

Institution: De Montfort University		
Unit of Assessment: 3		
Title of case study: Stories of Dementia: Improving Experiences of Care for People Living with Dementia During Acute Hospital Admissions		
Period when the underpinning research was undertaken: March 2015–present		
Details of staff conducting the underpinning research from the submitting unit:		
Name(s):	Role(s) (e.g. job title):	Period(s) employed by submitting HEI:
Andy Northcott	Senior Lecturer	March 2017–present
Period when the claimed impact occurred: May 2017–December 2020		
Is this case study continued from a case study submitted in 2014? N		
1. Summary of the impact <p>A programme of ethnographic research, co-led by DMU and funded by the National Institute for Healthcare Research (NIHR), identified how care for people living with dementia during an acute hospital admission could be improved. The findings resulted in an increased policy focus in England and Wales on improving the experiences of hospital admissions and hospital-related health outcomes for people living with dementia; they influenced parliamentary debates and inquiries and supported the rollout of the Welsh Government's dementia action plan. The research changed clinical practice through the design of specialist online and face-to-face training for NHS staff and Dementia UK's Admiral Nurses. It enabled social inclusion through the creation of a dementia-friendly film programme and by inspiring a new play that highlighted the experiences of dementia care among under-represented and vulnerable communities.</p>		
2. Underpinning research <p>One in four acute hospital beds in the UK are occupied by a person with dementia. However, people living with dementia are a highly vulnerable group within the hospital setting. Following an acute admission, their functional abilities can deteriorate significantly. A previously published longitudinal cohort study of acute emergency admissions found that patients over 70 with cognitive impairment had markedly higher, short-term mortality, with 24% dying. Collaborative research by DMU's Northcott and Cardiff University's Dr Katie Featherstone sought to identify the ways in which the delivery of nursing care could be adapted to improve the quality of care for people living with dementia during an acute hospital admission.</p> <p>The NIHR-funded research programme [G1, G2] used ethnography to examine the care that people living with dementia receive when they are admitted to hospital, and to understand the organisational practices and cultures that inadvertently contribute to poor health outcomes and experiences of this patient group [R1, R4].</p> <p>Researchers observed 360 shifts at eight hospitals in England and Wales [R1, R4], providing an original empirical foundation for how people living with dementia are cared for in hospital, and how overlooked everyday aspects of care can have significant consequences for these patients and their families [R1-R5]. The team focused on a common but poorly understood feature of caring for people living with dementia: the refusal and resistance of care. The findings, first published in an NIHR research report in 2018 and later in peer-reviewed journals [R1–R5], described a ward landscape of dehumanisation, staff burnout and a setting that was not meeting patient needs. The key findings were:</p> <ul style="list-style-type: none"> • High levels of resistance to bedside care among people living with dementia within acute hospital wards: Every patient living with dementia observed during the study resisted care at some point during their admission. This had implications for experiences of care and outcomes, contributing significantly towards delayed discharge, interruptions to transfers within the hospital and institutionalisation at discharge [R1, R4, R5]. 		

- Ward staff tended to interpret resistance as a feature of a dementia diagnosis. However, this behaviour was not because they lacked capacity. Resistance to care was typically a response to ward organisation and care delivery (routinised and compartmentalised care provided by many different people). These findings were shared with hospital staff so they could recognise these issues and respond appropriately [R2, R3, R5].
- All behaviour of people living with dementia could be interpreted as potentially problematic by ward staff in the context of ward routines. Walking or walking unaccompanied within the ward and getting out of bed was typically discouraged and problematised, which has implications for mobility and rehabilitation. The findings helped hospital staff to recognise that by supporting the mobility of patients (for everyday activities like going to the toilet) they can minimise resistance to care, benefiting patients, while reducing their own workload and lowering staff burnout [R1, R4, R5].
- A key response to people living with dementia in acute wards was the use of containment and restraint, which was largely undocumented. Techniques employed to reduce mobility included the raising of bed siderails, tucking bedsheets tightly around patients, placing walking frames out of reach and sedation [R1, R4, R5].
- For ward staff, the restricted repertoire of work and low levels of training and knowledge of dementia contributed to cultures of dehumanisation and staff exhaustion. Outsourcing of dementia care and expertise means it is seen as other people's work [R4, R5].
- Everyday elements of personal care such as continence are deprioritised in hospital and present serious concerns for patient dignity and basic human rights [R1, R4].

