

Institution: University of Hull		
Unit of Assessment: 03 – Allied Health Professions, Dentistry, Nursing and Pharmacy		
Title of case study: Changing perceptions and developing effective management tools in dementia care		
Period when the underpinning research was undertaken: 1995 – to date		
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:
Esme Moniz-Cook	Prof (Clinical Psychologist)	1995 – to date
Peter Campion	Prof (General Practitioner)	1995 – 2010
Andrea Hilton	Senior Lecturer (Pharmacist)	2012 – to date
Emma Wolverson	Senior Lecturer (Clinical Psychologist)	2016 – to date
Period when the claimed impact occurred: 2014 – to date		
Is this case study continued from a case study submitted in 2014? No		
1. Summary of the impact		
<p>The impacts from the Hull team have transformed thinking around ‘challenging behaviour’ in dementia, from its association with pathology, to that of a clinically-defined marker of distress. Researchers have systematically captured the care-gap associated with behavioural changes in dementia by: rigorously defining ‘Challenging Behaviour’; developing personalised psychosocial and health intervention tool-kits for recognition and management. The programme provides health and social care professionals with alternatives to potentially harmful drugs for managing distress, thus benefiting both people with dementia and their families. Furthermore, Hull’s research has led to a change in public perceptions of dementia from challenging behaviour to a care-need that requires multi-professional support and intervention.</p>		
2. Underpinning research		
<p>Before 2000, the most costly and burdensome aspects of dementia, that is, behavioural changes such as agitation and aggression, occurring in 90% of cases, were diagnosed as ‘Behavioural and Psychological Symptoms of Dementia’ (BPSD). This neuropathological assumption about causation resulted in psychotropic management, which had limited efficacy and additionally raised serious concerns about risks of morbidity and mortality among people diagnosed with dementia. Work from the University of Hull (UoH) shifted BPSD research, towards psychosocial diagnostics and interventions for common behavioural care-challenges, defined as ‘Challenging Behaviour’ - and over two decades ago, launched the highly influential, international, multidisciplinary psychosocial dementia care research network for ‘early detection and timely INTERvention of DEMentia’ (see INTERDEM). In September 2020 the organisation had > 230 members (academics and clinicians) from 23 countries, and supported an academy of >200 PhD and early career researchers. INTERDEM has placed the psychosocial needs of people with dementia and their relatives on the international research agenda.</p> <p>The multidisciplinary Dementia Research Group at UoH (Professors Moniz-Cook, Clinical Psychologist; Campion, GP; Markova, Psychiatrist; and Dr Hilton, Pharmacist) led the UK-wide research programme ‘<i>Challenge Demcare</i>’ (Ref1); Moniz-Cook and Wolverson (Clinical Psychologist) disseminated best practice across the NHS, social care and voluntary sectors.</p>		
Key research findings		
<i>Personalising care beyond ‘symptom-management’</i>		
<p>At the end of the 1990s, the Hull team discovered that behavioural changes in dementia were influenced by staff understandings, emotional states and related responses to the care-recipient (Ref2). This shifted research away from BPSD symptom-management to a focus on staff training, showing that behavioural care-challenges in care homes, later defined as Challenging Behaviour (CB), could be successfully resolved (Ref1). Through systematic assessment of the idiosyncratic psychosocial causes of CB, safe personalised interventions were demonstrated (Ref3). In 6 months, the Hull clinical team led by Moniz-Cook successfully resolved 98% of care home</p>		

referrals. Then, through training community mental health nurses, the efficacy of personalised psychosocial approaches for CB in family care was demonstrated, in the UK's first randomised controlled trial (**Ref4**). Finally, an implementation research programme '*Challenge Demcare*' up-scaled this work for 'wider reach', by developing and testing evidence-based, providing interactive e-learning and decision-support interventions for CB, bespoke to care homes and family settings. This technology provided standardised, but personalised, 'action-plans' for health (medication review / lifestyle management) and psychosocial unmet needs of patients. In addition, given our knowledge of how families' and care-staff perception of behaviour can influence rates of CB (**Ref5 & Ref2**), the technology provides bespoke guidance for specialist dementia teams on how to support the differing needs of families and care homes. Implementation involved reviewing 2,386 residents from 63 care homes for clinically significant CB, and 5,360 consecutive family referrals to 33 specialist mental health teams across England (**Ref1**).

Improving CB in dementia care

The work reported in *Challenge Demcare* (**Ref1**) demonstrated that:

- Specialist mental health services fail to recognise all clinically significant CB in dementia, particularly for families referred by the GP, i.e. CB is either 'hidden' or unresolved by specialist teams (**Ref6**).
- Higher levels of CB were recorded in families than was expected; as 60% of home-dwelling people with mild dementia have clinically significant CB.
- Care home staff appreciate CB-specific e-learning, but efficacious personalised intervention for clinically significant CB requires additional multidisciplinary-based support, particularly for sub-optimal prescriptions of psychotropic drugs.
- Smaller 'non-hierarchically managed' care homes compared with large organisations, show greater readiness to engage with novel support programmes.

