward team 'No, the patients don't decide when they are going home, the doctors do'. In another case, we saw a family carer telling a nurse that he was discharging his relative and taking him home, arguing that the person living with dementia was becoming agitated on the ward as he hated hospitals. He asked about his 'legal position' should he do so. The nurse responded that he could not take his relative home as the doctor wanted more tests done, implying that the doctor had the legal authority to require this man to remain in hospital. This patient was not subject to DoLS; there was no legal basis for refusing to allow him to leave with his relative. The staff's implied authority to control patients' freedom to come and go, despite lacking any clear legal basis, was mirrored in many patients' obedience to exhortations not to leave the ward, or to remain in their bed, or within their bay of beds. Formal legal frameworks such as DoLS tended only to be used in relation with patients who actively resisted the staff's implied air of authority – by trying to leave, or through acts of verbal or physical distress at not being able to walk around the ward, which was typically viewed by staff as aggression.

Wanting to leave

A recurring theme throughout our observations on these acute wards was patients wanting to leave, and being prevented from doing so.

At one end of the scale, we saw patients living with dementia actively attempting to leave – sometimes managing to exit the ward or even the hospital altogether. Others would demand to leave, sometimes quite forcefully, or take steps towards leaving – such as packing their bags. Some patients living with dementia repeatedly challenged the legal basis of being required to remain on the ward, one threatening to call a solicitor, another threatened to call the police. Many patients living with dementia, however, did not directly challenge staff's authority to prevent them from leaving the ward – but might *ask* to leave, or ask *when* they could leave. The majority spoke about their desire to go home. This would often manifest as significant distress, with patients repeatedly asking or shouting about leaving. Some patients would gravitate towards the exit doors (sometimes their one-to-one staff member would bring a chair and sit near them to prevent them from trying to leave through them). In conversations with patients, one pointed out the window 'It's a great view isn't it. That's my whole life out there', before commenting that they were 'stuck in here'. Another man pointed out the window, saying 'That's where we need to be: out'. Other patients living with dementia spoke of feeling 'trapped' or feeling like a 'prisoner'.

Safeguards

The DoLS were intended to provide 'safeguards' to comply with article 5 ECHR.¹⁹⁵ In hospital settings, the process is initiated by the hospital making an application to the 'supervisory body' (local authorities in England, and Local Health Boards in Wales) seeking authorisation for a deprivation of liberty. The supervisory body should then send out independent assessors to carry out assessments of the person's mental capacity, best interests, and other criteria, including whether the detention is necessary and proportionate to the risk of harm. The supervisory body can impose 'conditions' on authorisation, for example reducing specific restrictions or exploring less restrictive alternatives.

If authorised, the DoLS are supposed to bring other key safeguards, including a 'relevant person's representative' to support and represent the person, and potentially also an Independent Mental Capacity Advocate. If the person objects to their confinement, they are supposed to be supported and enabled to 'appeal' against it in the Court of Protection.¹⁹⁶ The aim of these complex networks of safeguards is to ensure that nobody is inappropriately or arbitrarily deprived of their liberty, meaning that any confinement is genuinely necessary and proportionate and in line with the MCA's principles.¹⁹⁷

In practice, although we did observe patients who were under the DoLS, we saw very few signs of 'safeguards' and no evidence that they made any concrete difference to enabling people to leave hospital earlier or reduce restrictive practices in their care. In practice, we were more likely to find a tightening of restrictive practices for this group of PLWD.

On most of these wards, DoLS applications were only made for patients living with dementia identified as the most resistant and those who were actively trying to leave. This means that more compliant or less ambulant patients, who

were nevertheless subject to 'continuous supervision and control' and 'not free to leave', were not subject to DoLS processes, despite quite likely being deprived of their liberty within the terms of the *Cheshire West* judgement. In some wards, we were told that staff were now discouraged from using DoLS; in another, we were told 'we don't do DoLS on this unit', that it happened when patients go downstream. At law, however, a deprivation of liberty requires authorisation wherever it occurs, and even if for a relatively short period of time. We also met patients where staff knew their DoLS had 'expired'.

It was often not clear which patients living with dementia were 'on DoLS' and which were not (and therefore whether staff had legal authority to prevent patients from leaving the ward). It was also unclear whether the DoLS applications made by these hospitals had been duly 'authorised' by the supervisory bodies. Legally speaking, an 'urgent' authorisation issued by the hospital would expire after a maximum of 14 days if the supervisory body does not authorise it. Nationally, since *Cheshire West*, the average time taken to 'complete' a DoLS assessment (i.e. to carry out all the relevant assessments and make a decision whether to authorise it or not) is 144 days, and in many cases the assessments are not completed before the person's situation has changed and the original DoLS application is no longer relevant.¹⁸⁸ This means that for most acute hospital patients, there will be no assessment and no further 'safeguards' to speak of. One staff member described DoLS as 'more trouble than help'. Yet in cases where patients were actively resistant or relatives were objecting to confinement, DoLS seemed to solidify the authority of ward staff.

Even had the 'safeguards' all been in place, one of the key limitations of DoLS is that (as part of the MCA) it only reviews decisions among the *actually existing options* and it cannot generate better options than those that actually exist.¹⁸⁸ In many cases, PLWD were considered 'medically fit to leave' but were awaiting assessments by social work, social care, or other teams linked to discharge planning, or they were considered unsafe to return home and there were problems identifying a suitable placement within the community. In these situations, the safeguards potentially offer independent scrutiny of whether the risks really are significant enough not to permit a person to return home, or whether restrictions in the ward (e.g. confinement to beds, bays or wards) could be reduced, but they could not actively generate support options to facilitate discharge.

Safeguarding duties

Healthcare staff have legal duties to protect patients. These include a duty to take reasonable care to avoid acts or omissions which could reasonably be foreseen to cause harm (known as the 'duty of care'), and operational duties to take reasonable steps to avoid the death of a patient where there is a real and immediate risk and the public body has control over the person.¹⁹⁹ This arises even in cases where there is not (yet) any formal legal basis for confinement; the *Rabone* case concerned an 'informal' patient who was allowed to leave hospital instead of being detained under the MHA, despite a known risk of suicide.

Staff occasionally spoke of having a 'duty of care' towards patients, but more often spoke of 'safeguarding' duties. Staff referenced safeguarding duties as a reason why they could not let patients leave, particularly in circumstances where others – such as the patients' family – might request for a patient to be discharged home. We observed, however, that some vulnerable patients were allowed to leave, despite presenting considerable risks to themselves. For example, one patient who was an ex-prisoner and was now homeless had been admitted to the ward with alcohol intoxication and seizures. He had assaulted a nurse in a lift and was asked to leave. Once outside the ward he was distraught and talked of not knowing where to go. Curious, we asked staff why this patient had been allowed to leave the ward when a large number of other patients within this ward were not permitted to. They replied that he was 'compos mentis' and chose to leave, some of the patients here are not so much with it, so cannot be released to go out like that'. The phrase 'compos mentis' seemed to serve as a rough proxy for 'he had capacity', but it was not clear whether staff had carried out any mental capacity assessment for this vulnerable homeless patient. Evidently, however, they did not regard their 'safeguarding' duties as extending towards him.

Capacity

Many of the restrictive practices and restrictions on liberty that we observed within these acute wards were motivated by staff's desire to keep patients safe. One of the main risks staff worried about was falls. Other risks included patients 'wandering' out of or 'absconding' from the hospital's protective environment entirely. Yet legally speaking, protective duties do not confer unfettered authority or powers on staff to restrict patients. The duty of care is limited

when the person has the mental capacity to make decisions around the risks.²⁰⁰ And even if the person lacks the relevant mental capacity, the duty of care also requires that the relevant legal processes (e.g. the MCA) are followed in protecting them.¹⁸⁶ Yet, we saw relatively few signs of mental capacity assessment taking place on the wards. Capacity assessments were sometimes described as having taken place elsewhere, for example staff might speak of patients as 'lacking capacity', or a patient (who was permitted to leave) being described as having 'capacity to decide'. But capacity assessment did not seem to be a routine practice on the wards themselves, particularly in relation to the kinds of everyday restrictions we observed staff using. Instead, ward staff seemed to use rough proxies of capacity, for example speaking of patients as 'compos mentis' or not or asking patients' questions when they tried to leave the ward or bay area to see if they were rational enough or had a good enough justification for wanting to leave.

Rationales for restrictive practice: containment at the bedside

In the previous sections, we explored how restrictive practice is conceptualised and practised in these hospital wards, and the legal frameworks they operate within. In this section, we will explore why staff feel the need or are required to employ restrictive practice in everyday care. We will look at the rationales for containing a patient at the bedside, and how these rationales provide the foundations for routines of restraint and cultures of containment.

Across our observations we saw multiple rationales for the models of restrictive practice used, from the explicit (times whereby a patient poses a clear risk to themselves or others or has been assessed via a legal or social framework), to the perceived, where restraint was based on the assumed best interests of the patient.

Explicit rationales for containment at the bedside

Within the acute setting ward, staff referred to a number of explicit rationales for the use of restrictive practice in the care of PLWD. These are typically when a person has been assessed by either liaison psychiatry or a social worker and a clear need for some degree of restriction was identified. Some examples of this include when there was a risk to self, a risk to others, or due to the requirement for infection control.

Risk to self

Restrictive practice could be imposed on a patient if they had made a clear statement of risk to themselves, even when this sits outside of diagnosis of suicidal ideation. This would typically always take the form of seclusion, moving the patient to a side room, and constant one-to-one supervision or observation with the room. The example below comes from discussions in a handover meeting, explaining why one woman admitted to the ward has a private security guard assigned to her side room:

At time in the meeting patients are referred to by outlandish behaviours and statements they have made. The senior nurses are discussing 'the knife lady' a lady who has repeatedly threatened to kill herself 'with a knife', always with a knife.
Site B, Day 2

As in the example above patients with a known explicit risk are visible in the ward and known to staff. The form of restraint is highly visible and acknowledged.

Risk to others

People living with dementia may be assessed as a risk to other patients, to members of ward staff or to a specific individual or patient group, in which one-to-one supervision and exclusion is enforced as a means of risk management and protection. In the example below, a patient (bed 2) is living with dementia and also does not speak English. A deprivation of liberty order is in place and she has been assigned one-to-one care, which in the following excerpt is provided by a HCA assigned one-to-one as part of her rota-ed work.

The lady from bed 2 keeps approaching bed 1. The HCA keeps pointing at bed 2, 'this one's yours'. The lady in bed 1 joins in points at bed 2 as well. The lady from bed 2 stands up from the chair at bed 1 and heads towards her own bed before turning back towards 1. The HCA uses her body to block her path, causing the patient to shout out at her.
[30 minutes pass]

The one-to-one HCA comes back to the bay, holding hands with the lady from bed 2. They both seem content until they approach the bay door, when the lady from bed 2 quickly lurches towards the locked ward doors, pushing past the one-to-one and grabbing the two handles of the door. Staff are waiting on the other side of the door and are unable to enter the ward, while a physio wanting to leave the ward on her rounds is now stuck inside.

Site B, COTE, Day 18

The explicit rationales for restrictive practice (in the form of one-to-one care) in this example are clear, in that the patient is at risk of leaving the locked ward (itself an everyday form of restrictive practice in the care of PLWD and older people) and at risk of escalation with other patients as she enters personal space and takes possessions. This example is also interesting in showing how this form of restraint does not entirely prevent these risks, but creates new risk when clinical teams are prevented from accessing and exiting the ward.

A similar example on another ward at the same site is observed below, with one-to-one care being used to control a clear patient risk, where perceptions of risk to other patients have led to one-to-one enhanced observation being employed, despite the risk being more to the 'wandering' patient himself, which in turn has significant impacts on his discharge routes and need for further legal restriction:

There is a long discussion of how one-to-one is being used on some patients. It makes sense for some patients in terms of ward management but then severely limits discharge route. One patient has one-to-one because he wanders and enters other patient's rooms, and is prone to hallucinations and misidentifying other patients as family members. Another patient has chucked a cup of water at him as a result of this, but this has been mis recorded in the notes suggesting he entered a patients room AND chucked a cup of water at another patient, meaning all available care homes have refused him. He is also in a paradoxical state of flux, he is consenting to treatment but he lacks the capacity to consent, so may need sectioning to treat.

Site B, Day 20

The need for one-to-one supervision, and more direct interventions such as sectioning, sedation and security guards, becomes apparent when a patient presents as a risk to staff. In the example below a patient with young-onset dementia has one-to-one care, plus sedation and security interventions, as his size, mobility and perceived aggression are assessed by staff as a threat, in particular for the smaller female HCAs typically tasked with one-to-one care.

I am told that the man in bed 21 has been constantly up out of bed, trying to leave the bay and the ward. He is agitated because he wants to be home as his cats need looking after [His carer have confirmed that this patient does have cats but their care is not an issue while he is admitted]. He will be staying overnight on unit as no enhanced care beds available elsewhere in the hospital. The male HCA tells me that he has 'got all of his steps in' this morning but this was OK as empty beds elsewhere on the unit meant he had the time to accompany the patient up and down the corridor.

21 has been prescribed Lorazepam, given one dose at lunchtime, no legal framework in place. HCA tells me he is staying with him because he is a big guy who can take being shoved around, other staff today are all female and much smaller than him, HCA says 'if [21] pushed them they would both go over'. He tells me the unit don't like using security but called them when he was on lunch as needed male cover to supervise.

At nursing station departing nurse in charge warns incoming team about 21 by miming a punch, pushing fist into open hand. Team roll eyes at this in apprehension at night to come. Says he has had a dose of 'loraza'

[... Evening Shift handover...]

Male HCA telling female HCA to call security if man in bed 21 goes to main door as he is strong enough to force door and to hurt her. 'You are half the size of me' – he gives her a fob with security alarm on it and explain how the panic button works. He reminds everyone at the nurses' station of the number to call security on. Later the clerk at the station dismissed the panic button 'normally when the panic alarm goes off we don't know what it is or where it is'.

Site D, MAU, Day 55

Infection control

Restrictive practice was also employed when a patient living with dementia was confirmed as having highly infectious conditions such as *Clostridioides difficile* (*C. difficile*) or suspected exposure to respiratory conditions such as coronavirus disease discovered in 2019 (COVID-19). This varied over the duration of the study. At the beginning of data collection, COVID was a rationale not only for restraint but in many cases complete isolation, with the patient alone in a closed side room or bay, with one-to-one care outside or in full personal protective equipment (PPE), and visitors prohibited:

A visitor arrives for bed 3 [notes say cognitive decline and grief response]. The Senior Sister tells the visitor that she does not advise her to visit & suggests speaking to the doctor instead. Visitor says her mother needs her, visitor looks visibly upset, says she will take risk. Sister advises against doing this a second time and then escorts the visitor to the day room to wait for doctor. Bay 1 is closed with a large yellow and red laminate sign on the door cautioning against entry without PPE [...]

The doctor is telling 3's visitor that her mother can go home tomorrow with a package of care once they have a negative COVID test. Visitor is very anxious about risk of infection on the ward. The doctor repeats that the mother cannot leave until she has a negative test and cannot have a side room unless she has a positive test.

Site B, COTE, Day 11

This strictness could vary from shift to shift, dependent on the leadership team, and also from patient to patient depending on their compliance with isolation and being restrained, as in the example below:

I have a long chat with one of the RNs. and the discharge co-ordinator. I ask why the lady from bed 4 is moving around today. They tell me bay 1 is COVID contact whereas bay 2 is COVID confirmed. All four patients on bay 2 have tested positive so are fully isolated. The lady from bed 4 is allowed to walk around because containing her would be worse – she would get aggressive and then require extra restraint, instead of restraint letting her move around. Discharge co-ordinator tells me it is 'the lesser of two evils', if they made her stay on her bay it could be much worse, and adds that the lady from bed 4 also refuses to take a Covid test.

Site B, COTE, Day 12

However, by the end of the study, COVID stopped being a reason for imposing isolation, although patients testing positive for COVID were typically still restricted, with bedbound patients placed in side rooms with raised side rails, but allowed visitors providing PPE was worn. Isolation and restriction due to infection control still occurred, but with *C. diff* as the main driver. In the example below, a patient has been allowed to leave their side room but is being managed one-to-one on a unit reserved for other infection control patients:

Speak to the discharge nurse. 17 has gone home but she points out the lady sat in unit through the closed double door windows. She is sat at the secondary nurses station in a mix of robe and own night clothes. I am told she has 'Dementia and wandering but C Diff so has to stay on unit'. She should be in her room but allowing a degree of monitored movement while separate from other patients

Site B, COTE, Day 28

Implicit rationales for containment at the bedside

What we observed on these wards was the containment of the patient at the bedside, that is an embedded everyday and routine aspect of ward care, that it is rarely perceived by ward staff as a form of restrictive practice. Containment, and the associated one-to-one enhanced care, or direct bay supervision, required to enforce it, was not seen by ward staff as a restriction of the patient, something that would require legal frameworks to operate, but rather as a non-invasive means to protect the best interests of the patient. The rationales for the direct supervision of the patient, be it one-to-one care, a security guard, an enclosed side room, or a monitored bay, are not seen as a means by which to contain the patient but rather a means to protect them, protects others, and to safeguard the smooth running of the ward.

Best interest

The perception of the need for containment of the patient, and the requirement for continuous direct supervision, in whatever form it took, was, to the staff on these wards, always justified by the risk that a lack of supervision could pose to the patient, to others, or to the running of the ward. Without supervision the patient could fall, could get lost, could abscond, or could cause harm to themselves or others, regardless of their condition at that time. The fear of patients coming to accidental harm during an admission was clearly expressed in our conversations with ward staff were replete with stories, anecdotes, and moral tales, providing accounts of patient harm or near misses as rationales for the variety of one-to-one enhanced supervision observed:

Long chat with the ward co-ordinator. She wonders what to do with all of the one-to-ones, too many assigned and not enough staff. The lady in F3 is just lying flat at moment but apparently if she is left alone for a minute when awake she will stand up, but she is also very frail and limited mobility. If the coordinator removes the one-to-one and that patient falls then its a fracture and a long-term admission. She says that a few weeks ago they removed the one-to-one from a patient on B bay, and when the nurse went to the storage cupboard opposite the bay door the patient fell, less than 30 minutes after removing the one-to-one. Coordinator got the blame for making the decision. That patient was only 'an 8, so only borderline' [Ratings scale used to assess frailty and support need], and has to balance one to one with wider needs for staff around the unit. Typically each HCA has 12 patients which is a lot, and mostly unsighted because of layout of unit.

Site F, MAU, Day 72

While the rationales and perceptions of patient protections are clear in this example (avoid falls, avoid injuries, avoid long admissions), the patients' best interest is also measured against the best interest of ward staff, and that risk means repercussions, blame and liability.

Fear and liability

Some of these best interests' decisions focused on issues of personal responsibility. Nursing staff and senior ward teams had a palpable and clearly expressed fear of liability should a patient under their care fall, abscond, or hurt another patient. This fear was at both an institutional level, fearing reprimand from hospital management, and also at a professional and personal level, fearing paperwork, tribunals and loss of professional standing.

Nurse in charge logging exact times of interactions with 19, who has absconded from the unit and required security to be called. HCA really worried she is liable, Nurse in charge reassures her the other One-to-one carer responsible (who is from the mental health trust the patient was transferred from).

Site D, MAU, Day 59

The sister is very protective of her staff. She tells me she is glad violence has not happened but knows it contributes to the high use of sedation on the ward, 'what other options do we have?'. She mentions that they do not have support from dementia team 24/7, she likes them, but they work 9-5 Mon-Fri across three sites so never available when they need them. They know the checklist of things to do (videos, taking notes etc.) when someone is violent but that doesn't always work so they are stuck with few options. She tells me that too many of the new staff do not know how to one-to-one so same staff are assigned dementia patients, but this is hard work and leads to burnout, but says they cannot not do it, and once a one-to-one has been assigned has to stay as then the person who removed it is liable if the person falls, giving another example of a case I missed the previous week.