3. References to the research

- [R1] Featherstone, K. and Northcott, A. (2020) *Wandering the Wards: An Ethnography of Hospital Care and its Consequences for People Living with Dementia*, Abingdon: Routledge; ISBN 9781350078451
- [R2] Boddington, P., Featherstone, K. and Northcott, A. (2020) 'Presentation of the clothed self on the hospital ward: an ethnographic account of perceptual attention and implications for the personhood of people living with dementia', *BMJ Medical Humanities*, ahead of print; doi:10.1136/medhum-2019-011757
- [R3] Featherstone, K., Boddington, P. and Northcott, A. (2020) 'Using signs and symbols to label hospital patients with a dementia diagnosis: help or hindrance to care?', *Narrative Inquiry in Bioethics*, 10(1): 49–61; doi:10.1353/nib.2020.0026
- [R4] Featherstone, K., Northcott, A., Harden, J., Bale, S., Harrison-Denning, K., Tope, R., Bale, S. and Bridges, J. (2019) 'Refusal and resistance to care by people living with dementia being cared for on acute hospital wards: an ethnographic study', *Health Services and Delivery Research*, 7(11): 1–112; <https://doi.org/10.3310/hsdr07110>
- [R5] Featherstone, K., Northcott, A. and Bridges, J. (2019) 'Routines of resistance: an ethnography of the care of people living with dementia in acute hospital wards', *International Journal of Nursing Studies*, 96: 53–66; doi:10.1016/j.ijnurstu.2018.12.009

KEY UNDERPINNING GRANTS

- [G1] NIHR (Award ID: 13/10/80). MemoryCare: Investigating the management of refusal of care in people with dementia admitted to hospital with an acute condition. GBP405,869.19. February 2015–January 2018. Featherstone was Chief Investigator on the grant; Northcott, as co-investigator, was jointly responsible for leading the ethnographic study, conducting site recruitment and local research governance. Northcott and Featherstone co-authored the final report. This project began while Northcott was employed by Cardiff University and he has continued to develop and co-lead the research since joining DMU as a VC2020 lecturer in 2017, generating [G2] and [R1-5].
- [G2] NIHR (Award ID: 15/136/67). Understanding how to facilitate continence for people with dementia in acute hospital settings: raising awareness and improving care.

GBP508,100.80. November 2017–May 2020. Featherstone was Chief Investigator on the grant; Northcott, as co-investigator, was jointly responsible for leading the ethnographic study, conducting site recruitment and local research governance. Northcott and Featherstone co-authored the final report.

4. Details of the impact

Ethnographic research co-led by Northcott has provided a detailed picture of the experiences of care for people living with dementia during an acute hospital admission, and a set of recommendations for how care can be improved for this vulnerable patient group. Through targeted media engagement, the study findings have stimulated high-profile public debate in the UK, influencing parliamentary deliberations and contributing to policy responses designed to optimise care for older people. The research has shaped new online and face-to-face dementia care training and informed a dementia-specific film programme to support social inclusion.

(1) INFLUENCING PUBLIC DEBATES AND POLICY RESPONSES TO IMPROVE HEALTH OUTCOMES FOR PEOPLE LIVING WITH DEMENTIA

In April 2018, Northcott and Featherstone shared their findings exclusively with *The Observer* and BBC Five Live to maximise their impact. The *Observer* article [C1] was viewed 48,718 times online and reached up to 160,000 people in print. It highlighted the key research conclusions: the organisation of wards is unsuitable for both people with dementia and staff, many of whom lack the required skills and training, and the use of containment techniques is frequently the trigger of resistance or cause of patient anxiety. The story was directly shared on social media 232 times and generated 348 comments, featuring the perspectives of carers and health professionals. The article prompted a formal statement from the Department of Health and Social Care (DHSC) [C1] and quoted the president of the British Geriatrics Society: 'These findings are a huge concern. Sometimes the use of containment techniques is not justified' [C1].

The study formed the basis of a 45-minute radio piece on *BBC Five Live Investigates* titled 'Dementia Care' [C2a], in which the research was featured for the entirety of the programme. Its audience reach was up to 5,000,000; it featured interviews with a carer, a person living with dementia, a nurse and a representative from Dementia UK. It prompted another statement from DHSC and a statement from the Royal College of Nursing, who cited the research as evidence for the need to increase hospital staffing levels, saying that unsafe staffing levels were contributing to a culture of dehumanisation [C2a]. The Five Live team made an accompanying two-minute film for the BBC News website about the research. It was the most viewed news item on the BBC News website for the relevant 24-hour period [C2b].