3. References to the research

Ref 1. Moniz-Cook E, Hart C, Woods B, Whitaker C, James I, Russell I, *et al.* (2017) *Challenge Demcare: Management of challenging behaviour in dementia at home and in care homes. Programme Grants Appl Res* 5(15)

Ref 2. Moniz-Cook E, Woods R & Gardiner E. (2000) Staff factors associated with perception of behaviour as 'challenging' in residential and nursing homes. *Aging & Mental Health* 4,1,48-55

Ref 3. Moniz-Cook E, Stokes G & Agar S. (2003) Difficult behaviour and dementia in nursing homes: five cases of psychosocial intervention. *Clinical Psychology & Psychotherapy* 10,197-08

Ref 4. Moniz-Cook E, Elston C, Gardiner E, Agar S, Silver M, Win T & Wang M. (2008) Can training Community Mental Health Nurses to support family carers reduce behavioural problems in dementia? An exploratory pragmatic randomised controlled trial. *International Journal of Geriatric Psychiatry* 23, 2, 185-91

Ref 5. Feast A, Orrell M, Charlesworth G, Melunsky N, Poland F & Moniz-Cook E. (2016) Behavioural and psychological symptoms in dementia and the challenges for family carers: Systematic review. *British Journal of Psychiatry* 208,5, 429-34

Ref 6. Manthorpe J, Hart C, Watts S, Goudie F, Charlesworth G, Fossey J & Moniz-Cook, E (2018) Practitioners' understanding of barriers to accessing specialist support by family carers of people with dementia in distress. *International Journal of Care and Caring* 2, 1, 109-23

Selected Collaborative Research awards

The Dementia Research Group at UoH has been highly successful in achieving applied research funding from the mid 1990's, with > £16 million awarded since 2014; > £2.5 million as CI. Examples are:

i) Moniz-Cook E (co-CI) with Mountain, G. & Øksnebjerg, L. (2014 - published October 2015) Dementia Outcome Measures; charting new territory [JPND-Research: Cohort Working Groups **€50,000** [Danish Innovation Foundation, Denmark under the aegis of JPND]

ii) Moniz-Cook E (CI), Champion P, Markova I, Hilton, Mason A, Woods B, Mozley C, Russell I,

Edwards R, Downs M, Stokes G, James I. & Orrell M (2007 - published 2017) *Challenge Demcare: Management of Challenging Behaviour in Dementia at home and in care homes* [NIHR-PfAR **£2,079,654** - additional DoH infrastructure **£343,375**]

iii) **Moniz-Cook E** (co-I) with Orrell et al (2007- published 2017) SHIELD Support at Home - Interventions to Enhance Life in Dementia [NIHR-PfAR **£1,979,387**]

iv) **Moniz-Cook E** (co-I) with Ballard et al (2010 - published 2020) WHELD An Optimized Person Centred Intervention to Improve Mental Health and Reduce Antipsychotics amongst People with Dementia in Care Homes [NIHR-PfAR **£2,106,004**]

(vi) **Moniz-Cook E** (co-I) with Orrell et al (2014 -2021) PRIDE Promoting Independence in Dementia [ESRC/NIHR- Ref ES/L001802/1 **£3,686,671**]

vii) **Wolverson E** (co-I) with Cortés et al (2016-2019) CAREGIVERSPROMMD [Horizon 2020 EU. 3.1.6 **€4,087,198,75** -Universitat Politecnica de Catalunya, Spain; UoH **£372,543**]

viii) **Moniz-Cook E** (co-I) with Mountain et al (2015-2020) Journeying through dementia; randomised controlled trial of clinical and cost effectiveness [NIHR-HTA Ref14/140/80 **£1,964,888**]

(ix) **Moniz-Cook E** (co-I) with Orrell M et al (2014 -2022) AQUEDUCT: Achieving Quality and Effectiveness in Dementia using Crisis Teams [NIHR-PfAR **£1,978,647**]

4. Details of the impact

Hull's research impact has demonstrated conceptual and practice-based knowledge with positive outcomes. Outlined below is how it has: changed professional thinking about 'behaviour in dementia', through implementation of guidelines and toolkits (4.1); improved approaches to meeting psychosocial needs of people and carers, thus reducing the need for psychotropic drugs (4.2); provided a suite of online digital support tools (4.3) and; benefitted people affected by dementia through changes in public perceptions of dementia care (4.4).