Site F, MAU, Day 89

This fear of liability exacerbates the ward cultures that meant once a person living with dementia was classified as needing one-to-one care, this must continue across an admission. Once a patient living with dementia has been assigned one-to-one care, be it through a care assistant, a security guard or a tagged bay, there will be a reluctance by the ward team to remove this across the admission, returning to the example from the previous section:

[A] few weeks ago they removed the one-to-one from a patient on B bay, and when the nurse went to the storage cupboard opposite the bay door the patient fell, less than 30 minutes after removing the one-to-one. Coordinator got the blame for making the decision.

Site F

This means that once a patient living with dementia had been assigned supervision, they continued to incur restrictive practice across their admission, with the one-to-one carer assigned to them following them as they were transferred through the hospital. Liability for one team ends at the doors of the next ward. This means that the one-to-one carer, in the example below a student nurse, will directly supervise the patient, at the bedside, then accompanied them from their ward, an assessment unit, to the door of the triaged destination, whereby the need for continued one-to-one care is expressed not just in the notes but in the embodied communication of the one-to-one supervisors presence:

It is lunchtime. Bed 2 is wheeled to the bathroom on the commode by HCA, who stays with her. We can hear doctors having a zoom meeting in the day room, and the domestics muttering about it, not happy as they want to go in there for their breaks.

While the HCA is waiting by the toilet, the nurse tells her not to let bed 3 go without her. She is given strict instruction to accompany the patient [who will go on her bed, side bars raised, with a porter] all the way to the next ward door, but not to go into the next ward, handover must start and end at the door. She goes into the bathroom to assist the lady from bed 2 and immediately a porter arrives and wheels bed 3 from the bay towards the doors. A minute later the HCA comes out and sees that bed 3 has gone. I let her know which way they went and she dashes after them, catching up at the lifts.

Site F, MAU, Day 68

In protecting staff and the ward from liability, the person living with dementia becomes a liability, and the management of this risk reclassifies them as needing restraint and containment throughout their admission.

Compliance and non-compliance

The containment of the compliant patient is somewhat paradoxical as their compliance within the ward, their classification as a compliant patient, is founded on the basis of self-containment. The compliant patient is the patient who either understands the ward, requires them to remain at their bedside and follows these rules, or is unable to challenge the rules and expectations of the ward due to their condition. This conceptualisation of the compliant patient leads to an almost paradoxical application of restrictive practice within these wards. Restrictive practice is not required should the patient understand the needs of the ward and stay in bed. For any other patient restrictive practice, typically one-to-one care, will be applied to enforce this action and protect the ward.

The routine use of one-to-one enhanced care highlights the many ways the lack of resources and options staff recognise or feel are available to them. There were many forms of non-compliance, but all were initially managed in the same manner. The patient who was independently mobile and energetically walking about experiences the same restrictive practice enforced as the immobile patient deemed a falls risk, or at danger of removing medical equipment (cannulas, catheters). While mobility and immobility are at opposite ends of the spectrum a physical ability and independence, both were managed through the application of one-to-one enhanced care to maintain the patient at the bed or bedside, as in the example below:

On S bed 4 has now gone, S1 is one-to-one. HCA (same HCA who is always assigned one-to-one) is sat at his bedside. Could not see before as they are tucked in between wall and bed, invisible from corridor. His chair is also on this side of the bed and he can sit or walk a couple of steps along his bed but is otherwise blocked in by the seated one-to-one and her computer trolley. He is stood in hospital pyjamas, blocked in by the computer trolley. They bicker, she tells him not to shout at her, he loudly complains to her that he hasn't. He sits back down in his chair, contained to the area. [...]

I3 is the same patient as yesterday, previously very vocal, shouting a lot. The one-to-one carer assigned to her is agency [unusual for this ward] and is wearing the same-coloured scrubs as the nurses rather than the other HCAs. I3 is awake today, the bed has been raised high, and she is propped up, the bed at angles like a large raised seat. Side bars are fully up on both sides. She is complaining to her visitor about what a horrible place this is - 'get me out'. He tries to tell her that if she can eat her food she can go home in a couple of days. She ignores and continues to appeal for home - 'get me out'. I3 does not look like she could get up, but she is getting louder though, I can hear down the corridor now, shouting to go home.

Site F, MAU, Day 77

Staffing and ward management

The everyday nature of one-to-one enhanced observation as a form of containment means that for many wards in the acute setting it had become essential for workload management, and that by placing HCAs at the bedsides of patients with dementia that may otherwise require attention the ward was free to deliver routine tasks required of staff away from patients bedsides, as in the example below:

09:15. Lots of doctors talking in the corridor outside of bay 6 but rest of unit is very calm. Most are patients in bed. There are four patients with dementia today. One seems to have capacity and lives independently, wants to get home to his garden. Two patients on bay 6 have dementia and are flat in bed, side bars up, a HCA is with bed 32. There is no clear risk from patients this morning so nursing staff are being told to prepare for upcoming audits. They are doing jobs like charging devices and clearing the corridors rather than rushing around for patients. Lots of doctors talking in corridor outside bay 6 but rest of unit calm. Most patients in bed. 31 is in robe, has side bars up now. One-to-one is behind curtain with 32, unlike with 6 and 31 I cannot hear her responding. When curtains open she is awake and being spoon fed breakfast, sidebars up, nurse leaning across the bedside.

Site D, MAU, Day 49

An issue with this approach can come at the extremes, such as when staffing is low and auxiliary or supernumerary staff involved in one-to-one enhanced care or bay tagging are linked to a patient. At this point decision that may be in the interest of the patient, for instance a transfer to another ward, is triaged to other patients so that the hosting ward can keep the extra supervisory staff for another shift. Similarly, questions will be asked as to where a one-to-one is if relieved and this creates further work for the ward team, as in the examples below:

15:45: HCA says 'Shouldn't she have a [Security Company]' to which RN replies 'She had one overnight, don't know where they have gone'. The patient is blocking the door so the Matron comes over guides a visitor out via the sluice room fire exit.

Site D, COTE, Day 18

The example above was symptomatic of the very real staffing pressures experienced by all of the wards, and how restrictive practice in the form of requesting staff for enhanced observation becomes an organisational tool to make this institutionally visible.

Speak to senior nurses. Both say just wish had more staff. A couple more nurses and HCA join in and say could talk to all the patients & have fun with them, can't be where they need to be.

Site B, COTE, Day 22

What is clear through of all of this, despite the rationale, was that while to the ward one-to-one enhanced care and unseen everyday practices of restriction have both rationales for the patient and the ward, for the patient themselves the impact can be highly significant, and a negative experience, as expressed by the patient below:

This is absolute torture, I am being tortured, I have done nothing wrong

You have had a chest infection, you are in the hospital to get better

Thank you, you are the first person to tell me that ... There is just nowhere to go

She trails off, sounding dejected and bored. A few minutes pass before she starts to complain again, constantly returning to similar issue, wanting to be at home, not wanting to be here, about her family not visiting, about not getting breakfast.

Site B, Day 5

In the next section, we will explore the impacts that restrictive practice can have on patients living with dementia, as in the example above, and also the impacts on the staff delivering restrictive interventions.

The impacts and consequences of the use of restrictive practices in the care of people living with dementia

In the previous sections, we have outlined how PLWD were subject to a wide range of restrictive practices, often experiencing multiple forms of restraint during their admission. The patterns of restrictive practices used also varied within and across these sites. However, the impacts experienced by PLWD within these wards and subject to these forms of restrictive practices were similar across all the wards and hospital sites. We identified a range of impacts of the routine use of restrictive practice on PLWD, on ward cultures of care, and on ward staff.

For PLWD, the impacts of restrictive practice included:

- Emotional impacts, expressed by PLWD as feelings of dread, fear, sadness and distress.
- Experience their admission as a form of imprisonment, as being held as a prisoner, being held captive, in custody, or as a hostage.
- Cumulative impacts, over time, with the use of restrictive practice across an admission usually accompanied by increasing the person's emotional distress and their visible physical and cognitive deterioration.
- The use of restrictive practice during admission was also highly distressing for care partners and families.

The use of restrictive practices also informed ward cultures, fostering the experience of an admission as one of loneliness, isolation and disconnection and increased the inequalities in care experienced by PLWD within these wards.

Ward staff often described feeling inadequate to provide appropriate care and recognised they lacked the skills to support PLWD, also experienced a significant emotional impact from using restrictive practices in the patient care.

The emotional impacts of experiencing restrictive practices

For PLWD, the experience of being subject to restrictive practices was highly emotionally distressing, taking a significant toll on their well-being. Across all wards and sites, it was common to observe PLWD experiencing a strong emotional response to continually being subject to the use of restrictive practices in their care across their admission. This emotional distress was typically cumulative, increasing over the length of their admission and was expressed by people with dementia as feelings of dread, fear and sadness. However, these were typically understood by ward staff as features of their dementia diagnosis, requiring further restrictions and containment.

We found that elevated levels of distress were not confined to individual or a small number of patients within these wards, but was widespread, reflecting the experiences of an admission for PLWD. Across all wards and sites, it was common to observe PLWD experiencing a strong emotional response to being subject to the ongoing use of restrictive practices in their care across their admission, albeit in different ways, or in response to observing restrictive practice on others. Feelings of hopelessness and powerless from the impacts of experiencing repeated verbal commands from ward staff not to move or to return to their bed, through to staff not responding to their calls for help and support.

Many PLWD talked within the ward of how upset and angry they were at being held in circumstances they felt were against their will. They expressed confusion as to why they were being held in hospital without receiving explanations about why their treatment had been changed or why they were not allowed to leave and go home.

For example, an 86-year-old woman living with dementia described by staff as a high risk of absconding is on the ward due to safeguarding concerns following a fall. She cannot make sense of why she is on the ward, and she has been angry and upset with her husband each time he visits. Despite her diagnosis and mood, she is highly aware and articulate. She feels he has neglected her and left her there, allowing her to be held in hospital so he can have the house to himself. Refusal by the ward staff to let her go home is even more perplexing: 'everyone is holding me in here for no reason'. Her distress at being 'abandoned' here increases over time:

'I have accepted being on the Ward. I feel that though I want to go home I can stay in for a bit [...] It's because I have never understood the system and how it works. I have had a new pill, and I didn't think It was useful. but if they stop giving me Lorazepam I get these feelings and moods. But no one explained I was on Lorazepam. and why I was given then I don't I

know. maybe it was to calm me down. Now I have been taken off then and now I am back on them. I can't keep up and they didn't tell me you see. It annoys me, I wish there was someone to talk to me and tell me what's going on. They think that if they have done it on the machine then it's okay. I know I need it because it relaxes me. I don't take it often but for bedtime. They don't want me to be hooked on it, so they try to stop you taking then in high closes. cause you can't drive. But then I am here I can't go home, and my husband has abandoned me. I am on my own and everyone is holding me in here for no reason. Its infuriating and upsetting we live in a free country but now see the state I am in. I can't wash or change, and I am living in this tiny messy place. Look at the state of this hotel. Look'. Shakes head and wells up...

Site B, Day 16

Feelings of being imprisoned

It was extremely common for PLWD to experience their admission within these wards as a form of imprisonment. During our observations and interviews with patients, they typically likened the ward to a prison in which they were being held or were being held captive, in custody, or as a hostage. We also found that PLWD often responded to being within the ward as an inmate, talking to each other about how they came to be here, and sharing plans to 'escape'. This was to some extent a rational and reasonable response to the ward environment, which was reinforced by the routine use of restrictive practices, the locked doors, the verbal language used by ward staff of command, the institutional tone of voice, and the routine presence and use of security guards (wearing full tactical uniform) in their care.

This experience is clearly explained by a 78-year-old male patient, living with dementia, who has spent 5 weeks on the ward:

I don't like the idea of being here. I am being held here and I feel stuck. I don't know why I am here [...] I think I am here because someone thinks I should be on the ward. I want to know when I will go home. Is it today, tomorrow next week? ... Stopping in the ward is affecting me mentally that much. ... I want to go home to see [partner]. it's like I am in police custody here.

Site B, Day 16

The language used by ward staff of commands and tone of voice was exacerbated by the presence of close surveillance and shadowing in the form of enhanced observation:

The HCA tells two patients to move away from the door. 5 gets cross saying 'it's a joke I can't be allowed to go out and walk her dog' One-to-one calls them back 'come and sit with me' 23 follows but 5 walks off, irate now, talking to herself. no one follows.[...]

5 is standing at the intersection of the two wings shouting about. 'being detained against my will. No one cares about my dogs and my liberty. I need to go and take the dog out'.

In this instance, the distress and the negative impacts it has are recognised by staff but not acted upon, as if there are no other options or tools available to them:

SHO 'of course there is an impact being kept on the ward and especially the use of security guards. That's why they can't go home. This place just deconditions them. They get worse and discharge is delayed'...

Site B, Day 29

It was not only PLWD who viewed their admission as a form of imprisonment, but visitors and relatives often referred to the person remaining within the ward as a form of restriction that contained a person in place much like in a police or prison cell. For example, this daughter at site D felt her father's condition has deteriorated significantly following 2 weeks of being isolated within a single occupancy side room, a ward environment 'akin to a prison cell':

...being kept in here in bed would not benefit anyone. not even I would survive. I have not seen him sit up or walk since he was brought in here ... He has these rails on the side, I know it's for safety, but It means he can't get out of bed without help. It's limiting and restricting but you know staff want to reduce falls and injury on the ward but when all you have all

these four walls it would break even the strongest of persons. The admission is a kind of restriction because he can't walk or do what he wants.

The use of restrictive practice also resulted in staff viewing these wards as an institution that required patients to conform to the expectations of the ward. For instance, this HCA resorts to calling security and also 'pretends to call the police', with the security guard then presenting himself as police to manage the person, escalating to allow coercive administration of sedatives to ensure this patient will 'stay in one place'.

[H]e was refusing and was very abusive and kicked at me and the nurse he was using the F word and called me a bitch. he couldn't move or let us change him. He was agitated any upset, we had to call security. I pretended to call the police and that set him off again as he worried that he may be taken away to prison or something, but when the security came he was still not behaving. One of them presented himself as police and he calmed down saying he will take his meds and change.

[...]

HCA: He was given lorazepam and the other usual' meds but I think he was given something else ... I need to check with the doctor. I am not sure what it was.

[...]

You can see he is still up and down very stubborn. He is really difficult. he is so restless. up and down all the time and he is at risk of falling as well, so he needs to stay in one place. But no, he never sits.

Site F, Day 82

Containment at the bedside

While the physical and cognitive impacts of sedation across an admission are highly visible, there are also notable impacts from less overt form of restraint. For many PLWD in hospital, restrictive practice meant they were being contained at the bedside, and with that the boredom and isolation of sitting in bed without stimuli for extended periods of time, not just across a day, but over an admission, which typically last weeks and often months, with significant uncertainty of what was to follow. The restrictive practices of containment and the monotony of life on these wards foster experience of an admission as one of loneliness, isolation and disconnection.

The lady from bay E is clearly bored again, she wants to leave the ward. I have not seen her for over a week but nothing has changed. She wants to know when she will be leaving and why she can't make a phone call to a relative. She leaves the desk and heads back to her bedside. I suggest to her to use the day room.

I don't like it there it's too quiet and I like to be around people. No one else sits in there, it's boring and can't have a conversation with anyone

Site F, Day 63

The monotony of these wards is understood and recognised to some extent by the hospital institution. Within all the wards we observed, there were examples of technologies and environments designed to engage with older people and in particular those living with dementia. For example, one ward had a faux pub and film room, another had day rooms designed to look like a hair salon and an American Diner, one had a bus stop set up at one end of a corridor. All had a range of resources that could be used at the bedside (games, picture books, drawing materials, jigsaws etc.) or within the bays. However, these resources were rarely, if ever, used.

The lady from bay one is sat in the day room, closely watched by a one-to-one private security guard, she is in a robe, he is in full all black uniform. They are sat looking bored, they are not talking to each other, they have not turned on the TV or the turntable, They are just sat looking out of the window at the walls and windows of the hospital quadrangle.

Site B, Day 8

In this example above, the room is being used, not to engage the patient, but as a means of allowing the continuation of containment and restraint via the assignment of a security guard. This approach means patients who have used these spaces view them with distrust. They are used as a means of distraction and containment of patients who cannot be contained at the bedside, but who must not 'wander' or leave the ward. The impacts of this approach for the patient were one of further isolation and disconnection.

We highlight this seemingly ordinary aspect of the ward because the emptiness and neglect of these spaces and resources are indicative of the high levels of restrictive practice in the everyday life of PLWD within these ward settings. Cultures of restrictive practice meant patients were contained in beds, side bars raised, staring out at nothing, despite the existence of available stimuli. Strikingly, this meant care and stimuli were delivered in exactly the same way in settings that lacked resources, such as the units at site D, as on well-resourced wards with dayrooms, gardens and facilities at site B and F. Rationales of safety, the risk of falls, of absconding, of patients being unobserved, mean large cohorts of PLWD were instead contained at the bedside for days and weeks with no opportunities for rehabilitation and little to no stimuli:

Both bays remain very quiet. No TV or radio can be heard, lights off, beds flat, side bars up on both sides of all beds. The lady in bed 19 is awake and looking around but none has spoken to her, nothing to do, it's very quiet & very boring. Only noise is the wind loudly rattling through windows [...]

Speak to SHO, she talk about how few DoLS are in place currently, says they have been on a good run recently. She says she also does orthopaedics at another trust and the use of DoLS is much worse there. We joke about it being a boring ward, she adds that being bored is a bonus sometimes.

Site B, Day 13

Today is boring so far, very little patient movement or engagement. All of PLWD are in bed, all but one are in hospital robes on, and are laid flat in bed with both side bars raised. These patients have no interaction or engagement outside of care and observation. There is no stimuli, no TVs on bays or rooms, no radio in the corridor, no volunteers or trolley service, no newspapers on tray tables. The unit feels very isolated and boring. Time is dragging for me, let alone the patients.

Site D, Day 36

So far it's typical containment today. One of the four ladies on the bay is being assisted to toilet by a HCA, who is watching the whole bay. The lady gets up super slowly and then darts off once on her feet. The HCA has to ask her to stop and wait as she moves her computer & chair out of the way. With the patient on the toilet the HCA comes out and tells me it has been hard today. One patient has only just calmed down having been very agitated from bed all morning, and the other two both like to get up and move about. She sighs when I tell her that everyone on the next bay are all asleep. While this bay has three patient that are very alert and active, plus the bay tagging HCA there is no engagement. They are not talking to one another despite their very close proximity to one another on a small four bed bay. There is no TV to watch and no radio or newspapers. It looks and feels really boring.

Site F, Day 68

What was more common to see was that when hospitals could offer resources to engage with PLWD, the ward would prevent them from doing so. At one site, various weekly activities were provided for patients, from visiting musicians to engagement with animals. Unfortunately, due to the over-riding rationales of safety, risk of falls and, in particular, risk of absconding (a perception that patients would flee into roads should they get past the ward doors), people with dementia were not taken to engage with these activities and events. Perversely the patients living with dementia remain on one-to-one enhanced observation or bay tagged at their bedside, while ward staff went to engage with the therapeutic activities of that day.

Domestic tells me there are therapy pets 'outside' – rabbits and chickens. Go back out of the ward and down a long corridor and past a chapel – it's a largish church on the site, numerous people sit in praying, quiet contemplation. Past a narrow garden I am directed to a petting zoo with three large chicken/hens ('Beyonce, Arianna and Taylor are being handed around to hold) and several large rabbits. Each are surrounded by doctors and nurses. The fire doors on bay A,

B and C leads directly to it, but all are closed, only staff and one patient from another ward accompanied by their carer (wearing carers passport in a lanyard around neck) are present with the animals.