The Five Live piece led to an invitation from care charity The Edith Ellen Foundation to discuss the findings at a panel event on dementia and healthcare at the House of Lords in June 2018 [C3]. This led to an invitation to present the evidence at the All-Party Parliamentary Group on Dementia inquiry on Dementia and Disability in November 2018 [C3]. The research was cited directly by the Royal College of Nursing (RCN) in its formal recommendations on education and training in a NICE review of quality standards and indicators in dementia care in November 2018 [C4, p112].

In Wales, the media coverage of the research in April 2018 resulted in it being cited in the Senedd the following month, in a question put by Welsh Assembly Member Lynne Neagle to the Cabinet Secretary for Health and Social Services. She cited the studies to support her call for the provision of 'person-centred care to people with dementia'; the Cabinet Secretary said the Welsh Government would address this [C5 paragraph 168]. The findings were presented and discussed at a meeting of the Welsh Assembly Cross-Party Group on Dementia in October 2018, at the invitation of Neagle (Group chair) [C6]. This led to the launch of the Group's inquiry into hospital care, which was due to report in spring 2020 until delayed by the Covid-19 pandemic [C6].

As part of the rollout of the 2018-2022 Dementia Action Plan for Wales, the Welsh Government and Public Health Cymru related the study findings to Improvement Cymru (improvement service for NHS Wales). From November 2019 Improvement Cymru presented the research to health boards in Wales to guide best practice and improve recognition of dementia within acute hospital

wards [C8]. The BBC and *Observer* coverage also led directly to a request for research data by the team authoring the All Wales Safeguarding Procedures (measures protecting vulnerable adults), which were published in April 2020. This data contributed to the sections that provided guidance on professional abuse and protecting the well-being of patients.

(2) CHANGING CLINICAL PRACTICE THROUGH SPECIALIST ONLINE AND FACE-TO-FACE STAFF TRAINING

As a direct result of the research, Public Health Wales and NHS Cymru invited Northcott and Featherstone, in 2019, to design and deliver a training programme for the leaders of all seven NHS Health Boards in Wales. This was accompanied by training for nursing and ward staff from three NHS Trusts in collaboration with Dementia UK [C8]. The aim of the programme was to raise awareness of the needs of people living with dementia at an organisational level, and to provide the tools for these organisations to develop their own low- or no-cost strategies to improve care. Initial training took place at Cardiff and the Vale University Health Board in November 2019. Nine further sessions were scheduled to take place from March 2020 onwards were postponed due to Covid-19. The research also featured as an 'NIHR Signal' in the BMJ in 2019 – Signal briefings are aimed at healthcare decision makers [C7a, b].

Northcott and Featherstone produced training films based on the research, in collaboration with professional film-makers, Dementia UK and Open University. They included testimonials from research participants, carers, nurses and people living with dementia themselves. Shortened versions (under a minute each) were also produced for dissemination via Facebook and Twitter during annual events like Dementia Awareness Week [C3]. These films, together with the project website www.storiesofdementia.com and the media engagement, were recognised by the NIHR as best practice for engaging non-academic audiences in health research [C3]. Parts of these films have been used (and continue to be used) by acute hospitals within Aneurin Bevan University Health Board as part of their ongoing CPD provision for nursing and ward staff [C8]. The Board's R&D Director wrote that the research has 'supported nursing leadership around dementia care within our acute hospital care settings [which serve a population of 600,000] and promoted the research culture and capacity within our organisation' [C8].

The same resources were used for training days organised by Dementia UK and attended by its Admiral Nurses. Beginning in October 2017, these sessions enabled Admiral Nurses to design 'hacks' or mini-interventions to implement practice improvements in hospital and community settings [C9]. Dementia UK wrote that the research was 'particularly influential in helping us to refine the Admiral Nurse "offer" in supporting the acute sector to deliver person-centred care ... the numbers of acute care partnerships we have are increasing exponentially as a result' [C9]. The NIHR funded the development (with the Open University) of a CPD-approved FutureLearn online course: Dementia care in hospital: Caring for people living with dementia in acute hospital wards, the launch of which has been postponed to 2021 due to Covid-19.