4.1. Changing the thinking around perceived care challenges

Hull research has informed the NICE guidelines since 2006. Coinciding with the NICE update in 2018, the British Psychological Society (BPS) launched a "Call for Action", highlighting the still unresolved need for specialist practitioners to support care homes and families in implementing non-pharmacological alternatives to psychotropic medicines, based largely on Hull's research (E1). **The BPS also commissioned a team of clinical experts to prepare a toolkit for multi-professional teams to apply the new evidence, including Hull's seminal findings**, on the management of CB. The BPS endorsed this guidance with circulation to 609 UK NHS specialist dementia care clinical psychologists (October 2019) and made it freely available to download (E2). This has influenced thinking across the NHS: A Quality Improvement Manager, NHS England/NHS Improvement (NE and Yorkshire) says: '*Thank you colleagues at Hull University for work on the dementia behavioural guidelines programme (London 2019) and disseminating this at our oversubscribed 'Whole system' event Leeds (June 2019) (E3i); Hull's Challenge Demcare e-learning has been adopted by many from our 550 strong practitioner-network; we are piloting the CLEAR © training and Hull's CBS tool in care homes*' (E3ii).

4.2 Customised non-pharmacological dementia care for managing CB

Professionals tended to misunderstand and miss the huge burden of clinically significant CB in family care, which therefore remained 'hidden' until it was too late to prevent breakdown of home-care, so antipsychotic drugs were commonly prescribed. Hull's research has provided knowledge-based tools to better identify support-needs for this previously missed cohort, and also for those at risk in care homes. The Challenging Behaviours Scale (CBS) care-home tool was adopted by 78 registered NHS service locations across the UK (2016-2019). Hull's website, where the tools are freely available, had 489 visits (11.08.20 - 31.12.20) to access the CBS care-home tool and its equivalent for family care. Feedback on the tool has been extremely positive, e.g. Two service users state, '*Repeat CBS is used to evaluate final outcome*'; '*in care homes we will go back and evaluate what difference there has been and use the CBS score*'. (E4). NHS services in Scotland and Northern Ireland have adapted the CBS for their services (E5). **Thus, Hull's diagnostics protocols allow for timely recognition of clinically significant care-needs, and also enhance resolution of challenges before these become so burdensome that care breaks down.** The wide adoption stems from the fact that the protocols are written in the everyday language of carers, with psychometrically sound cut-off points for the recognition

of clinically significant CB and focussed behaviour support plans for family and care home settings. A Trust-wide Pathway Lead for Psychological Intervention, (Cumbria, Northumberland, Tyne and Wear NHS FT) writes: *'A particular strength of Hull's work has been its focussed 'easy to use' behaviour support care plans, tailored to the individual health and psychosocial needs of the person with dementia with additional targeting of support needs of family carers and care home staff.'* (E6).

4.3 A digital repository of support for the management of behavioural care

As CB was previously not recognised as a clinically-defined dementia 'care-need', specialist professionals struggled to support families and care-homes effectively. **The Hull team developed a website to create a digital platform for making best practice training and resource tools widely available.** An online tool-kit is available alongside a digital training programme; the latter has received over 1000 viewings for some products (as of 31.12.20). The platform includes, the interactive, real-life, video-based e-learning tool for producing personalised care plans, completed by 541 registered users (11.08.2020-31.12.20). The Head of Quality Improvement & Research from NHS Vale of York Clinical Commissioning Group writes: *'..your e-learning is absolutely fantastic! I have shared with York network - all 525 CCG staff, care homes, domiciliary providers and wider (local authority/acute/ primary care/ mental health etc)'* (E7i). The community feedback of videos such as ("Mick shouts for Lilly and aggressive with carers"), are widely appreciated as they easily communicate the huge struggles that people with dementia and carers can face: feedback from a Core Psychiatry Trainee: *'I found it really helpful to review why people become aggressive or display certain behaviours and actually rather than putting it all as due to dementia, often there is a very clear, personality and lifestyle related reason which we can make practical steps to address.'*(E7ii). **During the COVID 19 pandemic, the website's digital material functioned as a ready-made template for shifting training resources online.** For example, the Newcastle Communicating and Interacting Training (CAIT), intervention for dementia practitioners, included much of the functionality from the Hull website into their own COVID online training animations on behavioural care-challenges (31.12 20 almost 7,000 views). (E6 & E8)

4.4 Empowering people with dementia, their families and the public to manage the perceived behavioural changes associated with the condition

The research findings have been widely disseminated beyond scholarly journals. For example, Moniz-Cook was invited to speak at the 2018 Latitude Festival (a rock festival with 35,000 attendances), addressing issues around preventable behavioural challenges in dementia (E9). Hull's research has **stimulated widespread discussion and debate about the terminology.** Moniz-Cook was invited to present a symposium at the Alzheimer Europe conference (The Hague, October, 2019) attended by 954 participants from 46 countries (E10i). Worldwide debate on language followed the symposium, involving people with dementia such as the #BanBPSD campaigners, the European Working Group for people with dementia and individuals such as an individual who lives with dementia and blogs about her experiences with over 3,000 followers noticed. In January 2020 at the launch of Hull's work on the **Power of Language** she wrote: *"I've had long held views about the language used by professionals. My pet hate is 'Challenging behaviour'...which makes us out to be at fault instead of others simply not understanding our distress."* (E10ii). This work gathered international 'voices' of people with dementia (54), carers (229) and stakeholders (378) to re-shape language and enhance positive practice.