Site F, MAU, Day 82

When PLWD were engaged with these activities, it usually required the specific intervention and support from a dementia team within the hospital. However, the behavioural expectations of the institution in how to engage with these activities could quickly lead to the reinforcement of restrictive practice of the patient and admonishment for staff, as in the example below.

*On Friday they had a 'therapy donkey' brought in for [Ward X], placed in the garden on the ground floor. Three referred patients were collected by dementia team. One of the volunteers suggested one further lady and was cleared by the consultant. When the party of patients living with dementia arrived at the ground floor the additional lady refused to come out of the lift. In blocking the lift this became an issue that involved multiple passing non-specialist doctors trying to help, and three members of security being called who eventually took the patient back to her ward where she continued to be 'agitated', the dementia team were then given a 'b*****ing' by the nurse in charge of [Ward X] for taking that patient with them.*

Site F, Day 74

These examples reinforce that, with or without restrictive practice, the expectation of the ward was for people to be contained, but not that they should be stimulated, engaged with or entertained. The expectation was that the person living with dementia will be content to sit still and to conform to the requirements of the institution.

Restrictive practice and staff well-being

It was common across all sites to observe staff experience the emotional impacts of restrictive practice. This was often the case when the intervention elicited a strong or distressed response from the patients. For example, following over an hour working one-to-one trying to restrict a patient who was attempting to leave the ward, which involved staff using the routine established approaches of standing in front of exit doors, body blocking, and redirecting patients to other parts of the ward, a male HCA in his late 40s could not hide his feelings and the emotional exhaustion he felt following these interactions with patients. This is illustrated in the fieldnotes below:

The HCA comes by. He has been shadowing 17 for a while today and has heard how we talk about his shift so far and seeing and hearing. Says 'I have to be honest and say I have found today a bit stressful and exhausting. Emotionally. 17 is not very happy today and has taken a dark turn its sad you know. I have worked on my own with 12 patients. on my own all day on the wing and it's exhausting. and all of them have been at risk of absconding and needed very close checking. we talk coping mechanisms says staff useful help and to laugh and find joy in the midst of the madness...'

Site B, Day 16

For ward staff, it was also the emotional impacts of administering both physical and chemical restraint. A senior house officer (SHO), female in her mid-30s, reflecting on times she has been involved in administering chemical restraint to patients who were considered disruptive and at risk of harm to self and others, described the emotion as 'heart breaking', 'hard' and 'very emotional'; this is illustrated below:

SHO reflects on the experience having to apply and use DoLS on very aggressive patients in other wards. 'we often use nonpharmacological means first. Often this involves talk therapy and if this does not work, we then we administer pharmacological interventions'. 'Normally we have to ask patient consent to administer anti-psychotics. This is because most anti-psychotics usually have to be injectables if patient can't take them orally. If patients are unable to consent, then we have to hold them down to administer. This is very emotional for both staff and patient. I mean it's very hard to make decisions to force a patient to give sedatives to patients who are aggressive. Of course, it is for their own good and safety. but even then, it's so heart breaking but it has to be done. As I said often, we first offer talk therapy first, most times it works but does not always work because sometimes you just can't get through to some patients who are in distress.'

Site B, Day 10

Others talked of 'feeling bad' having to subject older people to such interventions. Reflecting on having to administer chemical restraint and involve security in the care of older patients, a male charge nurse talked of feeling stressed having to administer such interventions to older patients. She paints a stark picture of the high levels of threat she fears and experiences, the 'aggressive and violent' patients within the ward.

The people you see in bed during the day as angels are horrible at night?

You should come see us lock ourselves in offices while we wait for security. This happens all the time. we sometimes have to lock ourselves up as we wait for security because some of the patients can be very aggressive and violent

So how does the use of restraint make you feel?

obviously safer than before the incident but of course it depends on use of security guards means I don't have to deal with them but sometimes we have used medication to calm them down, it can help. it just is stressful having to deal with it all. But also, sometimes you feel bad having to subject an older person to such measures.

Site B, Day 19

Ward staff, such as the nurse in the extract below, often described feelings of inadequacy by not being able to provide appropriate care and instead implementing restrictive interventions. That they continue to utilise these interventions despite the distress they cause highlights the limited toolbox they feel is at their disposal.

[I]t's hard doing his job, it's emotional even more so in the morning not best way to start your shift. I find it I lack the skills needed to work in this role to keep the patients controlled. The mental health nurses know what to do. I think they have specialist training. We do not. couldn't do what they do. I feel like I lack the skills needed to work in here to be honest because the patients are challenging and difficult to engage...

Site F, Day 82

In the following section, we look at examples of where wards were able to offer alternatives to restrictive practice, how they could de-escalate the needs for restrictive practice, and the ward cultures that can prevent this from happening.

Good practice and de-escalation

While the use of restrictive practices within these wards was 'what we do here', with the behaviour of PLWD something to be contained and restricted to minimise risk to patient and staff and embedded within the care cultures of these wards, this was not always the case. We identified variability from ward to ward, influenced by both ward leadership (site B) and by individual members of staff (site D and F). However, a key limitation with this finding is that ward leadership operates on a rota, so when a leader who allows for and promotes engagement and de-escalation over the use of restraint is off shift, we observed that this ward quickly reverted to a cultural mean that utilised practices of containment. Similarly, where an individual nurse or HCA tried to promote engagement and movement in a culture of containment, ward leadership could quickly curtail this. In this section, we will explore how these cultures of containment remain dominant, while demonstrating the impact of challenging them.

Enhanced care

Almost all of the data examples within this section involve patients living with dementia for whom a process of restrictive practice has begun, typically with the application of one-to-one enhanced care. As we have seen, this practice varied from site to site, from 'enhanced care' in place alongside requisite legal frameworks, to informal 'bay tagging' covering supervision of a whole patient cohort. In everyday care within these wards, these approaches typically led to a cycle of escalation as these patients were increasingly limited, required to stay in a bed or in a limited space, to minimise their risk of falls, absconding, or violence. This pattern was widespread and with predictable impacts of one-to-one care; however, this does not have to be the inevitable outcome. Within this section, we demonstrate how one-to-one enhanced care can be used to support mobilisation, engagement and de-escalation, reducing distress and allowing for the relaxation of the use of restrictive practice rather than the tightening of these practices in the care of the person.

In the example below we see a patient living with dementia whose behaviour has escalated to being assessed as requiring the outsourcing of their one-to-one care to a security guard, quickly de-escalate through engagement. Not only does the nurse engage with this patient, but she also seems interested in the patient's responses and responds accordingly. In this instance, the nurse uses the resources available to the ward, such as the day room and make up, which otherwise would be overlooked:

3:10: The lady from bed 3 is stood in the corridor near reception. The one-to-one carer is behind her but talking to a male visitor. 3 speaks to one of the nurses, complaining that someone has taken her place, pointing at the bay. The nurse cheerfully changes the subject, asking 3 by name who did her hair today and tells her it looks great. She checks her nails and says she has been picking at them, they talk about nails for a bit and why 3 picks at the varnish. The nurse then offers to fix them for her. The kitchen porter walks past and joins in, 'do you want a cuppa [name]'. The nurse and 3 head off down the corridor holding hands 'you have got your good trousers on today, not those pyjama things you had on yesterday? I think they were ours'. They walk together towards the day room. 3 takes a seat and the RN kneels down in front of 3 and starts doing her nails, offering her all the colours and talking through what she is doing. I speak to the one-to-one [male security guard] 'she just moves around a lot, need to watch her... she is going home soon... happy today because daughter has been to see her'.

The impact of this is significant. The patient in question has been within the ward for several days and has until now been contained or accompanied at all times. In engaging with the patient, this is reduced. More surprising is the impact this has on the wider ward. Other staff were unaware that they would be allowed to do this, that this kind of engagement with patients living with dementia is permitted within this ward:

3:20: The lady from bed 3 is back at her bed, she seems much happier now, staff seem happy too and are drifting back to their various jobs. In the nearby side room the staff are all talking about how happy she is now. The nurse in charge shows the HCAs where the make-up is kept: 'Are we really allowed to do this' she says, then she is off, enthusiastically going around the bays offering patients their nails done. She includes patients who otherwise look unresponsive, and it is surprising seeing a patient who has barely moved sit up or offer out a weak hand, and the smiles that follow.

The impact of this sort of engaging practice, in place of cultures of containment, is significant, not only from the responses of patients but also for the ward staff delivering care:

One of the nurses is trying to get into the treatment room because patient 19's blood pressure is spiking, but her card still doesn't work. She needs the other nurse, but does not know where she is [she is painting nails in side room 5]. When they find each other, the nurse says 'that was the best half hour of my career that'.

This approach also signals a loosening of controls within this ward more generally, the relaxed interactions leading to relaxed behaviours for the patients:

The nurse goes into the side room: 'I've got a nice colour for you [name]'

The one-to-one carer leaves the bay leaving the lady in bed 3 alone and unsupervised, but she does not move from the bed.

Another patient from a side room comes to reception and tells RN1 they are going down to the M&S to get things, the nurse agrees and closes door to her side room.

The impact of what became only an hour of engagement across the whole ward resulted in a notable change of atmosphere within the ward, which felt more relaxed and friendly, and had a longer impact afterwards. The smell of acetone aside, such interactions had the other patients (all female) showing off their newly painted nails to one another, and beginning conversations across previously quiet bays. The nurse in charge seemed unsurprised at this, but was clear that they were not always able to deliver care in this way:

'We all know what the patients want, but we never have the time to do it'. Today they have enough HCAs that they can spare one to go around doing hair and nails, which makes the patients happy which makes things easier for the other staff

as they do their rounds. They say happy patients mean happy staff. They go off to do scheduled turns and checks, the times signposted on the door to each room and bay.

Site D, COTE, Day 6

While this example focuses on 1 day within one ward, it was not the only example of engagement working as a means to achieve de-escalation. Responding to distress with engagement and mobilisation had positive impacts across these ward sites as a means to prevent the escalation of distress. At site D, for example, some of (albeit not all) the HCAs seemed aware that it was easier to accompany a patient to walk up and down the corridor than it was to keep the person at the bedside, although with little in terms of engagement or entertainment considered or available beyond this:

Speak to the senior HCA. He tells me that the lady from bed 13 has been great today [Was one-to-one yesterday and contained to the bedside]. She wanted the toilet this morning so mobilised her, walked with holding hand, then her neighbour visited and she has slept. He says at home she walks all the time so keeping to bedside is upsetting for her. Safe for her to walk now so would enable and walk with. Tells me that if he has to walk up and down the ward 1000 times that is the job, it's all about relationship building & walking helps that.

Site D, MAU, Day 42

An issue noticeable here however was that this HCA, a confident and well-spoken male, held considerable influence over senior staff, and was a champion for mobilisation. Not all staff, especially the HCAs and security staff assigned to one-to-one care, had such privileges in their relationships with nurses and senior ward staff. As in the earlier example, we found ward staff who did not recognise they had 'permission' to engage with patients living with dementia in any way, or, when they asked to provide this support, were denied it by senior staff:

Speak to one-to-one [male HCA] outside of the side room. He tells me yesterday the patient 'exploded!' [gestures hands from head, fingers spread], shouting he wanted to be outside, but the nurse in charge wouldn't let him take him off the unit. Today they have been allowed and went for a walk together around the front of the hospital, the patient has since been happy all day, thanked the one-to-one for 'serving him' when he brought breakfast and lunch. One-to-one clearly takes pride in having done this and having calmed patient and built rapport, repeatedly states that the patient is happy now, not a problem anymore.

Site F, MAU, Day 84

This relationship with ward leadership was integral to the ability of ward staff to implement strategies to engage with and de-escalate distress in their patients. In the example above, ward leadership recognised the benefits of mobilisation and engagement as a means to de-escalation, but felt this did not outweigh the risk of falls and violence towards staff, meaning cultures of restraint remained the norm:

I mention the lack of movement to the senior nurse, but she points out that many of the patients here are simply too ill to move around. She has a real fear of patients absconding, discussing how the fire doors at one end of the unit lead straight out on to the main road and the main exit of the unit also quickly leads outside. They asked last year for a sensor alarm for the rear fire door but were told there were no funds for it. She tells me when patients can move it can be tricky, last week one patient got off the unit twice and tried more, distracting staff by requesting cups of tea then dashing when their back was turned.

Site F, MAU, Day 89

These cultures of control and risk management seem well established within everyday nursing practice. If we return to the first example of the ward with the use of nail varnish, the practice of supporting movement and mobilisation continued when the matron and nurse in charge were present, but when they were not on rota, the culture within this ward shifted and quickly returned to patients contained at the bedside, or in bed with bedside bars raised, wearing hospital-issued pyjamas in place of clothes:

The lady in bed 18 tries to get out of bed. The HCA stops her 'you have to stay in bed, let's get you sorted'. He adjusts her and reasserts side bar, lowering then re-raising it 'you'll have your lunch soon'... 'should I move your table over...' 'do you want to be lifted up'. 18 is still in a hospital robe, 'let's get you straight, you're not straight'... 'you have to stay in bed love,

do you understand, would you like another pillow'. This lady normally gets dressed and sits in her beside chair, she is mobile and continent and can go to the toilet by herself, why must she stay in bed?

The ward is so boring today time just drags. The TVs are turned off, there is no interaction. Even the radio is off now, everyone just awake in bed in silence,

18 is trying to get out of bed again. 18 has sat up and pulled her legs around but trapped by the side bar. She has pressed her buzzer but nobody is responding. Her legs are dangling from the bed and do not reach the floor.

Site B, COTE, Day 29

This swift transition from containment to engagement and back to containment was powerfully visible when observing care. In the example below, a patient who had been distressed is now happily talking to her one-to-one HCA, who speaks the same language and has developed a relationship with her.

HCA doing one-to-one, singing and dancing in front of her, calls the patient auntie. She is called to do 30-minute training but she says can't leave, jokes about taking with her as they sing and clap. The patient doesn't speak English but HCA speaks her language, (Farsi?).

Site F, MAU, Day 86

Ultimately, the HCA has to leave for training. On arrival at the training (in the patient dayroom), she is rebuked for being late, while the patient gets out of bed and begins attempting to leave the bay, being contained by the new one-to-one. At the end of the training, the staff joke about how boring it was, while the trainer proudly tells the matron how engaged the staff were. In the meantime, the patient has now been contained at the bedside.

Mental health wards for people living with dementia

Data collection included three dementia specialist mental health inpatient wards to provide a detailed examination of the social and organisational context influencing the everyday care of PLWD, to explore the ways in which restrictive (and alternative) practices manifest in everyday care, the organisational and interactional processes involved, and their impacts on patients and staff. Because these wards are also sites with expertise and established guidelines, protocols and reporting systems in the use of restrictive (and alternative) practices, the focus was not comparison, but to examine the potential transferability of alternative and good practice in the use of restrictive practice to the acute setting.

People admitted to these wards typically have a primary diagnosis of dementia,^{201,202} with high levels of physical illness.⁷⁹ These are sites where PLWD, typically with more advanced forms of dementia, are admitted for high levels of distress or psychosis²⁰² and are usually transferred from acute wards (anecdotally these teams report around 60% of their admissions are transferred from acute wards) when their behaviour has been perceived as 'challenging', 'disruptive' or 'aggressive'. As the nurse in charge of the ward in site C tells us in describing the population of these wards, few return home and most are discharged into long-term community care:

They are all acutely unwell, too unwell to be in their own environment, they need treatment and more understanding about their behaviour – long-term or short-term treatment, and to go home or long-term placement or a new environment because the dementia might not be able to be completely managed. They come in very unwell and to get them well enough to get them out, like all mental health wards. It's not usual for them to go home but a few do go home and are able to – others no.

Site C, Day 14

A goal of the study was to actively look for and understand what is recognised within institutions, teams, specialisms and roles as good practice in the use of restrictive (and alternative) practices, strategies drawn on to support PLWD, and their impacts on individuals, that can provide transferrable learning.

Legal frameworks within mental health wards

The main legal framework governing restrictive practices in acute wards is the MCA; however, within mental health wards the MHA 1983 could also be used and this was the main legal framework applied to PLWD within these ward settings. The MHA provides a statutory authority to detain patients – often known as ‘sectioning’ – referring to the different ‘sections’ of the MHA that can be used to authorise detention, primarily section 2 (admission for assessment for up to 28 days) and section 3 (admission for treatment, for longer periods) – and if people are detained it provides the legal authority (and protection against liability) for administering medical treatment for mental disorder without the patients’ consent, and for any associated restrictive practices. Clinicians working with the MHA must have regard to the MHA Code of Practice,⁹⁹ which provides further detailed guidance on the use of restrictive practices, including restraint, seclusion and sedation.

Patients may validly consent to their admission, but if patients do not consent but are subject to continuous supervision and control and are not free to leave the ward at will, then they are legally considered to be deprived of their liberty and there should be some formal legal authority for this. Clinicians must decide whether to authorise this detention under the MCA or the MHA. Clinicians often prefer the MCA DoLS to the MHA to authorise the detention of PLWD, particularly if their care needs are considered primarily ‘social’ (i.e. to keep them safe) rather than ‘medical’ (i.e. treatment intended to cure them), although practice can vary depending on which frameworks professionals feel more familiar with.²⁰³ Legally speaking, the question of whether the patient should be subject to the MHA or the MCA is closely linked to whether they are *objecting* to their confinement; the MHA is supposed to provide stronger safeguards for more resistant patients.¹⁸⁷ Objections should be interpreted broadly, to consider the patients behaviour, wishes and feelings (1A, para 5).¹³¹

Like the DoLS, the MHA is supposed to provide safeguards for patients, for example access to independent advocacy and the opportunity to challenge their confinement before a tribunal. Decisions about whether to detain patients using the DoLS or the MHA has implications for discharge planning for patients living with dementia. A patient who is detained under section 3 MHA when they are discharged is entitled to free after-care under s117 MHA. This after-care is jointly funded and arranged by the NHS and the local authority. Meanwhile, a patient who is detained under the DoLS when they are discharged has no entitlement to free after-care; their care needs must generally be met either through means tested local authority social care or through their own resources. Therefore, decisions about whether to use the MHA or the DoLS can carry significant resource implications for both the person living with dementia and the public authorities and can impact on discharge pathways.

Everyday recognition and use of restrictive practice

The use of restrictive practice was an everyday feature of care within these mental health wards and were routinely and explicitly discussed and used by staff within them. Importantly, restrictive practice typically took the forms of physical and chemical restraint that were also made visible within the organisational, legal and risk assessment frameworks used within these wards. The use of furniture, verbal commands and so on were rarely observed, if present at all within the routine practices of the teams within these mental health wards.

High levels of patient distress was a feature of this patient population, present at all times within these wards and as such was both recognised and accepted by staff as a feature of these patient admissions. Behaviour viewed as ‘violent’ or ‘aggressive’ was also expected by staff and occurred routinely during the shifts observed. Across the everyday work of these wards, there was an explicit focus on implementing strategies for individual patients and at the ward level aimed at limiting the potential for distress and reducing opportunities for this distress to escalate. This meant management plans routinely included de-escalation strategies, and team meetings including handover and MDTs explicitly discussed and routinely revised the appropriate use of restrictive practices and de-escalation strategies for individuals over an admission.

Staff responded to a person’s distress by focusing on utilising restrictive practice to support their safety and minimising harm to the person and others, but typically did not intervene or use restrictive practice until they assessed that point had been reached. In the example below, the team use restrictive practice in response to a patient becoming a danger to others, a fellow patient and two members of the ward team. Throughout this incident, although it was fast paced and they reacted quickly to protect the patient, their body language remained calm, working together in a co-ordinated

approach, and they move swiftly to either side of the person firmly taking an arm each at the elbow to walk her away from the situation.