(3) ENABLING SOCIAL INCLUSION THROUGH THE DESIGN OF DEMENTIA-FRIENDLY FILM SCREENINGS AND A NEW PLAY ON THE EXPERIENCES OF UNDER-REPRESENTED COMMUNITIES

The studies highlighted the invisibility and precariousness typically experienced by people living with dementia. Northcott and Featherstone created the 'Tinted Lens' film initiative, as part of the public engagement strand of the research programme, to support the integration of an often-excluded audience. Working alongside charities and arts organisations (including Carers UK, Dementia UK, British Film Institute (BFI), Film Hub Wales (FHW) and Chapter Arts), they co-designed the toolkit: Dementia Friendly Screenings: A Guide for Cinemas. They co-organised film screenings during Dementia Awareness Week in 2017 and 2018, in collaboration with Chapter Arts and funded by the BFI and FHW. They were attended by 600 people living with dementia and their families. The 2017 event led to monthly dementia-friendly screenings that were attended by 20–100 members of the public and covered by *The Guardian* [C10a] and the BBC [C10b]; cinema-goers had an opportunity to chat with each other and staff and the auditorium was adapted to be as calming and comfortable as possible. FHW reports that the Tinted Lens initiative helped them 'gain momentum and crucial awareness' and demonstrate that the model worked and could be replicated on a wider scale. Its Strategic Hub Manager wrote:

'Dementia friendly cinema is now a staple in many cinema calendars, with cinemas confident in offering this to their customers as part of their core programmes' [C11].

A play exploring the experiences of dementia care among vulnerable or under-represented communities (e.g. the D/deaf community, BAME groups) drew directly on the ethnographic approach of Northcott and Featherstone's studies [C12]. *Next of Kin* was written by Cardiff University Research Fellow Sofia Vougioukalou and directed by Julia Thomas from National Theatre Wales. The play was shown online in December 2020, as part of the 2020 Festival of Social Science, by Y Lab, a Cardiff University and Nesta collaboration. Produced in partnership with Alzheimer's Society Cymru and Reality Theatre, an accompanying webinar 'shared insights from a diverse group of people with the aim of creating shared learning, an impactful understanding of diversity in adult dementia care and a more equal care system' [C12].

5. Sources to corroborate the impact

- [C1] *The Observer* and *Guardian* online article:
<https://www.theguardian.com/society/2018/apr/21/dementia-patients-dehumanised-hospital-restraint-techniques>
- [C2a] BBC Five Live Investigates
<https://www.bbc.co.uk/sounds/play/b0b01djz>
- [C2b] BBC Five Live accompanying film
<https://www.bbc.co.uk/news/av/uk-43843230>
- [C3] NIHR case study: Stepping away from the desk: Using patient and carer networks, film and social media to improve acute dementia care, July 2019.
<https://www.nihr.ac.uk/documents/case-studies/stepping-away-from-the-desk-using-patient-and-carer-networks-film-and-social-media-to-improve-acute-dementia-care/21430>
- [C4] NICE Health and social care directorate, Quality standards and indicators, Briefing paper. 'Quality standard topic: Dementia', November 2018 (p112)
- [C5] Minutes from the proceedings of the Welsh Assembly, 8 May 2018.
<https://record.senedd.wales/Plenary/4981#C83834> (see para 168)
- [C6] Cross Party Group on Dementia. Minutes: October 2018.
<https://business.senedd.wales/documents/s94888/Minutes%20of%209%20October%202018.pdf> and Hospital care inquiry homepage: <https://www.alzheimers.org.uk/get-involved/our-campaigns/wales-cross-party-group-inquiry-hospital-care>
- [C7a] Practice: NIHR Signals. 'Steps to better understanding resistant behaviours in hospitalised patients with dementia', *BMJ*, 2019:
<https://www.bmj.com/content/366/bmj.l4912>
- [C7b] Practice: NIHR Signals. *NIHR expert commentary*
- [C8] Corroborating statement from the R&D Director, Aneurin Bevan University Health Board.
- [C9] Corroborating statement from the Head of Research & Publications, Dementia UK.
- [C10a] Coverage in *The Guardian* of dementia-friendly film screenings run by Film Hub Wales.
https://www.theguardian.com/social-care-network/2017/sep/21/dementia-friendly-screenings-cinema-film-alzheimers?CMP=share_btn_tw
- [C10b] Coverage on BBC Radio 5 Live (Kermode and Mayo's Film Review) of dementia-friendly film screenings run by Film Hub Wales. <https://www.bbc.co.uk/programmes/b093lc81>
- [C11] Corroborating statement from the Strategic Hub Manager, Film Hub Wales.
- [C12] *Next of Kin*: a performance and discussion about dementia, D/deaf communication and healthcare: <https://ylab.wales/research/dementia-and-diversity/next-kin-performance-and-discussion-about-dementia-ddeaf>; Corroborating email from the writer of the play.