Moniz-Cook presented Hull's international collaborative research at the first dementia summit (February 2020) attended by > 80 leaders, live streamed to > 700 participants across the UK. The organisers commented, *'This session was one of the most popular during the day for our online audience and we have been asked by many to share footage of the session'* (E11). Since the start of the REF period in 2014, when Moniz-Cook was the winner of the NHS Innovator of the year (E12), **Hull's research has helped change thinking and actions from simply responding to behaviour, to understanding the psychosocial needs of people with dementia and carers and offering tailored support.** The diligent work of everyone caring for people with dementia, is slowly shifting the public debate around dementia and how distress can be alleviated (E13). In 2020 the National Institute for Health Research recognised the distress faced by people with dementia and the needs of care homes, and awarded £1.2 million to support the widespread adoption of our approach thus continuing the impact into the future (E14).

5. Sources to corroborate the impact**Corroborating evidence for 4.1**

E1 British Psychological Society - Click here: *Evidence Briefing 'Behaviour that Challenges' in Dementia* (2018) for Commissioners and Policy Makers

E2 Best Practice Guidance for BtC (CB). The FPOP Bulletin, 2019 148, 51-61 download free of charge Click here: *BPS, Faculty for the Psychology of Older People (FPOP)* - October 2019

E3 i 6th June 2019 NHS England (Yorks & Humber):Leeds *A Whole Systems Approach to understanding psychological symptoms in delirium & dementia* Click here: NHS Clinical Network

E3 ii Testimonial. Improvement Manager, NHS England/NHS Improvement (NE&Y)

Corroborating evidence for 4.2

E4 CHALLENGING BEHAVIOUR SCALE - CBS <https://www.dementiahull.co.uk/toolkits.html>; service user feedback (<https://hull-repository.worktribe.com/output/3183671>)

E5 The CBS has been renamed for i) Scottish NHS services as '*Stress and Distress*' in dementia http://dsdc.bangor.ac.uk/documents/PromotingpsychologicalwellbeingforPWDandcarers_NHSScotland_000.pdf; and used in the roll out of ii) Northern Ireland's adopted CLEAR programme www.northerntrust.hscni.net/CLEAR

E6 Testimonial. Trust-wide Pathway Lead for Psychological Intervention, Cumbria, Northumberland, Tyne and Wear NHS FT, Clinical Psychology Services &. Professor (Hon). Centre for Applied Dementia Studies, University of Bradford, UK.

Corroborating evidence for 4.3

E7 i Testimonial. Head of Quality Improvement & Research, NHS Vale of York Clinical Commissioning Group and Vale of York Bulletin 4 09 19

E7 ii Feedback from Core Psychiatry trainee

E8 Newcastle CAIT Training. Examples of shared digital tools are:

- i Meeting the needs of people with dementia during Covid-19 (Uploaded 01.05.2020; 7,470 views by 31.12.2020)
- ii Formulation in dementia care (Uploaded 21.05.20; 735 views by 31.12.20)
- iii Therapeutic lies in dementia care (uploaded 26.05.20; 1036 views by 31.12.20)

Corroborating evidence for 4.4

E9 13th July 2018 Digital Innovation: *Learning in the Digital Age: Esme Moniz-Cook talks about Dementia and Challenge Demcare at the Latitude Festival* (Click here for further detail)

E10 i <https://www.alzheimer-europe.org/Conferences/Previous-conferences/2019-The-Hague>;

<https://www.alzheimer-europe.org/Conferences/Previous-conferences/2019-The-Hague/Detailed-programme-abstracts-and-presentations/P12.-INTERDEM-Care-and-services>

E10 ii <https://www.dementiahull.co.uk/experts.html> 'The Power of Language' and January 2020 Social Media Post - Person with Dementia and Blogger

E11 News Flash INTERDEM Click here: <http://interdem.org/?p=7272> Dementia Care Research Summit. <https://youtu.be/QXgQKV9hrQY> starting at 38.28

E12 Moniz-Cook (2014, February, London) NHS England Leadership Academy: Click here: NHS Quality Champion/Innovator of the Year 2014 - National winner.

E13 ScienceDaily, 6th February 2018 - Click here: Science News: Dementia care improved by just one hour of social interaction each week.

E14 EurekAlert! News Release 6th October 2020:Click here: £1.2 million to roll-out dementia care home program to COVID-hit sector.