P5 is wearing smart pants and matching top and has short salt and pepper hair. She has been walking in and out of the day room and back and forth in the corridor, occasionally coming briefly into the room and pointing at the HCA, becoming angry and then leaving again. She comes back in just as the HCA and P3 are in the doorway and trying to turn round and reach a chair. P3 is very wobbly and it's a tricky manoeuvre, she only has one hand on the chair and is very hunched over, the HCA is now taking most of her weight to keep her up.

It is very sudden and fast and violent as P5 passes them in the doorway she starts shouting and pointing at the HCA and is very angry, she lashes out and hits the very frail patient P3 on the back. As this happens a nurse comes in and with the HCA works together to get P3 into the chair and keep P5 at a distance. Once P3 in the chair they focus on P5 – the nurse and the HCA's body language is to keep their arms down and away from her body to keep P5 at a distance trying to protect the other patient. P5 again lashes out at the HCA, clings on the door frame and as she moves into the corridor lashes out at the nurse. It is a frenzy of lashing out and she lands a strong blow to the side of the nurse's head which knocks her face mask off and it falls to the floor. The HCA and the nurse quickly move forward in unison, they don't say anything but each firmly take one of P5's arms, one at each side holding at the elbows and walk her down the corridor to her room.

The HCA comes back into the day room to check P3 is ok. 'Que sera sera' they sing gently together. Later I ask the nurse if she is ok, she says yesterday she had bruises (from another patient) all down one arm and now she has a scratched and bruised face she is going to a and e to have this checked.

Site A, Day 3

Here the staff member remains calm and passive as he is hit repeatedly by this patient. Although her blows do not appear to have any force, the pinch he receives was clearly very painful. His response throughout was to remain passive and calm; his only intervention was to block her blows and stand in front of the door to the nurses' station to restrict access. He did not use further restrictive practice and the situation quickly de-escalates; she sits and immediately falls asleep.

A member of the team is one-to-one with E they are walking together along the corridor. She occasionally bangs the wall with her hand as they go. She suddenly lets out a piercing scream it is truly ear splitting as though she is being violently attacked. She then starts hitting the one to one carer, who stands there with his arms up to deflect her blows while backing away down the corridor towards me, I back away as well as she heads our way. She continues to hit him and he defends himself with arms up. She is very blank eyed as she moves towards us. We are now at the nurses station at the end of the corridor and she is trying to enter the locked nurses' station. He passively stands in front of the door and bars the way and she takes his hand and pinches his arm hard with both hands and does not let go. She says 'you are acting like a baby' hitting him repeatedly over the arms. Her blows do not seem hard, but the pinch was clearly very painful. She strides along the corridor and back again, sits in one of the chairs next to the nurses station, gives a loud yawn and falls asleep.

Site C, Day 9

Both examples above demonstrate the routine physical and emotional impacts for staff within these wards of being hit, pinched and shouted at repeatedly during a shift. This is challenging for staff who described this leading to a heightened awareness of the patients and the unpredictability of their behaviour. Here, for example, this staff member flinches when one of the female patients kisses him on the cheek. Although the kiss is unwelcome, it is tolerated; however, the flinch is of someone expecting violence. Another staff member intervenes and de-escalates the rapidly increasing frustration and fury of this patient with a hug and the distraction of an offer of a cup of tea.

'Waaagh!', there is a deep sound from the end of the wards it is primal. P clenches her fists as she heads into the nurses' station and goes up to the nurse M. He flinches as she reaches up and gives him a kiss on his cheek. He gets a wipe and cleans his face. P marches over and demands to be let out of the ward. The one-to-one carer standing at the door starts to guard it. He tells her 'no' in a gentle tone and stands in front of her.

GET OUT OF THE WAY, LET ME GET IN, I WANT TO GO TO THE TOILET

He shows her the toilet opposite the door and she then wants him to go in with her, he gently says no. She then refuses to go in and sees another staff member and cries.

In response, the staff member goes over and hugs P, a cup of tea?

*P then becomes very angry and marches back to her chair looking furious. 'SHUT THE **** UP' to the patient sleeping opposite.*

Staff member with her says – she is asleep, can I take your temperature?

P allow that and then curls up in the chair and falls sleep.

Site C, Day 9

As the nurse in charge states, the levels of violence and assaults within these wards meant staff could become distressed, remaining on 'high alert' during shifts. This discussion with a senior nurse highlights the focus of these wards on using the 'least restrictive option', recognising that this is not always possible.

Senior nurse – Lots of psychological input but we have to prioritise infection and safety. But it can be distressing for staff. Someone came up behind me and I flinched, I am on high alert. Yesterday was so violent we have had serious assaults. People with dementia are younger and more physically able. We want to use the least restrictive option but its not always possible if there is a risk to the self or others.

Site C, Day 8

There were multiple ways in which the use of restrictive practice was recorded and communicated within these wards. The Datix process was used routinely to record incidents of violence and any injuries, the intervention (the use of restrictive practice), outcomes and importantly strategies put in place to prevent or manage this. However, as the nurse in charge states, the level of incidents meant they were required to make judgements about which incidents to record, and for some patients and some shifts, this could become a process they continually submit Datix reports. The Datix was also utilised to make the work of the ward, patient acuity and staff distress visible to the wider institution. These teams also explicitly discussed communicating the use of restrictive practices to the person's family. Medications and any medication given covertly are regulated and the potential to request the use of covert medications was also explicitly discussed by these teams.

Visibility of legal and risk assessment frameworks

Legal frameworks

The legal frameworks governing patients and their admissions were explicitly discussed and visible within the everyday work of these mental health wards. It was a routine focus during the weekly MDT meetings and handovers and visible within the wards during routine care, particularly during medication rounds and throughout the shifts.

For example, during the weekly MDT meetings, the MDT including the ward and psychiatric team and allied healthcare professionals review and discuss each patient. This always included an examination of the legal frameworks applied in their care, as in these cases below, both patients have been 'sectioned', admitted within the ward under the MHA using section 3. They also noted when the 'section' expired and discussed the next stage of their treatment and the legal frameworks that would apply, the appropriateness of moving to a different legal framework (DOLs) for one person and of extending the section 3 for the following person. These discussions were part of the ongoing wider assessments of patients over an admission, such as whether the person's condition had shown improvement, if they had expressed that they wanted to leave the ward, and whether they had capacity to consent to treatment.

MDT (in activity room)

The team are discussing L and W

RESULTS

L-looking at her M. H. Act status, she's on a section 3. It expires in 2 weeks

T 3 in place

Her medication?

she's compliant with medication

Has she expressed a wish to leave?

No she's been asking to leave, but not shown an intent to leave

L-so not actively says if she wants to go or go home

J-no but she's not fully oriented, its not that simple.

L-think about doing a DoLS, she's a bit more settled.

let's review that

L-any feedback from?

anything else

no

ok

[..]

L Discharge?

We escalated several times but don't know what's going on with social care. Don't know what's happening.

I will also escalate. She is as good as we are going to get and could be (rhythmic banging on the door) a shame to lose that because she remains on the ward. MHA Status is expiring. Section 3.

Expiring in 3 weeks, still thinking MHA is appropriate. She is significantly improved, but I'd like to keep that in place. Still expressing the desire to go home?

-yes but not aggressive, they explained and if you explain to her she says it's her memory problems and she understands

she is more insightful, but still a question of her capacity to consent to admission. I will have a look next week.

Site A, Day 6

In the excerpt below, the team focus on the person's non-compliance with medication and potential other underlying health conditions [a urinary tract infection (UTI)] which may be impacting her health and may explain her behaviour. They discuss the legal frameworks informing her care (MHA section 3) and decide to renew this legal framework and keep her within the ward.

MDT

They discuss T

[rhythmic and insistent banging on the door]

How has T been?

Deteriorated and tried to lash out at staff a couple of times today, reported feeling cold and we tried to get her temperature. Dr said no concerns.

They discuss her catheter and the look and smell of her urine and consider she has a UTI.

Medic: 'no overriding mental health or psychotic health, we are not treating BPSD, we need a better handle on what is going on'

Medically fit.

She is on a rerun of Section 3 which expires soon, she's pretty non-compliant with meds across the board. She is under the mental health act but I will renew that over to the next couple of weeks.

Site C, Day 6

These discussions of whether it was appropriate to move a person from one legal framework to another did not appear to acknowledge the impact of this decision on discharge routes. Patients who are under section 3 when discharged are eligible for free after-care under s117 MHA. However, if they moved this person to be under DoLS, during their discharge process they will only be entitled to means tested local authority social care. Because dementia care can be costly, the decision whether to use section 3 or DoLS has huge resource implications for both the NHS and the patient and their family. However, these implications were not something that was ever raised within these discussions.

Risk assessment

The weekly MDTs was also a site where there was explicit risk assessment with a focus on the patient's mental health needs (i.e. agitation, distress), their physical health (i.e. falls risk) and the wider social context of their health (such as and care planning). At law, the use of the MHA should only focus on the 'mental health' needs of the person; however, for PLWD, their risk profiles are a hybrid of physical and mental health-related risks, and as such their care needs cannot be so neatly parsed into these categories.

Risk assessment within these wards was typically discussed and assessed through the framework of a CPA – *Care Programme Approach*.⁹⁹ Here the consultant psychiatrist, the nurse in charge of the ward, and occupational health (the physiotherapist is not attending this meeting) discuss the person's risk status, whether the person requires one-to-one observations or other approaches. The team are explicit in their goals, which is not to prevent the person from falling and completely remove risk, but to review and identify what increases their risk, what can 'minimise the harms', and promote 'positive risks' and 'promote risk taking'. The nurse in charge acknowledges the challenge of achieving this balance in practice 'we are caught between the devil and the deep blue sea'.

Handover meeting

They discuss P1, who is still on one-to-one and requires eyesight levels of observation

Any changes?

No

No behaviour?

Aggression with physio but apparently laughing and joking

CPA [meeting] this afternoon. It's about discharge

Its going to be a difficult conversation we can't stop people falling we can only minimise the harms

He hasn't fallen since on observations.

[...]

Next they discuss P2. Pretty much the same, still has risks with falls documented.

Same as yesterday, tricky, we are caught between the devil and the deep blue sea.

Yes, maximum dosage?

Still eating and drinking well

Mental state nothing overtly there, just supporting him

Falls review may pick up, put that in his care plan

Site A, Day 1

Below there is an explicit discussion of positive risk taking for a person described as a 'significant falls risk'. In response, they identified the cause of her falls (standing hypertension) and what increases her risk (agitation, attempting to use the toilet on her own, overconfidence in her abilities) and have put interventions in place to manage the risks (one-to-one carer observation, walking frame, head protector). The nurse in charge explicitly acknowledges that the role of the ward is not to 'completely eradicate the risk of injury' but 'must promote risk taking'.

MDT

The team discuss a woman at significant fall risk,

Nurse in charge: 'she cracked the back of her head open, we explained she has standing hypertension which causes falls, we are good at responding the falls and falls protection, its positive risks she's back up and down so good to keep up. That's the biggest obstacle today'

Presentation of falls starts as soon as she came in, for her the identification she's got postural hypertension, agitation, attempting to use the toilet we've identified what increases her risk and we have things in place

[Directed to researcher] 'They have a protector (helmet for her head), we have had it and didn't use it so we got it on yesterday and today. if agitation it is a challenge, every falls prevention is unique for each person. She has postural hypertension, fear of falls, unmet need, overconfidence in her abilities. People typically have a fall and then into A&E and then they are in hospital and come in here. Falls can be quite problematic and can cause lots of issues, but we must promote risk taking'

Site A, Day 5

Cultures of care to minimise the use of restrictive practice

A focus on strategies to support patients and reduce distress

These ward teams all focused on developing and delivering strategies to support and reduce distress in the person. Awareness of the distress patterns for individual patients and how to manage and reduce their distress during the shifts in terms of observation levels required and the early signs to look out for were routinely discussed and shared by ward staff during handovers and meetings. For example, in the handover below, staff discuss individual patients and the strategies to manage their distress, with one female patient described as having a tendency of 'targeting patients', while another 'needs to be redirected'.

Handover*Discussing Patient B*

Was level 2 but there was an incident. She can be good and can be very aggressive and verbally abusive, if good very good, but can target patients and not let them pass. Now [observation] level 3

Patient C

Sleeps most of the time, is a high risk of going AWOL, very pleasant, will want to go for a walk

Patient D

Advanced dementia, not even 60 years, completely abandoned, can be aggressive. Now settling here from hospital.

Patient E

Level 3 [observation], hit staff and given PRN, can be very agitated. Can be very down and will stay in her room. Can be very aggressive and thinks a male patient is her husband so needs to be re-directed.

Site C, Day 1

Within handover meetings there were also explicit discussions between the outgoing and incoming teams of how to respond to patient 'aggression', with a focus on the importance of using interactional approaches before the use of restrictive practice. Here the focus on ensuring one patient was supported by approaches that ranged from providing reassurance to a cup of tea. Only when one patient was described as having 'hit staff with wheelchair' did they administer PRN ('pro re nata', which means 'as needed') of a sedative (lorazepam).

Handover

Nurse in charge: 'Our happy family for today!'

Patient DH:

Calm and settled. Last night a bit aggressive towards staff. Threw things on the floor. Got her a cup of tea. Datix done. She was settled at bedtime. No PRN just reassurance given. Today just walking around no concerns

[...]

Patient C:

Last night agitated and hit staff with wheelchair trying to get into a patient's room. Used PRN lorazepam. Later she was calm and slept. Eating and drinking fine and apart from the incident was fine.

Site C, Day 1

During the handover the team discuss a patient, whose behaviour is concerning and is monitored using a behaviour chart. Here, the nurse in charge acknowledged that they do have the option to administer PRN medication in response to his behaviour but emphasises to the team the importance of being proactive and to focus on changing the environment to ensure this person does not become distressed to the point where this is required.

The team discuss B at handover

He is on a behaviour chart

Nurse in charge: 'Don't let him get to that stage, be proactive and tell the nurses we can use PRN but we can also change the environment'

Site C, Day 2

Strategies of engagement and flexibility of care

These wards all demonstrated cultures of care that promoted flexibility in the delivery of routine care and valued approaches that reduce patient distress by recognising and responding to individual need. These were all strategies to minimise the use of restrictive practice.

Compliance to medication for this patient population was a key issue for these ward teams and was routinely discussed as a key factor in discussions of the progress of a patient at MDTs. Importantly, staff administering medication were more likely to take an approach to patient medication compliance as something they would encourage but did not view as essential or indeed possible to achieve, or as a task required to be completed in the moment. This strategy was described by a clinical manager as a key approach to 'keep the setting as calm as possible'. Even if care such as medication was viewed as essential, this was more likely to have flexibility in its delivery, with approaches used that recognised the needs of the individual, required their consent, and through an understanding of what approaches would best support them and minimise distress.

As in the excerpt below, staff within all these wards explicitly talked about the importance of taking time, when carrying out routine care such as medications and observation rounds focusing on the person and flexibility in delivery. They discussed the importance of maintaining a calm ward environment to support patients living with dementia.

We talk about the timetable of the ward and mealtimes and observational rounds.

Nurse: 'It doesn't work with dementia, they need time and space, you can't make them fit a medication round'

[...]

We've got to see people and its different for a new patient after you have the experience its trying to keep the setting as calm as possible.

Site C, Day 1

Within mental health wards, these routine timetabled rounds of care were understood as essential care, but also as care that must respond to the needs of the individual and thus takes time to deliver for PLWD. This meant that routine care such as the medication or observations rounds did not keep to a fixed task-driven timetable, but extended and often continued across a shift, with little gap if any between one round, for example the morning round and the following afternoon round.

Engagement strategies utilising reassurance and touch

Throughout our observations of routine care, these ward teams appeared attuned to the emotional needs of their patients living with dementia. Ward staff were all attuned to relational ways of working. They actively engaged with patients, listened to their concerns about what was happening and where they were, taking time to focus on the person and responded to their distress. This reassurance often involved touch, with the staff member holding the person's hand or rubbing their back or shoulders and encouraging calming techniques 'take some deep breaths'.

A focus on physical touch and taking time to support independence included recognising what is usual for the person, as in this case this woman routinely bangs on the wall, which is not prevented but recognised as a communication of distress.

P1 is a lady in pale blue top and dark trousers and slippers walks down corridor banging doors. A one-to-one is with her, holds her hand and hugs her.

The HCA adds to me 'She likes to bang on the walls as she comes down, I am used to it now if that's what she needs to do to get the feelings wide out then that's what she needs to do. Sometimes we are all sitting here and someone strips off in the room – anything can happen! There's things here I saw that you would not believe.'

Site A, Day 4

As we see in the example below, the team routinely suggest moving to a quiet area, occupation (folding blankets in the laundry and assisting with the tea trolley), calming techniques (deep breaths) and reassurance 'you are ok'.

P strides up to the nurses' station. The nurse says 'what can I do for you [name]?'

Its [Name]! (she annunciates her name loudly and angrily)

Nurse: That's what I said

She wants the one-to-one carer (who is with someone else) to go with her and he can't: 'I have to stay here.'

In response she starts crying.

You don't need to cry I have to stay here.

The nurse asks the team, 'does P have any PRN for distress?'. The other nurse checks in the medication room.

Nurse: Shall we sit somewhere quiet?

*P: **** OFF*

The nurse takes hold of her hand and they walk hand in hand down the corridor to the linen room where they fold blankets together

Nurse: 'it keeps her occupied'

[...]

Later I see them together. Holding hands. P says take some deep breaths.

Nurse: 'Sit here.'

P is Sobbing

The nurse rubs her shoulders and is crouching down in front of her. 'You are ok'

P jumps up and strides down the corridor, the nurse has difficulty catching up with her.

[...]

P is now shouting at the one-to-one carer guarding the door (the lock is broken) and then begins to march up and down the corridor.

One to one carer: 'Do you want to help me with the tea trolley?'

One-to-one carer holds P by the hand and they walk towards the kitchen. 3pm is tea time. The one-to-one carer holding hands with P is same the carer that P had screamed at and hit earlier in the day.

Site C, Day 9

Importantly in the example above, the team do not respond to this woman crying. Here the nurse in charge discusses the judgements about how to engage with the person and the right level of support to ensure they do not encourage emotional dependency. Here the nurse in charge discussed the importance of achieving this balance for the person and that this is always discussed by staff and is part of the patient's management plan.

Nurse in charge: 'it's a balance, all the time we take judgements about how engaged, under engaged, not good but over engaged is also not good to be under. A couple of ladies when agitated we are a lot closer because we know there is a risk to other people. Touch is important, but if ladies want that we need to reduce that – if used to having that support then it is detrimental to them. We communicate to each other in handover, for example handholding is thought out. It doesn't mean you can't hold their hand, it more a considered plan.'

Site C, Day 14

While these discussions also included orienting people to place and reminding people they were in hospital, this was typically only in response to their direct queries and requests by a person to know where they were.

Approaches to care that support mobility and independence

Within these wards, PLWD walking within these wards was rarely viewed as problematic. There was a strong ethos of supporting mobility and independence in this patient population, reviewing their abilities and emphasising approaches that could increase mobility and reduce dependence. This was supported by the secure nature of these wards, there was a reduced risk of people being able to leave these wards via the main ward exits, which were all airlocked doors.

Assessment practices informed approaches to care that supported mobility and independence. Here, during handover a senior nurse emphasised the importance of maintaining and improving patient mobility and independence, clearly stating to the rest of the team that on this ward 'no one becomes bedbound'.

Handover

Patient A Calm and settled. Ate and drank well. Awaiting urine culture results

Nurse in charge: 'How is this lady?'

Bed bound.

We need physio for a plan and we can take it from there

Nurse in charge: 'No one becomes bedbound on our ward. We work on it. We need the physio report.'

Site E, Day 2

Here the day room used by the male patients the team approach focused on supporting independence. One of the men A, who looks very unsteady on his feet, is encouraged to use his walking frame and is supported in walking even when he does not comply with their requests to use the frame, with the HCA walking with him and holding his hand, guiding him out into the garden and the fresh air.

Nurse in charge: 'it's a good day!'

We head out to the men's day room where 3 men are sitting in the high-backed chairs circled around the TV screen. This room has a door to the garden which is propped open with a chair and the men are encouraged by the team to go outside – it is a beautiful day. The fresh air comes into the day room on a breeze, it feels fresher and mingles with the cleaning fluid.

A, who is a very thin frail looking man, gets up from the high-backed chair. He looks unfocussed and leans slightly forward as he walks unsteadily. The HCA takes a walking frame and places it in front of him, encouraging and reminding him to use it to walk with. In response he picks it up and carries it in front of him rather than using it to walk with. In response the

HCA offers him her hand and she walks around the room with him leaving the frame by the chair 'lets go out for fresh air'. They walk hand in hand out to the garden.

I follow and the fresh air is wonderful, blue skies and the beautiful chestnut trees.

The other HCAs encourage the two other men to go outside as well and they all sit on the benches for a few minutes.

A says he is cold and the HCA walks back inside with him. Everyone comes back inside. We have only been outside for 5 minutes.

Site E, Day 2

Organisational strategies to support independence

A key organisational strategy to support this population were locked doors of the ward, enhanced observation, escorted leave and trial discharge from the ward.

These wards all had air locked exits, which meant people had to pass through two key-coded locked doors to enter and exit. This level of security appeared to give patients more freedom within the wards. All these wards also provided their patients with opportunities to leave the ward. All had supervised walking groups (site 1) and escorted leave (site 2 and 3), this is 'section 17 leave', part of the MCA. These wards also had approaches to discharge that encouraged trial discharge, keeping the patient's bed to ensure they could return to the ward if the discharge placement failed. Here a person had been discharged to a care home which was not able to 'manage him' and respond to his needs. This strategy supported the person to eventually have a successful discharge.

Nurse in charge '3 patients are on trial leave, they are supported to keep their room but sometimes we use them. We leave them on the system, and they have 2 weeks leave, although we may extend it, and we keep them on the books until the final discharge letter. G is on leave for one month, he has been in and out of the nursing home, it couldn't manage him. This one he seems to be settling well so he will have a trial discharge next week. We have 3 on leave, some go to dementia homes. This is a 20 bedded ward very few, less than 20% go back home we give trial leave to family but recognising it rarely works very challenging so difficult to place them they may need to be placed outside of the area.'

Site C, Day 3

The use of activities

All the wards had a meaningful activities co-ordinator at some point; however, there was not always a person in post during data collection, with the funding of this post described by the nurse in charge of the wards as 'challenging'. Where wards had this role, this was important in supporting patients and interrupting the boredom of the day.

We are in the cinema room with the ward OT, who does a lot of the activities on the ward, along with 2 of the women from the ward. The OT has a usb stick with 30-40 films on from the 40s to the 80s he chooses Grease. He closes the curtains to dim the room and asks them 'what snack do you want? Popcorn or ice-cream?'

Ice cream!

He comes back with tubs of ice-cream and puts it in a handmade traditional cinema serving tray, which he wears, lifting the strap over his head to serve the ice cream

They are engrossed, J keeps her bag close to her with the strap cross her body.

I check on them later, they are still engrossed, finishing their ice cream and sitting in the dark watching Grease. I can hear 'hopelessly devoted to you...'

Site C, Day 7

Discussion

The use of restrictive practice was an everyday feature of care within these mental health wards. Importantly, these restrictive practices typically took the forms of physical and chemical restraint that were also routinely and explicitly discussed and made visible within the organisational, legal and risk assessment frameworks used within these wards. The main legal framework applied to PLWD within these ward settings was the MHA 1983, which provides a statutory authority to detain patients – often known as ‘sectioning’ to authorise detention and provides the legal authority (and protection against liability) for administering medical treatment for mental disorder without the patients’ consent, and for any associated restrictive practices.

However, our analysis revealed that these mental health wards all fostered cultures of care that minimised the use of restrictive practice. These were wards caring for PLWD, typically with more advanced forms of dementia, who had been admitted for high levels of distress or psychosis and when their behaviour has been perceived as ‘challenging’, ‘disruptive’, or ‘aggressive’. In response, these wards promoted flexibility in the organisation and delivery of routine care and valued approaches that prevented and reduced patient distress by recognising and responding to the needs of PLWD.

Throughout our observations of routine care, these ward teams appeared attuned to relational ways of working and to the emotional needs of their patients living with dementia. There was a strong ethos of supporting mobility and independence in this patient population, reviewing their abilities and emphasising approaches that could increase mobility and reduce dependence.

These ward cultures actively promoted ‘positive risks’ and promoted risk taking’. Ward teams were explicit in their goals, not to prevent the person from falling and completely remove risk, but to review and identify what increases their risk, what can ‘minimise the harms’.

We identified a number of strategies drawn on to support PLWD, and their impacts on individuals within these mental health wards, that can provide transferrable learning for the acute setting. This is explored further in our discussion and findings.

Chapter 4 Discussion

The aim of this research was to explore the everyday cultures of restrictive practices used in the care of PLWD during an acute hospital admission. Our goal was to understand the nature, rationales for their use, and the experiences of people within ward settings. Prior to this research, the examination of restrictive practices in the care of PLWD with NHS hospital settings had not been the true focus of any substantive rigorous research.

As we set out in our introductory chapter, public inquiries, reports, reviews and research have consistently identified significant variations in both the accuracy and definitions of restrictive practices being used. This means examining NHS routine data or using quantitative methods to establish the nature or scale of its use across NHS settings was not possible. In response, we utilised ethnography, a methodology particularly useful for examining topics and answer research questions where measurement is either not easy or inappropriate. A key focus of ethnography is to examine organisationally invisible work,¹⁴⁵ involve populations and settings where the issues are sensitive and multifaceted, where the aim is to access the unspoken and tacitly understood¹⁴⁶ and to understand complex social relations, routines and institutional forces as they influence everyday cultures¹⁴⁷ of care.

Utilising ethnography allowed us to identify and explore the hidden mechanisms and undiscussed rationales for the use of restrictive practices, embedded within the technical and organisational work of NHS hospitals. Ethnographic methods enabled us to demonstrate how ward staff accounted for and made sense of their actions and practices in the care of PLWD, how they responded to and rationalised the needs of patients and the ward, and the impacts of these practices – for individuals and ward cultures – over time. Our findings present a novel and detailed exploration of the social, cultural and organisational forces that explain and influence the delivery of care within these institutional settings, for one of the most vulnerable patient groups within them.

Our approach provides an ethnographic ‘thick description’²⁰⁴ of our detailed empirical findings, allowing the reader to develop a strong connection to the social worlds of these institutional settings, exposing the nuanced and complex, everyday interactions involved in decision-making surrounding the use of restrictive practice in these wards. These findings demonstrate that while person-centred care²⁰⁵ has long been promoted as the ethos in providing care for PLWD, we continue to see ward practices guided by wider institutional policies, priorities and expectations.²⁰⁴ Instead of care drawing on person-centred principles, we identified the routine use of a wide range of restrictive practices, with acute wards adopting informal strategies not just to reduce, but to eliminate risk applied to a population of PLWD, without accompanying risk assessment practices, informing powerful ward cultures of containment, with significant impacts on the personhood, dignity and independence of this patient population.

Our aim in collecting and analysing data across a range of hospital and ward settings and from multiple perspectives was not to achieve representation or comparison, but to reveal and identify the organisational practices and institutional contexts that underpin these cultures, and the everyday practices at the bedside that were in turn, shaped by them, allowing us to show how containment remains a central feature of the care of PLWD. We found these practices also extended to inform the care of older patients within these settings.

Cultures of containment

In this report, we have focused on identifying and presenting the types of restrictive practice commonly observed within these wards. Reflecting the international literature, our conceptual framework for defining restrictive practice is expansive, taking in practices that appear very different in their application and impacts, from the routine use of raised bedside bars, the positioning of furniture, and verbal commands (e.g. ‘sit down’, ‘back to your bed’, ‘wait there’), through to the non-consensual sedation of a person living with dementia. Our analysis demonstrates how these apparently diverse practices should not be viewed in isolation. Rather, these practices form part of established and embedded institutional cultures of practice. The frequency and means by which these practices utilised multiply in the care of both individual and cohorts of PLWD. These practices form a tacitly understood hierarchy of restrictive practices, escalating over a shift or an admission, as a patient failed to comply with the expectations of the ward. These

cultures of containment 'tightened' around the patient as their distress at the experience of containment increased over a shift and over an admission, only loosening when the patient demonstrated they could 'behave' in ways that meet the expectations of the ward. Within these cultures of containment this meant the only way for a person living with dementia to avoid experiencing restrictive practice in their care was to demonstrate an awareness of the codes of behaviour required within the ward and only left the bedside in ways deemed acceptable by the ward or by being unable to leave the bed independently due to their admitting condition, remain in bed or at the bedside. This has impacts on the recognition of the individual and their opportunities for rehabilitation, which were overshadowed by the priorities of the institution.

The cultures of containment we observed across these wards emphasised risk management to the point of risk removal and the requirement to safeguard patients (from falls, from absconding, from imagined future harm), as a priority over the communicated (verbal and embodied) or rehabilitation (mobility, continence) needs of the person living with dementia. This meant that what may appear to the ward teams to be inconsequential, 'harmless' forms of containment were used as routine, embedded within everyday routine care practices, without being considered as forms of restrictive practice. Raised bedside bars, the placement of furniture, verbal commands, and closed doors were used habitually without record. However, the pervasive use and acceptability of these practices meant that escalation to the use of other forms of restrictive practice became culturally acceptable, leading to escalation including one-to-one enhanced care, the use of security guards, and sedation, because restrictive practice in the forms of containment at the bedside was already 'normal practice' for patients living with dementia.

The requirement to remain at the bedside, or to only be permitted to leave if closely supervised and supported, was in place regardless of the recorded and expressed desire for independence, and the capacity and functionality of the person. These practices were focused on PLWD; however, they could quickly spread to inform the care of older patients, particularly on bays with a mix of older patients and patients living with dementia placed under one-to-one supervision.

This contagion could become a permanent feature of care, because 'challenging' patients were routinely (planned and unconsciously) cohorted together within specific bays on each ward. Patients within these bays automatically experienced an element of containment in their care regardless of diagnostic need (raised bedside sidebars, e.g.) that was not seen for patients allocated to 'self-care' bays. The unpredictability of admissions meant overspill between these two types of bays; however, within the 'self-care' or 'self-caring' bays, this contagion was much less observable. Patients also appeared to be aware of the impacts of specific bays after short stays on a ward, for example, refusing in-ward transfers to the contained bays (site F).

Patterns of tightening and intensification of restrictive practices

While these cultures of containment remained stable across these wards, and while we do not wish to focus on comparisons in our analysis, it is important to acknowledge there was some variation between sites in the type of restrictive practices staff used as routine within care. There were variations, typically associated with local patterns of staffing and resources assigned to provide 'one-to-one' or 'enhanced' care to patients living with dementia, which meant the personnel delivering restrictive practice as part of one-to-one care could vary significantly: there was an emphasis on the use of non-clinical private security guards (dyad 1), agency HCAs (dyad 2) and rota-ed HCAs taken out of standard staffing, impacting the staff-to-patient ratio elsewhere (dyad 3). The impacts of these approaches were that these personnel were typically unsupervised during a shift and so the judgement and skill of these individual staff members (some private security guards were very engaging, while some HCAs lacked interpersonal and communication skills to support PLWD) could powerfully inform the impacts on individual patients (distressed by a guard in uniform, building relationships with regularly attending staff). Similarly, some sites (dyad 1) were better placed to properly engage with capacity assessments and DoLS, seen only in specialist settings at other dyads. The use of antipsychotics and sedatives such as lorazepam or haloperidol varied from ward to ward, from non-existent to everyday routine use in the care of PLWD. Importantly, however, the cultures of containment underlying the use of these restrictive practices were the same at each site: The person with dementia must remain where they have been told to stay (remain in bed, at the bedside, walking only if supervised) and cannot return home until the institution allowed it.

There was an expectation across all settings, tacitly expressed and in stark contradiction to dementia-friendly signage visible within these wards, that PLWD within these wards must be compliant, that is required to stay in bed, sit in a chair, comply with timetabled care, or engage in activity (only an option in some mental health settings) when prompted. Within acute settings, this often meant the expectation that the person must remain in bed or in their bedside chair for 12 hours a day with no stimuli, and then sleep when instructed to meet the ward schedule. This conduct, despite the obvious isolation, seclusion and boredom, was required of the person throughout their admission, which meant this often lasted weeks and after the patient had been assessed as medically fit for discharge, and regardless of the patients (and families) explicit desire to return home.

Concerns over safeguarding, care support provision and patient safety were significant within all of these wards. Conversations with ward staff were replete with stories, anecdotes, moral tales and atrocity stories of patients who had 'absconded' or 'escaped' and accounts of near misses or PLWD found in various locations miles away. These stories featured heavily in staff accounts despite their rarity in our observations. This affect of these concerns resulted in patients being expected to remain within these rigid cultures of the ward, rather than receiving a formal assessment of risk and consideration of returning home. Any attempt by the person living with dementia to challenge these expectations would begin a spectrum of restrictive practices, escalating from the routine use of raised bedside bars, the placement of furniture, and verbal commands to the consideration and use of one-to-one care, and restricted movement, leading to sedation. Should the patient become distressed, lash out, try to leave the ward or 'abscond', this would further limit an individual's potential pathways from the ward, intensifying the restrictive practices of the institution while leaving the patient to face further days within the ward. In turn, these practices could trigger further patient distress, which would be met by the ward with increased 'tightening' of restrictive practices in their care.

A further issue to be considered is the age and independence of patients. While fall risk is a frequent rationale for containment and restraint, the patients who enter these cycles of restrictive practice were frequently independent and mobile. It is this mobility, and the physical strength that goes with it, that often meant staff were scared of physical reprisal from patients, particularly those at the earlier stages of their dementia, or those presenting with younger-onset dementia (site D and site F). Because these patients (especially when male) were mobile, they were able to verbally challenge staff and could appear to be physically imposing; they were far more likely to experience restrictive practices that quickly escalated to the use of sedation (site D), security personnel and isolation (site F), than patients who were older and had frailty. These findings are reflected in the experiences of our PPI groups, who are living with dementia, who shared their fearful and often angry recollections of past hospital admissions and the use of containment and restrictive practices in their care.

Consequences for patients and ward staff

These patterns of care and the recording practices associated with them had powerful but unacknowledged consequences for the person. Any negative reaction by the person living with dementia to the experience of restrictive practices in their care was recorded in handover notes and the patient's medical records, often using limited and highly pejorative language, including: 'violent' 'aggressive' or at 'risk of absconding'. Care homes will not admit patients assessed as 'violent', including recording of punching, shoving, or the application of restraint in patient notes. Similarly, we found older patients and patients living with dementia who express their wish to independently return home were typically not supported by the health and social care teams due to the risk of them leaving their home unaccompanied in the future, despite having no legal framework to do so. Within these settings, the widespread use of restrictive practice meant the person living with dementia, regardless of their capacity, was entirely stripped of their agency and autonomy of when and how they could leave the ward, and where they were discharged to. Cultures of containment moving beyond the ward to control an imagined everyday future for the person.

Our observations of these cultures of containment are that they did not only distress patients. Our interactions with ward staff identified they also felt powerfully constrained and restricted in their work, unable to act or respond differently towards their patients living with dementia. We observed variance in this, from staff member to staff member, from ward to ward, as demonstrated in our findings: The HCA who was committed to walking with all of his patients, the senior nurse who was so fearful of her patients walking through fire exits into the road that they all

remained in bed throughout the 12-hour shift. Each ward team, however, had clear limits, the point where routine restrictive practice was viewed as requiring escalation. For all, that point was the fear that the patient would fall, 'abscond' from the ward or from the hospital, or that somebody would be hurt. Rationales varied, from worry for the patient's safety to staff concerns about their personal liability. However, once challenged by a person living with dementia who strongly expressed their desire to leave the ward, these fears resulted in the escalation of restrictive practices, from one-to-one care, to further containment, and ultimately sedation.

Restrictive practice normalised as organisationally required

Ward staff typically described that they felt unable to challenge these organisational approaches to containment. As we have seen in our analysis, requests to relax containment and allow a patient to move and walk around a ward would be over-ridden by the concerns of senior staff, or the relaxation of containment practices would be quickly reversed at shift handover as a new team took over. Nurses' suggestions that a patient was ready to go home would be over-ridden by absent social work or medical teams, and the requests of carers, family members and friends for a patient to go home would typically be dismissed, drawing on 'safeguarding concerns' or 'doctors' orders', even when such frameworks were not in place (or were applied post hoc).

The use of restrictive practice was viewed by staff as the only way their wards could function, even when the application of restrictive practice had significant implications for the functioning of the ward, obstructing everything from physical doors, lifts and corridors to wider organisational requirements of patient flow and adverse events. Restrictive practice and a palpable fear of what would happen without containment in place were embedded within cultures of care for this vulnerable patient group.

This ethnographic study has revealed that restrictive practice represented a significant but unrecorded and invisible aspect of care work for nursing and care staff within these wards, and the agency HCA and security staff within these hospitals. At the extremes, the use of sedation, experience of violence, or the use of security staff would be recorded; however, these recorded practices also led to reduced workload for the ward team, the patient would soon be in a sedative state, or their care and containment delegated to other external staff. Within these wards, the use of containment and restrictive practices was a physically and emotionally demanding aspect of care, with enhanced care or observation routinely delegated to care staff thought to be 'good at it', or to staff viewed as external to the ward team, such as student nurses or students on T-Level placements. This work was isolating, with containment practices often meaning the staff member was also in the same isolated position as the patient, lacking stimuli (bar the surreptitious mobile phone) and often required to care for highly distressed patients pleading to go home, threatening violence, or cursing the staff member responsible for their containment.

Ward staff were aware that the strategies they were institutionally expected to draw on and use neither reflected the needs or desires of the patient, nor how they wished to engage with and care for their patients. However, the lack of agency felt by ward and hospital staff meant these cultures of containment also meant high levels of distress and isolation for all within them. What we did see is that where ward staff felt empowered to offer alternatives to restraint, be it through engagement (site F), mobilisation (site D), and interaction and use of resources (site B), it was often possible to de-escalate a patient whose behaviour posed a risk to themselves or others without resorting to restraint. While there will always be exception where the risk posed by or to a patient requires restraint, it does not need to be the default, which was the pattern we observed in these settings. Many of these wards had the resources available to offer distraction. Resources for engagement and entertainment (built environment features such as day rooms and gardens, technology such as televisions and reminiscence devices, human resources such as visiting entertainers and specialist teams) were available in all of the observed wards. However, the organisational focus on risk reduction, using containment to minimise adverse events, meant these resources were not used to engage with patients living with dementia. Instead, day rooms continued to act as supply rooms and staff break out areas, televisions could be seen still in their boxes and entertainment was reserved for 'self-care' patients without a dementia diagnosis. Meanwhile patients living with dementia remain at the bedside bored and disengaged for hours, days and weeks at a time.

In conclusion, our findings demonstrate that, while there is significant variation site by site on the types of restrictive practice most commonly employed within them, who was conducting enhanced observation, and the use of legal

frameworks supporting it, cultures of containment were in operation in the care of PLWD across these settings. Containment (in bed, at the bedside, on the bay) was both a requirement and expectation as part of routine care, and any challenge to this was met with restrictive practice, starting with raised bedside bars, obstructions and supervision, and then either escalating should the person continue to challenge containment or de-escalating once the person accepts self-containment. These cultures were driven by genuine staff fears over personal and professional reprisals for allowing risk around movement and even discharge, and enabled by ward cultures in which visitors, volunteers and engagement have disappeared from many ward settings, creating challenging environments of ennui and isolation.

Equality, diversity and inclusion

Equality, diversity and inclusion principles are at the heart of the design and delivery of this study. We set out to explore restrictive practice in the care of PLWD, with our protocol recognising the need to include populations under-represented in research, increasing our focus on the recruitment of diverse minority ethnic communities, Lesbian, Gay, Bi, Trans and Queer (LGBTQ) identifying PLWD, and PLWD also experiencing homelessness. In response: (1) to support the governance of the study, our steering and oversight groups included PLWD who identify as LGBTQ, alongside community leaders representing the diverse minority ethnic communities living within the geographic areas covering the catchment of the hospital sites. (2) We involved representatives of diverse minority ethnic communities in the coproduction of this study via a programme of PPI outreach and events by working with community organisations to involve a diverse range of ethnic minority communities and communities recognised as experiencing socioeconomic deprivation with significant populations of older people. These included inner-city, rural and coastal communities (identified using the Index of Multiple Deprivation data sets) across England and Wales. Our engagement with specific communities in the production of this report is outlined below:

Inclusion of African and African Caribbean people living with dementia

To increase the inclusion of PLWD involved in research, we established a long-term collaboration with community organisations Nubian Life, Experience Culture, and Black History 365 Network, to involve African and African Caribbean PLWD in my NIHR research. We have:

- delivered a programme of arts workshops to support sharing of experiences and priority setting (in collaboration with Nubian Life)
- sponsored and collaborated on three annual outreach and consultation events (July 2022, June 2023 and August 2024). Each event attended by over 100 African Caribbean Elders and PLWD from across London.

The events were positively evaluated (feedback survey following each workshop and event) by participants, community groups and social services. The collaboration and involvement of people with lived experience have been positively evaluated: 'It continues to be a great journey working with you, this was only possible due to your commitment to our clients and service' (Jazz Brown Director of Nubian Life, July 2024), with our long-term commitment to collaboration described as 'empowering' and showing 'respect' to these communities (Adult Social Care, Hammersmith and Fulham, June 2023). Our Artist Academic team member (Wyatt) was described by participants and staff as 'inspiring'.

These events established trust and led directly to establishing a steering group of 15 London-based African-Caribbean PLWD and care partners to support their inclusion in the research, involvement in coproduction, and to ensure we responded to their priorities. The first meeting was held in November 2022, meeting quarterly. The group contribute to the delivery of the study and coproduction of outputs.

The steering group also contributes to priority setting, coproducing the design and development of a further study (NIHR160824) which focuses on 'identifying inclusive strategies to facilitate timely and culturally appropriate social care support for African and African Caribbean people living with dementia and their families'.

Inclusion of inner city, rural and coastal communities living with dementia

We have delivered a programme of outreach in collaboration with community organisations across England and Wales to support the inclusion of PLWD and their care partners (including Humphrey Booth Resource Centre, Salford; Imperial Wharf Resource Centre, Hammersmith and Fulham; The Ruthin Craft Centre; The Conwy Dementia Centre) within areas of significant inner-city (Hammersmith and Fulham), rural and coastal deprivation (Denbighshire, Colwyn Bay, Rhyl). Evaluation identified participants appreciated involvement, the opportunities to express themselves, to reflect on their experiences, and to participate in discussions about care.

Inclusion of people living with dementia who may find verbal communication difficult

To ensure we are inclusive of one of the most vulnerable groups of PLWD, we have embedded artists researchers working closely with community organisations using creative methods to offer new routes of expression and opportunities to empower individuals living with dementia to communicate their experiences, contribute to shaping research, and coproduce study outputs. Participant evaluation established they 'enjoyed the workshops' which provided a 'relaxing and enjoyable atmosphere' and 'enjoyed the discussions about care'. All Community Centres provided positive feedback, emphasising our approach using painting supports their clients by providing 'opportunities to communicate' and 'share experiences' and have requested regular collaborative events.

Experiences shared during these PPI and engagement events where participants powerfully discussed their experiences and perceptions of freedom since a diagnosis of dementia have directly informed our focus on the experience of restrictive practice and led to a specific focus on freedom (and restriction) of communication, expression and autonomy within data collection and analysis of NIHR132903.

Continuing work

Our impact and dissemination strategies are ongoing and we continue to work with Community champions who have a deep and established understanding of the communities they are working with. These include Southeast England (Nubian Life Community Resource centre, Imperial Wharf Resource centre, Clementina Support services, and Dementia in Dub); North-West England and North Wales (Humphrey Booth Resource Centre, Ruthin Craft Centre, and Conwyn Dementia Centre, BME Health and wellbeing Consultancy, Bangladesh Association and Community Project, and Deeplish Asian Women's Network). These organisations involve a diverse range of older people and PLWD from ethnic minority communities and communities recognised as experiencing socioeconomic deprivation. These collaborations will ensure our findings and the implications for policy and practice are coproduced, culturally sensitive, and support the needs of all service users.

Robustness of the results and limitations

This study set out to explore how restrictive practice interventions are applied in the care of PLWD across a hospital admission. We sought to understand the types of restrictive practice commonly utilised, the rationales for applying restrictive practice, and the impacts and consequences these have on patients, both in the moment and over time.

Our findings provide a novel and detailed exploration of the ways in which restrictive practice is embedded and normalised in the routine care PLWD experience during a hospital admission. We found these practices also extended to inform the care of older patients within these settings.

Issues of potential limitations and transferability have been addressed by the scope of our data collection. We collected 225 days of ethnographic data across nine ward settings in six hospitals in England, covering a diverse spectrum of hospital type and patient demographics. This was accompanied by a significant programme of PPI engagement and outreach across England and Wales to ensure the inclusion of diverse and vulnerable populations of PLWD who were

involved in identifying restrictive practice as a priority and in directing and coproducing the research. As a result, our findings transcend descriptive accounts of singular phenomena, presenting an analysis grounded in NHS institutional and organisational contexts in which observations took place, producing theoretical interpretations of the data and analysis.

Despite the variance built into each site (built environments, staffing levels, professional make-up of teams, available support services), our analysis identified the decision-making and social processes informing the use of restrictive practice remained consistent across these institutional settings. Patients perceived behaviour was classified as risk to be contained and viewed as institutionally required, which informed the routine and almost universal use of raised bedside bars and the placement of furniture to contain the person living with dementia in bed or at the bedside; these practices caused significant distress, which in turn were viewed as requiring the use of one-to-one supervision, leading to patterns of rapidly escalating distress and further restrictive interventions. Despite variance in staffing and the methods used across the sites, these underlying cultures of containment remained stable, producing the embedded everyday routine use of restrictive practices, accepted and normalised as institutionally required to deliver care to PLWD within acute ward settings.

Our intention in taking an ethnographic approach was to view a complex, sensitive and invisible practice for which rationales and actions were often tacit and unspoken. Our goal was to explore how the experiences of a range of professionals and patients within these settings relate to one another, producing action and interaction and the implications of these across a range of actors and perspectives. As experienced ethnographic researchers working within the acute hospital setting and in examining the care of PLWD within them, we were also acutely aware that the presence of an observer affects these relationships or can lead to 'performative' behaviour via the Hawthorne or observer effect. In response, based on our prior research within acute wards,^{52,68} our design included strategies to minimise this potential effect within our fieldwork: through extended periods of observation within each ward, allowing participants to become used to the presence of the researchers and to build relationships with them, and careful interpretation of findings, with attention paid to verbal and non-verbal cues that those observed are 'on their best behaviour' or presenting a performance to the observer.

It is important to note that ethnography does not aim to achieve distance and detachment, with one of the strengths of this approach the development of close ties with those being observed in the field. It has been argued that any performances observed, however staged or influenced by the presence of researchers, often reveal useful insights by displaying how people see themselves and how they want to be seen and may inadvertently reveal other interesting data. What was noteworthy in this study was how distinct these actions could be. At each site, a number of staff members were reluctant to talk about or were evasive about what restrictive practice interventions had been used with patients in their care. This was particularly notable around the use of sedation with lorazepam via injection, where withholding of data from the research team was notable. The researchers were still able to identify and record as data when lorazepam had been administered via medical records and from speaking to other staff members. Although a limitation of the method, this also enhanced our study, showing that while cultures of containment were pervasive within these ward settings, staff experienced some degree of conflict and difficult emotions around their use and the escalation of restrictive practice in care delivery. This reflects another key strength of ethnography and remedies a common weakness of qualitative interview-based studies, in that what people say to researchers may differ from what they actually do in practice. These approaches were central to collecting high-quality data, to achieve methodological rigour, and theoretical interpretation of the data.

During our extended periods embedded within these ward settings, PLWD would often tell us that they just wanted to go home, asking for help, and expressing clear rationales of why they needed to go home (feeling imprisoned, to feed a pet, to water plants). The researchers were often the only person present on or around these wards for uninterrupted periods of time. As a result of this, sometimes, when ward staff were not present or able to be called quickly to a bay, we provided immediate support or sought help from staff. If asked by a patient for something within reason the researchers would accommodate, such as getting a cup of tea, going to the shop to buy a newspaper. We also spent time sitting with PLWD and having conversations with them. This often meant we missed observations of other actions within the wards or polluted the data by acting as a supernumerary staff member assisting patients; however, the welfare and well-being of PLWD was always a priority over data collection.

Practical limitations presented by the organisation of hospitals were factors that informed data collection throughout the study. As a result of local governance permissions granted to the study, the team were limited to a small number of wards and unable to track patients once they were transferred to other wards. This was mitigated by patients living with dementia routinely being transferred from MAU units to older people's wards, which enhanced the potential to recruit PLWD at admission, following transfer, and through to discharge, observing full cycles of restrictive practice, from initiation, escalation, to the person's next transfer.

The researchers could observe and take fieldnotes for only a limited number of hours and shifts at each site. Often, the researchers would arrive at a ward and have staff excitedly tell us stories about what we had missed just after we left the previous day, or just before we arrived. However, these incidents and events often represented the extraordinary, and not the everyday routine practices and cultures we wanted to explore. These examples would not have allowed us to see how cycles of restrictive practice continued after an incident of activity or violence had occurred. This also reflected that, while staff knew of the purpose of our research and our goal to improve care, they often misinterpreted the context of our observations and data collection, and at times a level of exaggeration could be noted in the in situ rehearsals of their rationales for restraint compared to our observations of the routine use of restrictive practices at the bedside.

A significant limitation of this study was COVID-19. Outbreaks of COVID continued through data collection at dyad 1, which meant on several occasions the research team would travel to a site only to find they could not access the ward due to infection control and agreements for research governance. Outbreaks of COVID-19 (and outbreaks of flu, norovirus and other infections) continued to impact on access to wards throughout the study. These occasions also meant the restrictions in place were for infection control, rather than the everyday practice the team set out to observe. Where possible, these days were made up by the research team doing double shifts, such as a day and night shift, to make-up for a missed day.

Chapter 5 Conclusions and recommendations

Our in-depth analysis provides insights into the complex social contexts and everyday cultures within these wards and the ways in which the materiality of restrictive practice interventions are contoured by the ward and wider institutional policies, practices and priorities, in turn shaping personal experiences and impacts for PLWD and ward staff. Considering the scope of the study and data collected, for the purposes of this report we focus on presenting the main themes that derived from our analysis, namely: (1) everyday routine use of restrictive practice; (2) cultures of containment; (3) patterns of intensification and 'tightening'; (4) low tolerance of risk; (5) deprivation of liberty and everyday rights; (6) legal frameworks; (7) the impacts and consequences of the use of restrictive practices in the care of PLWD and (8) good practice and de-escalation.

Everyday routine use of restrictive practice

We identified the use of restrictive practice in the care of PLWD was an embedded aspect of everyday routine ward care, within all shifts observed within the acute wards, regardless of the ward, time of the day and day of the week. The restrictive practices used within these ward settings took a wide range of forms, with use of raised bedside rails, ward furniture and verbal commands, the most frequently used. These practices were typically carried out swiftly, and at pace, to contain and restrict the movements of PLWD at the bedside. What is of significance is that their use was embedded within timetabled care and viewed by staff as routine; thus, these forms of restrictive practices were typically unrecognised and unrecorded. We identified that ward staff found defining and identifying what constituted restrictive interventions in their routine practices as challenging.

Cultures of containment

Reflecting the international literature, our conceptual framework for defining restrictive practice is expansive, taking in practices that appear very different in their application and impacts, from the routine use of verbal commands, through to the non-consensual sedation of a person living with dementia. Our analysis demonstrates how these apparently diverse range of practices cannot be understood in isolation, but, instead, were utilised multiply in the care of both individuals and cohorts of PLWD within acute wards. The pervasive use and acceptability of these practices meant that escalation to the use of other and multiple forms of restrictive practice became acceptable features of ward care. In turn, this also shaped and normalised wider ward cultures of control, becoming routine aspects of everyday care, informing what patient behaviour was viewed as acceptable and also legitimised staff routine responses to perceived risk of falls, 'absconding', 'wandering', non-compliance and resisting care as normal practice.

Patterns of intensification and 'tightening'

Concerns over safeguarding, staffing, care support provision and patient safety meant PLWD were required to conform to the expectations of the ward, rather than receiving a formal assessment of risk and consideration of returning home. Should the patient become distressed, lash out, try to leave the ward, or 'abscond' over an admission, this could quickly intensify the restrictive practices used in the care of a patient in the moment and over time. We observed patterns of intensification in the use of restrictive practices, escalating from the routine use of raised bedside rails and furniture to the consideration and use of one-to-one enhanced care, to restricted movement to the bedside. In turn, these practices could generate further patient distress or responses that included attempts to leave the bedside and the ward, which were met by the ward with increased 'tightening' of restrictive practices in their care, ultimately leading to the use of sedation. A key impact was the further limiting of an individual's potential pathways from the ward and increasing risk of institutionalisation.

Low tolerance of risk

A key focus for staff in utilising these approaches to restrict patients' movement or contain them at the bedside was as an immediate solution to a key quality assessment metric (falls prevention, a legitimate concern in the care of PLWD) for these wards and the wider institution. Other key identified risks included patients living with dementia 'wandering' within the ward or 'absconding' from the hospital. Ward staff routinely applied restrictive practice not just to increase safety and reduce risk, but to eliminate these risks for the population of PLWD within the ward, without accompanying risk assessment practices, informing powerful ward cultures of containment and low tolerance of risk. Ward staff often explained their actions and applications of restrictive practice interventions as being in the best interest of the patient and as a means of safeguarding and protecting the patient rather than a form of restraint. Yet legally, protective duties do not confer unfettered authority or powers on staff to restrict patients. These approaches had significant impacts on the personhood, dignity and independence of this patient population.

The everyday nature of seclusion into side rooms and one-to-one enhanced observation as forms of containment meant that for the majority of the observed acute wards, this had become key practice to support workload management. By placing HCAs at the bedsides of PLWD who were viewed as disruptive and requiring significant attention and care, the ward team were released from the patient bedside to deliver routine tasks required by the wider institution. We identified patients considered a disruption to the routine work of the ward being subject to seclusion into side rooms and one-to-one enhanced observation. Staff did not typically recognise these approaches as a restrictive practice and a potential cause of significant distress, which in turn could lead to the use of psychiatric assessments and prescribed antipsychotic or sedative medication. Administration of such medication for patients was in some cases accompanied by physical restraint, often repeated until the required effect of sedation is achieved. Ward staff typically described that they felt unable to challenge these approaches to containment and restrictive practice.

Deprivation of liberty and everyday rights

People living with dementia within these acute wards were likely to be deprived of their liberty. As we have already seen, PLWD were often contained in bed for most of the day with the bedside rails raised. This had the effect of almost completely restricting the person's liberty of movement. PLWD were not able to leave their beds at will. We did not see any patients successfully lowering the bed rails themselves (although some tried to climb over the raised bed rails, posing significant injury risk). We did not observe ward staff offering to lower them, nor regularly offering PLWD opportunities to leave their beds with support. The intention and impact of the bedrails were that patients living with dementia were effectively *confined* to their beds. These 'informal' restrictions may not involve the kinds of hands-on contact and direct use of force associated with physical restraint, but these environmental restraints significantly impacted on people's well-being and their everyday rights and freedoms – interfering with article 8 of the ECHR.

Legal frameworks

There was significant variation across and within the acute wards in the application and assessments of the legal frameworks DoLS and the MCA. We found that PLWD classified as at risk of falls, 'wandering' or absconding were more likely to have DoLS instituted. The use of these legal frameworks in a patient's care was recognised as a sign that patient was, or could be, restrained, particularly allowing for the use of sedative medication such as lorazepam or haloperidol. It was common for these interventions, once put in place, to remain in place for the duration of the person's admission, rather than for the specific period of review. We identified that these measures were often used despite patients' repeated requests to be released from these wards.

The impacts and consequences of the use of restrictive practices in the care of people living with dementia

The use of restrictive practice had significant impacts on PLWD and staff in these settings. For PLWD, we identified increased emotional impacts including verbal and physical demonstrations of fear and distress. The use of restrictive practice saw some patients view an admission as a form of imprisonment or being held hostage. Cumulatively, the use of restrictive practice across an admission was usually accompanied by increasing the person's emotional distress and their visible physical and cognitive deterioration. The use of restrictive practices also informed impacts on ward cultures, fostering the experience of an admission as one of loneliness, isolation and disconnection and increased the inequalities in care experienced by PLWD within these wards. The use of restrictive practice during admission was also highly distressing for care partners and families.

Ward staff were aware that the strategies they were institutionally expected to draw on and use neither reflected the needs or desires of the patient, nor how they wished to engage with and care for their patients. The lack of agency felt by ward and hospital staff meant these cultures of containment also meant high levels of distress and isolation for all within them. Ward staff often described feeling inadequate by not being able to provide appropriate care and recognised they lacked the skills to support PLWD, and also experienced a significant emotional impact from using restrictive practices in patient care.

Good practice and de-escalation

Our analysis of mental health wards identified good practice potentially transferable to the acute setting. They all fostered cultures of care that minimised the use of restrictive practice in the care of PLWD through (1) the promotion of flexibility in the organisation and delivery of routine care; (2) supported staff in approaches to care that prevented and reduced patient distress by recognising and responding to individual need; (3) staff attuned to relational ways of working and to the emotional needs of their patients living with dementia; (4) ethos of promoting 'positive risks' to support mobility and independence; (5) the legal frameworks governing patients, and their admissions were explicitly discussed and recorded.

Examples of individual good practices were also seen at each acute site. While variable, these involved taking the time to engage with patients, listening to patients and providing distractions, entertainment and quality-of-life improvements (hair, make-up, cosmetic care). When these positive approaches were applied in lieu of restrictive practices, they often resulted in de-escalation, reduced distress and an improved atmosphere within these wards. However, within the acute setting, these approaches could be swiftly curtailed by ward cultures, managerial approaches and fear of liability.

Recommendations for future research

Our findings highlight a number of pressing areas for future research in order to improve hospital care for PLWD, to minimise the use of inappropriate restraint and to improve the experiences of staff caring for PLWD as part of their everyday workload.

There is a pressing need for a programme of research examining the role of security staff in the care of PLWD. While the many clinical facing roles within the MDTs that operate within the modern hospital are clearly demarcated and regulated, the role of the security staff is not. The recruitment, regulations, qualifications and remit of this role is vague and varies from site to site. Security guards are often called in to roles beyond the primary assumed role of protection and security, frequently called upon to help with patients without recognition or remit for their role as part of the everyday care. Research is needed to deliver the evidence base to inform the deployment, roles and organisation of security guards in the delivery of care and care cultures for these seemingly invisible, yet impactful, teams of professionals involved in the care of significant vulnerable populations in acute hospital wards. These teams have significant impact on experiences and delivery of care of PLWD in acute hospital settings including the potential for

increasing distress, deterioration and prolonging admissions for PLWD. We are currently working to develop and deliver research on this subject.

Implications for decision-makers

1. Training in de-escalation practices and positive risk taking within acute hospital wards could be carried out by mental health nurses' secondments. Training is required to support staff in recognising distress and how to manage and reduce distress in PLWD. Ward staff expressed a feeling of inadequacy and of helplessness with the responsibility of supporting PLWD within their wards. In response, training should promote the use of interactional approaches, de-escalation and drawing on the resources available to the ward, before the use of restrictive practice.
2. Promoting organisational ward flexibility and slower pace in the delivery of timetabled care at the bedside (this includes medications, personal care, observation rounds, continence care and mealtimes) to PLWD. By focusing on the person and flexibility in delivery, this supports and recognises the importance of maintaining a calm ward environment to support patients living with dementia.
3. Ministers making decisions about the introduction of LPS should examine our findings that the DoLS are not working within the acute setting to reduce the use of restrictive practices. Our findings suggest the urgent need to invest in the development and delivery of evidence-based nursing and allied professional education on restrictive practice and the legal frameworks underpinning their use in acute hospital settings.
4. What is recorded as a key metric by hospital trusts has wider consequences. A key performance metric in the acute settings is the recorded number of falls, which is a legitimate concern in the care of PLWD. There is need for NHS trusts to appreciate the unintended consequences of how such policies are consequential in sustaining and normalising cultures of restrictive practice in the care of PLWD. There is need for continued institutional evaluation of falls monitoring practices and their consequences on PLWD. Reducing the risk of falls and managing ward falls statistics was deeply embedded in staff rationales in rationalising the use of restrictive practices.
5. Our findings identified that a significant proportion of the everyday restrictive practice employed in the care of PLWD remained unrecognised and unrecorded. To improve care and promote the minimisation of restrictive practice in everyday care, it is vital that all restrictive practices are recognised and recorded, alongside why it was utilised. This will support an increased recognition and visibility of the impacts of restrictive practice on the PLWD, the staff caring for them, and on their discharge pathways and ability to return home following an admission.
6. Guidance and data on use of restrictive practice in the care of PLWD in acute wards settings are required. One way to do this could be expanding the application of Seni's Law [Mental Health Units (Use of Force) Act 2018 statutory guidance] from mental health to acute settings.
7. Guidance is needed on making better use of the resources already available and in place within and around wards, such as skilled one-to-one carers, use of day rooms, garden spaces and entertainment such as televisions and laptops.
8. National Institute for Health and Care Excellence Guidelines should have specific guidance around the application of restrictive practice on PLWD during an acute hospital admission.

Dissemination and impact

Our strategy of tailored knowledge transfer is to intervene at multiple levels, working with specific groups and networks to develop our findings and recommendations around the use of restrictive practice in the care of PLWD.

The research team have begun to engage with health and social care organisations, local authorities and policy-makers and to discuss the emerging findings.

- Katie Featherstone – committee member Dementia Partners National Steering Group (1 February 2023) and Hospital Charter for Wales Steering Group (21 February 2023), Public Health Wales, Welsh Assembly Government.
- Katie Featherstone – invited to be a member of the Restraint Reduction Network Steering Committee (20 February 2023).

- In March 2025, anonymised data collected from this report were presented by the Restraint Reduction Network to an All-Party Parliamentary Group (APPG) and have now been adopted by the CQC for use in its training of hospital inspectors.
- In June 2025, the preliminary findings of the research were presented to senior clinicians from across Wales as part of Public Health Cymru and Improvement Cymru's launch of its new programme to support Older Adults Mental Health Wards.

The research team will draw on networks they have developed to continue this engagement with policy-makers, charities, APPGs and NHS trusts following the publication of this report.

This will be supported and developed through our long-term engagement with wards, teams, trusts, local authorities and social care teams. We are developing a community of practice, in conjunction with Dementia UK and initially London-based NHS Hospital Trusts. This programme of training will launch in late 2025, expanding across 2026 to engage with NHS trusts nationwide, alongside Health and Dementia Boards in Wales. The preliminary findings of this work have already been discussed in seminars with nursing schools and dementia teams at University of West London, University of Sterling and University of Leicester to support the development and feasibility of training interventions.

Engagement and training so far events include:

- Katie Featherstone – invited speaker Royal College of Nursing training event – ‘Safe Dementia Care – reducing restrictive practice’ event (9 March 2023). Online event for Senior Nurses (30 delegates).
- Katie Featherstone – Professional training for Social Care on dementia. BIA workforce training – BCP Council and Dorset Council Refresher Training for their Social Worker/Approved Mental Health Professional/Best Interest Assessor team. Ninety-five professionals attended. January 2024.
- Shadreck Mwale – Understanding inequalities and dementia in minority ethnic communities, presentation at the Ealing Borough Council Dementia Group, 17 September 2024.
- Shadreck Mwale – Researching experiences of African and African-Caribbean older PLWD, presentation to the Hounslow Borough council Adult Social Services Team 19 November 2024.

Beyond ongoing training and engagement with practitioners, these events and discussions will focus the production of coproduced open access outputs on acute wards and service providers.

We will continue our programme of coproduction in the development of outputs and programme of future research building on this research. We will continue to work alongside PLWD and their families to produce appropriate social media engagement, to raise awareness and coproduce guidance and outputs. We will continue our work with relevant third-sector organisations and networks to support the impact and dissemination of our findings, and to support the work of these groups. This includes the DEEP network, Diverse Cymru, Nubian Life and our network of advisory boards.

Throughout the development of this report, we have published peer-reviewed academic papers to support and highlight our conceptualisations of restrictive practice,^{206,207} the impact cultures of containment can have on the delivery of care,^{208,209} and material to support future clinical researchers in identifying and responding to these issues.²¹⁰ The preliminary findings from our research have been presented at the 34th Alzheimer Europe Conference in October 2024 across two oral presentations, with the full results accepted for oral presentation at the 35th meeting to be held in October 2025, with a focus on presenting alternatives to restrictive practice to an international audience of activists, practitioners, people with lived experience of dementia and policy-makers. Presentations and workshops include:

- Katie Featherstone – plenary speaker: ‘*Wandering the Wards*’. The premiere of the Dementia Friendly Hospital Charter for Wales hosted by Improvement Cymru and Welsh Government. Wednesday 6 April 2022.
- Katie Featherstone – invited speaker ‘*Wandering the wards: institutional “rules” and their consequences for people living with dementia*’ ARK Ageing seminar series ‘Next Generation Thinking in Research on Ageing’, Queen’s University Belfast.
- Katie Featherstone – invited speaker on ‘hospital care’ to the 3 Nations Dementia Working Group and a panel discussion with Nigel Hullah and Keith Oliver. Webinar audience of 80+ people, 75% of the audience are

professionals working in the dementia field, with the remaining 25% being people with dementia and carers. 29 November 2022.

- Katie Featherstone – Keynote ‘Exploring restrictive care cultures in hospital care: the experiences of people living with dementia’ Restraint Reduction Network Conference. 4 November Birmingham Audience (121 in-person and 56 online) health and social care practitioners and policy-makers.
- Katie Featherstone – invited speaker – NARI Seminars in Ageing ‘*The limits and ethics of autonomy and choice in older people who are care-dependent*’. National Ageing Research Institute in Melbourne, Australia.
- Katie Featherstone – invited speaker – ‘Barriers & challenges in providing safe and effective care’ Royal College of Nursing training event – ‘Safe Dementia Care – reducing restrictive practice’ event – 9 March 2023 Online, attended by 30 senior nurses.
- Katie Featherstone – invited speaker – ‘Wandering the Wards’ School of Clinical Sciences, Auckland University of Technology New Zealand 18 April 2023 (in person).
- Katie Featherstone – invited speaker – Restraint Reduction Network steering group. Title: Exploring restrictive care cultures in our hospitals: the experiences of older people and people living with dementia. 15 May – 20-minute presentation (online).
- Katie Featherstone – invited speaker – NHS Wales Regional Dementia Conference: Influencing, Shaping and Improving Dementia Care. Title: Pad cultures: routines of intimate care and their consequences for people living with dementia. 24 May 2023, 15-minute in-person presentation (Newport, South Wales).
- Andy Northcott – invited keynote speaker: Experiences of care of people living with dementia within acute hospital wards: an ethnographic study. Institute of Ageing and Health Conference, West midlands. 4 September 2023 <https://iah-wm.co.uk/newsletters#a3f3a6af-78b5-47ce-9a7f-8ba0066098bb>
- Andy Northcott – invited keynote speaker: Pad cultures: routines of intimate care and their consequences for people living with dementia. Alzheimer.cz. Prague 11 October 2023.
- Andy Northcott – oral presentation: INTERDEM New member presentation. Helsinki, Finland 15 October 2023.
- Megan Wyatt – oral presentation: Using art to support PPI for people living with dementia. Alzheimer’s Europe. Helsinki, Finland 18 October 2023.
- Andy Northcott – The rhythms of the ward: Using rhythm analysis to understand expressions of bodily need in the care for people living with dementia during an acute hospital admission. British Sociology Association Medical Sociology Conference 10 September 2024.
- Shadreck Mwale – Privileges, and Permissions: theorising intersectionality and cultures of control in the care of people living with dementia in acute hospital settings. British Sociology Association Medical Sociology Conference 10 September 2024.
- Andy Northcott – oral presentation: The use of restrictive practice and restraint in the care of people living with dementia during a hospital admission: findings from an ethnographic study. Alzheimer Europe Conference, Geneva, 8–10 October.
- Shadreck Mwale – oral presentation: Understanding the support needs of African and African-Caribbean people living with dementia: an ethnographic study in the UK. Alzheimer Europe Conference, Geneva, 8–10 October.

A dissemination strategy for further open access academic publication is in place for the 12 months following publication of this report, targeting key audiences linked to the use of restrictive practice. Targets include high-impact journals for nursing, medico-legal, sociological and organisational audiences. Post publication, as with our previous NIHR studies,^{149,152} there will be a focus on engagement with high-profile mainstream media to publicise the findings of the report. We will use this approach to stimulate and support further policy and practice engagement.

Capacity building

The study supported training and fostered the academic career development of the research team. The core research team Dr Shadreck Mwale, Dr Andy Northcott and Dr Megan Wyatt all received mentoring and career development during this award. This resulted in:

- Dr Mwale obtaining a permanent academic contract and has been promoted from Senior Lecturer to Associate Professor. Dr Mwale has also progressed from co-applicant and researcher within this study to developing a

follow-up study as PI for the NIHR HSDR-funded study NIHR160824: 'Understanding late recognition and support seeking by African and African Caribbean people living with dementia and their families: identifying inclusive strategies to facilitate timely and culturally appropriate social care support'. He is also co-applicant for the NIHR HSDR study NIHR161439.

- Dr Andy Northcott has been promoted from Senior Lecturer to Associate Professor through his role as Study Manager on this study. Andy received training in project management and his growing research leadership within this study has been recognised through first authorship of this report. He is also co-applicant on the NIHR HSDR study NIHR160824. Andy is receiving bespoke media training to support study dissemination.
- Dr Megan Wyatt is obtaining a permanent academic contract, progressing from Research Associate to Lecturer. Megan took over as lead for the PPI programme within the study. Megan is co-applicant and leading the PPI work package design and delivery for two ongoing NIHR HSDR studies (NIHR160824 and NIHR161439).
- Professor Katie Featherstone has been appointed NIHR Senior Investigator (NIHR305894, April 2025). Katie has mentored mid-career academics to obtain NIHR funding as PI (2023–5): Dr Shadreck Mwale (NIHR160824); Dr Emma Wolverson (NIHR161439); Dr Jo Hope (NIHR206167); Dr Amber John (NIHR162340).

The study research team have been supported by the University of West London in attending national and international conferences to present aspects of this study and to support the development of their research networks during the life of this study.

Our programme of PPI outreach working with community organisations across England and Wales involved providing these community organisations and their staff with training in arts-based events to support PLWD and their families. This programme has supported these organisations in leading their own arts-based projects to support PLWD and their families and care partners.

Our programme of PPI outreach resulted in networks of PLWD who have experiences of a hospital admission and the use of restrictive practices in their care and their care partners who are working with us as experts by experience advisors involved in the coproduction of our analysis, dissemination, and output development and to priority setting outputs and interventions. For example, a person living with dementia and a care partner delivered a NIHR masterclass: NIHR Webinar Series – PPI in Action (30 October 2024). My expertise in PPI is recognised by the NIHR Patient and Public Involvement team, invited to deliver the first 'Webinars with Researchers – PPI in Action' (October 2024) to provide a real-life example of how NIHR PPI standards find expression in practice. Two hundred and eighty-one attendees with 356 views on YouTube (YouTube, LLC, San Bruno, CA, USA) in 1 month.

Due to the potentially upsetting and traumatic phenomena explored within this study, it was not considered appropriate to utilise early career research academics or research nurses in data collection. We will involve nursing and allied health professional staff with an interest in developing research experience and expertise through our programme of dissemination, training and output development. We are working with and supporting nursing staff within two of the study sites to develop follow on NIHR HSDR applications, which they will lead.

To support capacity building in the field of dementia research and health services research, we have delivered a programme of career development training for early and mid-career academics and health and social care professionals:

- Katie Featherstone invited by Alzheimer's Research UK (ARUK) to contribute to their Early Career Research (ECR) national capacity building strategy in dementia research. She designed and led a programme supporting ECRs (interdisciplinary cohort of 30) from across the UK working in dementia research (www.alzheimersresearchuk.org/research/for-researchers/ecr/supporting-your-career/career-development-groups/). Katie Featherstone mentored 12 ECRs from a wide range of specialisms, including psychology, neuroscience, law, philosophy, nursing, speech therapy, physiotherapy, pharmacology, psychiatry, sociology, neuropathology and neuroimaging. The 16-month programme was highly evaluated by ECRs.
- Katie Featherstone delivered in-person workshops and 1 : 1 coaching (in person) at the Centre for Person Centred Research (<https://cpcr.aut.ac.nz>), School of Clinical Sciences, Auckland University of Technology (Health Research Council of New Zealand, April 2023) and National Ageing Research Institute (www.nari.net.au/), Melbourne, Australia (November 2022). Katie Featherstone awarded Visiting Fellow status at both institutions.

- Katie Featherstone was invited speaker (Pathways to academic independence: strategies to recognising our strengths and developing our 'unique contribution to the field') Alzheimer's Society Early Career Researcher Retreat (ECRR), the University of Warwick (30 June 2022). Also, as expert discussant Katie provided advice and practical skills to support ECR career progression www.alzheimers.org.uk/dementia-professionals/conferences-and-events/ECRR-2022
- Shadreck Mwale was invited speaker and round table discussant: British Sociological Association Early Careers Forum event, '*Confidence, collegiality and context in career building*' Tuesday 31 May 2022.
- Katie Featherstone was invited keynote speaker 'Researchers in the eye of the storm' HSR UK Conference 2023. Thursday 6 July, in person, at the University of Birmingham.
- Shadreck Mwale was invited speaker 'Inclusion and Diversity – engaging minoritized and seldom heard voices in Dementia Research' at the Alzheimer Society ECR annual conference 27 June 2023.
- Andy Northcott was invited to present the workshop 'The realities of qualitative research in healthcare settings. Qualitative Research Seminars' as Nuffield Institute at Oxford University in November 2023.
- Katie Featherstone gave the keynote lecture for the Australian Post-Doctoral Training Programme and presented to DEM-COMM post-doc fellows in November 2023.
- Shadreck Mwale presented 'Ethics and Ethnography: A view from NIHR HSDR funded ethnographic research programme Understanding and improving the care of people living with dementia within acute wards, mental health wards, and social care settings' at the symposium on ethics and ethnographic research in NHS and social care settings – 'Better ethics Better research' at the Radcliffe Observatory, Oxford University, in March 2025.
- Katie Featherstone, Andy Northcott and Shadreck Mwale were invited to join the Ethnographic Observatory, a mentorship programme for better ethics in ethnographic research in healthcare settings hosted by Oxford University, in March 2025.

Chapter 6 Patient and public involvement

Patient and public involvement and coproduction has been at the heart of this research project. PLWD with lived experience of hospital-based restraint are co-applicants on this project, involved in study design, members of our steering and oversight committee and involved directly in our dissemination and impact strategy. We have delivered an ambitious PPI programme throughout the research, led by MW and PB, involving outreach and art workshops to gain insights into the use of restrictive practice directly from PLWD.

Patient and public involvement programme

Our approach to PPI involved creative methods to illicit original insights. We aimed to offer PLWD new routes of expressing themselves and provide opportunities to empower individuals living with the condition.²¹¹ Our Artist Researchers approach promoted social interactions between all participants, with the goal to develop mutual reciprocity between PLWD, carers and the research team.

Arts-based theoretical and methodological approaches

This study utilised ethnographic^{140,143} and arts-based methodologies to underpin our approach to support the examination of both verbal and non-verbal communication and experiences. Arts-based ethnographic research approaches are becoming increasingly utilised within healthcare research.^{161,162} Through the active engagement in creative processes, and the appreciation and examination of these non-verbal experiences,¹⁶³ new understandings can be obtained.^{162,165}

Sensory ethnography specifically underpins this methodological approach to ensure it both acknowledges and focuses on the multisensorial nature of the experiences and knowledge of both participants and the researchers.¹⁶⁶ Sensory ethnography enables a detailed exploration of the physical practices and skills, experiences, and tacit knowledge.¹⁶⁷ Focusing on the senses enables new understandings to develop which focus more predominantly on 'inscribed, negotiated, and embodied knowledge and practice' (p: 3).¹⁶⁸

We also draw upon arts-based approaches¹⁶⁹ to provide greater depth and understanding of the experiences and expressions of participants. Informed by an appreciation that non-verbal experiences within creative processes are important because there are numerous modes of knowledge that often defy verbal articulation.¹⁶³ Through the viewing and active engagement in creative processes, new knowledge can be obtained¹⁶⁵ and participating in art making has the potential to facilitate the expression and communication of traumatic and emotionally fuelled experiences.¹⁶⁴

Breakdown of patient and public involvement events

Events have been held regularly across the duration of the study to draw upon a range of experiences of restraint and hospital care from PLWD and their care partners. Efforts have been made to engage with as diverse a range of participants as possible. Diversity in this instance includes not only a wide spectrum of cultural and ethnic minority communities, but also socioeconomic background. For this, we focused engagement on communities in Wales and the North-West of England identified as having high indices of deprivation. A breakdown of location, participants and demographics of events is provided in [Table 3](#).

These events were supported by two rounds of one-to-one interviews with six PLWD from a South-Asian background in the North West of England, conducted by a Health and Wellbeing consultant able to conduct the interviews in the participants' first language, with the transcripts then translated into English by a certified translation service.

Findings of patient and public involvement engagement and outreach

In this section, we discuss key themes that emerged from these events and interviews related directly to hospitals and restraint. A considerable amount of data on restriction in everyday and non-hospital settings were also collected and will be reported in future publications, alongside assessment and consideration around art-based approaches to elicit experiences.

Negative experiences and perceptions of the use of restrictive practices in the care of people living with dementia in hospital settings

Several participants living with dementia described how they had experienced restrictive practices while being admitted to hospital. For example, one participant described how they had experienced delirium while being in hospital and this had led to a situation where they had been physically restrained by care staff. They spoke of the trauma associated with this experience and how this was still something that was impacting them months after the event had occurred.

They physically held me down which that in itself was a terrifying experience ... it was, it was absolutely terrifying. But another form of restraint that's not often considered is medication, you know I was put on sedatives you know and which basically just knocked me out but that is the other form of restraint. So I had three forms of restraint, I had medical, forcible restraint and what I would call placid restraint.

Participant living with dementia (2022)

Some individuals described how they felt that a restrictive practice that had been enforced on them was being 'put' onto a bed while being unable to move or access any help.

They put the bed in the middle of the room away from the buzzer so I had no way of communicating, they put my phone which is in my bag over that side of the room and me crutches over that side of the room and because I couldn't communicate because I had no buzzer and I couldn't get out of bed because if I'd have got out of bed I'd have probably fallen right on my face ... the restraint was when they left me in bed and left everything away from me. That's a restraining because you can't move.

Participant living with dementia (2023)

For participants living with dementia who had experienced a restrictive practice themselves, they largely described the experience as traumatic. Furthermore, participants voiced how the negative feelings associated with the experience still impacted them in their current daily lives. The majority of negative experiences of hospital care were associated with feeling that professional staff did not have an adequate understanding of dementia and how to support individuals living with the condition. In addition, hospital environments were described as chaotic which then exacerbated difficult situations.

A care partner described how they found out that their father had been restrained and placed in a tagged ward. They spoke about how they felt a lack of communication from hospital staff about their father's needs and care which led to them feeling unsure of what was taking place. Care partners who witnessed a restrictive practice being used in the care of a person living with dementia during a hospital admission also spoke about the difficulties of seeing this occur. They described how they felt unsure of what was occurring, and that staff did not inform them about what was happening or appear to have the training to deal with the situation.

Participants from all groups also felt that staff within hospitals did not have clear understandings of dementia or how to care for individuals living with the condition. They all felt that this led PLWD's to feelings of frustration and anxiety to escalate, and individuals described how they felt that this informed staff use of restrictive practices:

What made me feel that the nursing staff didn't know how to deal with dementia was their attitudes towards me, you know, nobody would ever speak to me about dementia even though they knew you know that was the telling factor in both my behaviour and the situation that we found ourselves in.

Person living with young onset dementia (2023)

TABLE 3 Patient and public involvement events and participants

Date	Event type	Location	Number of participants	Details of participants
August 2022	Art workshop	London	9	PLWD from an African-Caribbean background
September 2022	Art workshop	London	11	PLWD from an African-Caribbean background
October 2022	Art workshop	Greater Manchester	10	PLWD, care partners and former care partners
November 2022	Art workshop	Denbighshire	8	PLWD and care partners
November 2022	Individual art workshop	Denbighshire	7	PLWD working one to one with MW
January 2023	Art workshop	Greater Manchester	8	PLWD (one male, seven female)
February 2023	PPI workshop	Online		Two online sessions with people living with a diagnosis of young-onset dementia
March 2023	Art workshop	London	9	PLWD from an African-Caribbean background
March 2023	Individual art workshop	London	4	Female PLWD from an African-Caribbean background
May 2023	Art workshop	Conwy	7	PLWD from a community recognised for significant socioeconomic deprivation
May 2023	Engagement event	Lancashire	20	Older men of Pakistani heritage
May 2023	Engagement event	Lancashire	10	Older women, Punjabi and Urdu speaking
June 2023	PPI meeting	Online	2	PLWD experiences of Care Advisory Group
June 2023	Engagement event	Lancashire	13	Older men from the Bangladeshi community, supported by an Iman
July 2023	PPI meeting	Online	2	PLWD experiences of Care Advisory Group
September 2023	Art workshop	London	9	PLWD from an African-Caribbean background
September 2023	Engagement event	Lancashire	40	South Asian men (Aged 50+)
October 2023	PPI meeting	Online	2	PLWD experiences of Care Advisory Group
November 2023	Art workshop	London	Large group	Older people with complex mental and physical health needs
December 2023	PPI meeting	Online	2	PLWD experiences of Care Advisory Group
February 2024	Art workshop	Greater Manchester	8	PLWD and care partners
March 2024	Art workshop	London	Small group	Older people with complex mental and physical health needs

Participants across all groups felt that wards needed to be better resourced to support PLWD, with recommendations including activities, more comfort and separate waiting areas. They were also unanimous in the need for better training for all ward staff in caring for and engaging with PLWD, and recognising their needs.

Experiences of ethnic minority participants and participants across geographic areas.

Experiences of restrictive practices were relatively consistent over all of the groups that were involved in the PPI programme of work. Difficulties in language were stressed by one care partner who was from a South Asian background as they described the frustration at their loved one not having adequate access to translation services while in hospital. They relayed how the person living with dementia had become increasingly distressed because staff were not able to understand them and that this had led to more forcible restraint despite the cause of the issue being easy to resolve.

Another care partner from a South Asian background described how they felt that the person living with dementia whom they were caring for was restricted by hospital staff's lack of effort at providing translation.

In the psychiatric unit and she was kept in the room by herself with the door shut and I went one evening and I asked, 'Where's mum?' And she was at the very end of the corridor in a room by herself shouting and I said, 'Mum what's the matter?' and she goes 'They've left me in this room, they're not listening to me, they're not speaking to me'. So I wouldn't call that restraint in the conventional sense but I think that was restraint and when I was trying to find a member of staff who could, who I could speak with and ask what was going on with mum's care, I couldn't

Family carer (2023)

Significant emphasis was also placed on the importance of care staff having adequate religious and cultural competence and the need for robust translation services to avoid events escalating and the subsequent need for restrictive practices. It is also important to note that regardless of a dementia diagnosis, a lack of access to translation while in hospital has the potential to be experienced as a restrictive practice.

Restrictive practice as a safety requirement

Several participants, especially care partners, recognised the need for some form of restrictive practice in everyday care. Participants relayed the importance of restrictive practices in preventing a person living with dementia coming to physical harm.

For example, one participant who was a care partner described within a group workshop setting (North West) about how they felt it was at times necessary to restrain a person living with dementia. However, they re-enforced that this needed to be done in an appropriate way. They recalled memories of seeing people being secured to a bed or chair. They described how this had been harrowing and explained that they thought alternative restrictive approaches such as locking a door were more appropriate. They stressed the importance of restraint in caring for a person living with dementia in order to keep them safe.

HB, w2

In relation to care professionals and the use of restrictive practices, one participant who had cared for their partner (Wales) spoke about how they had felt frustrated at a lack of restraint within the care home that their partner was in with regards to medication. Their partner would often throw their tablets on the floor and so staff had informed the participant that this was their partner's choice and that they were unable to force them to take the medication. Their care partner spoke about how they had challenged care staff and reinforced the importance of the medication; however, they were still met with the same response. They explained that staff had informed them that legally they could not force medication; however, the participant explained that they felt extremely frustrating as they felt that without forcing their partner to take the medication, they would die. They also spoke about how they felt that, at times, there was a need for more restraint and that this was not done by the care agencies. They highlighted that there were locks on all the care home doors to stop residents leaving; however, when it came to medication, they felt that they were not listened to and that care staff should have applied more restrictive practices.

Participants living with dementia challenged the assumptions that restrictive practice was required. In the example below, a PLWD described how they associated restraint and restrictive practices with being treated like a child, and how with proper engagement and support, restraint would not be required.

During a group art workshop, a participant living with dementia (London) described how they associated the word restraint with something that would happen to a child. They described her memory of not being allowed to go out as a child. They also commented that as you grow older, you are not able to do the things that you want to. They did not elaborate on this statement and discussed how they thought that advice should always be given before restraining someone. they spoke about how if someone advised them, there would never be a need for her to be restrained. Within this, they also spoke about the importance of good communication when talking to people and that this created mutual understandings without a need for any restrictive practices.

Rather than restraint, PLWD spoke of the need for independence, engagement and perspective on recognising their needs, and how something as simple as a crossword or social engagement could have a positive impact on their mood and thinking.

Feelings of restriction prior to and outside of hospital admission

A significant theme to emerge in relation to restrictive practices related to how participants perceived 'restraint' within their daily lives.

Many participants described how they associated restraint with their experiences of social isolation and not being able to maintain their usual daily or weekly activities due to the symptoms of their dementia, other comorbidities and associated with the stigma they experienced as living with dementia. Participants described how the negative impact that not being able to adhere to their usual routine had on them. For example, some participants explained that they were no longer able to partake in weekly leisure activities that they had attended for a long time previously. Although this could seem like small loss for participants, findings demonstrate that this had a substantive impact on their well-being and perceptions of restraint. These feelings were then exacerbated upon hospital admission.

Differences across groups and areas

When describing perceptions and experiences of restraint, participants who lived in very rural areas of Wales often spoke about the difficulties of living in such an isolated area and not being able to access any social interaction. Participants explained that they would not see people for days or weeks at a time. Some participants described how they were no longer able to drive and that this felt like a huge 'restriction' and had a detrimental impact on their life.

While working with people from South Asian backgrounds, some individuals related 'restraint' to not being able to adhere to their usual religious practices in the same way due to symptoms associated with their dementia. Individuals spoke about how this had a detrimental impact on their well-being and was something that they found very challenging. They described feeling disengaged from their community and how this very quickly caused feelings of isolation.

Ethical issues around restrictive practice

A theme among care partners related to difficulties in how to perceive and apply restrictive practices in the care of PLWD. Although some care partners described negative associations of experiences within hospitals, others spoke about how they felt that the use of restrictive practices was necessary to prevent the person living with dementia from harm, for example, locking someone in a house or a car to keep them safe. Within this theme, care partners also described the ethical considerations and dilemmas that they felt in relation to this. This included feeling unsure of whether it was right to 'hide' PLWD's medication and whether it was ethical to lock someone in their house if there was a risk that they would leave and be unsafe. Furthermore, some care partners described wanting care professionals to apply restrictive practices to keep their loved ones safe but felt frustrated at a lack of restrictive practices within the care of PLWD.

Some participants voiced their thoughts in relation to the use of the word 'restraint' and 'restrictive practices' and how this should be used within care practices. Participants placed importance on the use of the word 'restraint' when referring to restrictive practices. They explained that it was important to use words that accurately describe a care practice even if this can sound harsh or unpleasant. Participants discussed how using words which may sound less severe does not always accurately represent the practice which is occurring. Although two participants led this discussion, other members of the group echoed their thoughts and agreed.

One participant who was a care partner of a person living with dementia spoke about how they felt that it was very important to use the word 'restraint' when discussing restrictive practices. They said that they felt that words were often used to try and diminish what was occurring within health and care practices.

HB, w2

A further participant living with dementia described how they felt that it would be better to use the word 'trapped' when thinking of restrictive practices. They spoke about how this could encompass more experiences. When asked if they had ever felt trapped, P1 spoke about how they had felt trapped when they had been told they could not go out when they wanted to.

NL, w2

During a group art workshop (London), when a participant living with dementia who found verbal communication very difficult was asked by the researcher about their perceptions of the word restraint they said the words 'strange' and 'squeeze'.

NL, w2

Investing time in understandings needs

The researcher (MW) invested significant time in working with organisations and individuals to understand their needs and preferences. This was done through numerous meetings throughout the project delivery, different outreach engagement events and regular contact and communication throughout the project. Organisations and individuals needs evolved over the course of the project and it was important for the researchers to be mindful of this and ensure that they understood this and adapted and responded appropriately.

It is also important to highlight that researchers went out into communities and spent a substantial amount of time working with organisations and individuals to build mutually and beneficial relationships. This proved to be very effective as researchers were able to work with individuals face to face. It is also essential to highlight the importance of working with community experts in understanding what individuals' and organisations' needs and preferences were.

Working with community experts

Community experts are individuals who have a deep and established understanding of the community or group in which they are working with. For example, one community leader who we worked with had a deep understanding of the religious and cultural needs of specific communities, were multilingual and had existing and established trust within their community.

Researchers worked with professionals who had deep understandings of specific communities to advise on the best approaches. Furthermore, community experts also delivered community engagement and PPI events. The community experts who were involved in the projects had a wide range of skills including deep understandings of the cultural and religious needs and preferences of groups, the ability to speak multiple languages and, furthermore, the community experts were trusted members of their communities. Working with these professionals was essential in establishing trust and building mutually reciprocal relationships.

Challenges to patient and public involvement approach

At times, there were challenges in working with organisations and individuals. This largely related to how some staff perceived the researchers and work that was taking place. It can be suggested that delivering PPI work within organisations is often different from the usual activities that are taking place. This can cause unease among staff and at times feelings of hostility. For example, staff often worried about the 'mess' of arts workshops or the consent process.

Furthermore, it was observed that some staff felt an anxiety about how participants would react to researchers or whether participants would be able to adequately engage. Researchers reassured staff that this was not a problem and that they were experienced in delivering this type of work; however, some staff still appeared to worry.

Researchers were experienced in dealing with any conflicting or difficult situations and to try and ease anxiety among staff, regular communication was upheld, and staff were always informed of exactly what would be taking place. This often helped to build trust between researchers and staff and subsequently positive working relationships were developed over the course of the project.

Additional information

CRedit contribution statement

Andy Northcott (<https://orcid.org/0000-0003-3030-9861>): Conceptualisation (equal), Data curation (lead), Funding acquisition (equal), Investigation (lead), Methodology (equal), Formal analysis (equal), Project administration (lead), Supervision (lead), Data, Writing – original draft (equal), Writing – editing and reviewing (equal).

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Data-sharing statement

This is a qualitative study and therefore the data generated are not suitable for sharing beyond that contained within the manuscript. Further information can be obtained from the corresponding author.

Ethics statement

Research Ethics Committee (REC) approval for the study was granted by the NHS Research Ethics Service via the London – Bromley REC (22/LO/0448) and given approval by the Health Research Authority on 15 July 2022. The research project was approved for the purposes of the MCA 2005 (section 31).

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Disclosure of interests

Full disclosure of interests: Completed ICMJE forms for all authors, including all related interests, are available in the toolkit on the NIHR Journals Library report publication page at <https://doi.org/10.3310/GJKF0714>.

Primary conflicts of interest: Katie Featherstone sits on the following funding committees: HSDR Funding Committee (Bevan) – 1 September 2018–2 September 2028 and Deputy Chair of the HSDR Funding Committee (Bevan) – February 2025.

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Appendix 1 Ward descriptions

Ward descriptions

Assessment units

This is where unscheduled admissions arrive for assessment from accident and emergency (A&E), the outpatient department clinic or their general practitioner. Names of these units vary between each sites, most commonly MAU but also acute medical unit (AMU), acute assessment unit or acute admissions unit. Following assessment, patients are discharged, transferred to a specialist centre, or admitted to an inpatient bed. These are high turnover settings, designed to manage the bottlenecks associated with A&E, with the goal of discharging or transferring patients within 24 hours. There is a different routine within this setting, with staff geared to manage acute admissions with fast turnaround, with a lack of apparent continuity or personalised care, and often a chaotic atmosphere. Our advisory group all had poor experiences of this setting and found it a frightening time, where they felt they were not listened to, and were often separated from their partner.

General medical wards

This is where patients are transferred to an inpatient bed following their emergency admission or from the assessment units. These wards usually provide greater continuity and more structured routines. However, although there is an increasing number of admissions of PLWD within general medical wards, they are typically not designed for this patient population. A routine admission for PLWD is 10–20 days; however, for many this is much longer.⁸ Our advisory all reported poor experiences of this setting and found that general wards did not understand the needs of their partner with dementia.

Older people's medicine

This is a key site for older people and PLWD within the acute hospital. Patients within these wards often have multiple long-term conditions exclusive from their admitting condition that need to be managed. Depending on the trust and site, there may be distinctions within COTE ward for patients classified or diagnosed as frail. Age cut-offs for COTE wards vary between sites. Patients admitted to these wards have higher probability of having issues with mobility, continence and/or cognitive ability. Admissions on these wards can be similar in length to general medical wards, but can be prolonged due to decision-making on the appropriate discharge route for the patient.

Older people's mental health

Older people's mental health wards provide services for older patients with organic mental health problems. Unlike the other wards discussed, these settings were often single sex. These wards are secure, and an admission is typically accompanied with legal frameworks from the Mental Health or the MCA. A wider MDT in in place including doctors, nurses, psychologists, physiotherapists, OTs and speech and language therapists. Admission to these settings can be extended with patients' admission dependent of a full assessment and decision-making around supporting the patient's discharge.

Appendix 2 Site details

Dyad breakdown

Each dyad for this study comprised sites recruited from two NHS trusts operating in the same geographic area, for instance an NHS Hospital Trust for acute wards and a Partnership NHS Trust for mental health settings. Often staff observed worked across these two organisations, and it was common for patients to be transferred or referred across these Trusts.

Dyad 1

Dyad 1 is based in the north of England, covering a city surrounded by rural areas and a number of large post-industrial towns. The demographics of the area are diverse, with significant socioeconomic diversity with pockets of high poverty and deprivation. The population is primarily White British, but there is a sizable Black British community alongside significant pockets of diversity including Irish, Indian, Pakistani and a small but notable Traveller/Roma community.

Site A

Older people's mental health

At this site there we observed care over two specialist older people's mental health wards, divided by sex. Each ward has < 25 beds (< 50 beds total) admitting patients over 65 years of age.

Site B

Older people's care

This site had several wards dedicated to older people's care. These wards were divided by sex, although this could be flexible depending on intake and demand for beds. Observers were based on two wards.

Ward one is a standard inpatient ward predominantly occupied by older female patients with a medical need requiring nursing and clinical support. This ward has < 30 beds plus a number of auxiliary side rooms for infection control.

Ward two is a nurse-led inpatient unit for older patients who have met the criteria to be fit for discharge but require further rehabilitation or care support in place before the patient is able to return to their home or be discharged to a suitable care setting. Admissions to this unit could often be much lengthier than for comparable discharges directly from the older people's ward. This ward has < 30 beds.

Dyad 2

Dyad 2 is based in the south of England. The trusts and sites are based in a large town serving as the commercial centre of an otherwise largely rural county. The town itself has significant socioeconomic diversity with areas of deprivation, while the surrounding areas are more proportionally wealthy. The population of the town is primarily White British alongside significant Black, South Asian and Chinese populations, while the wider area is primarily White British and less diverse.

Site C

Older people's mental health

This site had two specialist older people's mental health wards, with one ward supporting a general population of older people and another specialising in dementia care. Each ward has < 20 beds and were mixed gender.

Site D

Acute medical unit

This site has a large AMU for assessing patients on admission, alongside a high-dependency unit and a short stay unit for ambulatory patients. AMU at this site is large enough to be divided into two sections, each with their own nursing team. Assessment is scheduled to occur within 6 hours of an admission and transfer or discharge within 48 hours. Across the two units there are < 60 beds.

Older people's medicine

This ward is an acute medical ward caring for older patients and patients requiring end of life care. It is a mixed-sex setting with the sex of patients generally divided by bays. There are < 28 beds on this ward.

Dyad 3

Dyad 3 is based in a major metropolitan city in England. The two trusts serve specific boroughs within this city and none of the surrounding areas. The demographics of the populations covered by these trusts are extremely diverse, both in terms of socioeconomic and race and cultural backgrounds. A significant number of languages are spoken, and a significant proportion of admissions do not speak English as a first language.

Site E

Older people's mental health

This setting is a specialist care unit specifically catering for older PLWD and mental health problems. Each patient has their own room within a mixed-sex setting, accompanied by single-sex day room and activity facilities. There are 20 beds occupied at any time.

Site F

Acute medical unit

This is a large assessment unit admitting adult patients with a wide range of conditions. While a medical unit, it also admits mental health patients when required. The unit is old in comparison to our other sites, with patients spread between bays of varying sizes and a high number of side rooms. There are > 35 beds with the number of beds on each bay expanding if required.

Older people's medicine

There are two large older people's medicine units at this site located next to one another. Both are mixed sex. One ward has recently been renovated and is very modern and sleek in design. The other ward is awaiting renovation and looks old and tired by comparison. Each ward has < 25 patients (< 50 patients total).

EME
HSDR
HTA
PGfAR
PHR

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