

Impact case study (REF3b)

<p>Institution: University of Bradford</p>
<p>Unit of Assessment: A3</p>
<p>Title of case study: Improving care for people with dementia</p>
<p>1. Summary of the impact</p> <p>World leading research from the Bradford Dementia Group (BDG) has transformed policy and practice in dementia care by demonstrating the need to understand the experience and perspective of people living with dementia in order to ensure their well-being. It has provided a model of dementia care, Person-Centred Care (PCC), and an observational measure and practice development methodology, Dementia Care Mapping (DCM). In England, PCC and DCM are integral to the National Institute for Health and Care Excellence (NICE) guidelines and DCM is endorsed by the National Audit Office. Regulators use our DCM derivative, the Short Observational Framework for Inspection (SOFI) to audit care. Our research has wide international reach. Since 2008, 3616 practitioners have been trained in DCM in the UK and a further 3189 internationally.</p>
<p>2. Underpinning research</p> <p>Dementia is an international public health priority. In the last 10 years many western countries have developed strategies for dementia care, most concerned with transforming the quality of care to ensure well-being for people with dementia. Person-Centred Care (PCC), with its emphasis on living well with dementia and the importance of the person’s perspective, has influenced a range of policy and practice initiatives throughout the UK and internationally.</p> <p>Research on PCC began at the University of Bradford around 20 years ago. It started with the original idea proposed by Professor Tom Kitwood (Lecturer 1979-1998, Professor 1998), that the goal of care is to ensure well-being, achieved by affirming personhood, meeting people’s psychological needs and understanding their perspective (1). Kitwood provided the first operational definition of PCC and well-being in dementia. These definitions formed the basis for the development of the University of Bradford’s observational tool and practice development methodology, Dementia Care Mapping (DCM). DCM assesses the extent to which PCC is being provided and is a recognised method for improving care practice. It provides a range of professionals and practitioners with a common framework and language to record the experience of care from the perspective of the person with dementia. It yields both quantitative and qualitative data which can be used to develop evidence-based action plans. Kitwood’s later research proposed a range of routes by which staff could elicit the subjective experience of people with dementia (2).</p> <p>The Bradford Dementia Group (BDG) has continued to develop empirical research, conceptual thinking and application of PCC under the leadership of Murna Downs (Professor 2000-present). Dawn Brooker (Lecturer 2000-2001, Professor 2001-2009) summarised the key elements of PCC (3). In later work she empirically demonstrated the benefits of meeting the psychological needs outlined by Kitwood in PCC (4). Dr Claire Surr (Project Officer 2002-2003, DCM Consultant Trainer 2003-2006, Lecturer 2006-2009, Reader 2009-present) developed a short form of DCM, known as the Short Observational Framework for Inspection (SOFI) and is now testing the effectiveness of DCM in terms of quality of life and cost. Downs, Surr and Errollyn Bruce (Research Fellow 1993-2002, Lecturer 2002-2013), in collaboration with Professor Linda Clare (University of Bangor), empirically demonstrated that we can elicit the perspective of people with dementia in care homes (5). Later work by Downs and Clare developed an observational measure of awareness for people with moderate to severe dementia (6) and explored its usefulness in staff training (7). Currently Dr Andrea Capstick (Project Officer 1994-2001, Lecturer 2001-present) is using participatory video to elicit the perspective of people with dementia. Jan Oyeboode (Professor 2013-present) with Clare is testing person-centred cognitive rehabilitation for people with early dementia and Downs is exploring ways to ensure care home residents’ health care needs are addressed in order to avoid hospitalisation. In summary, PCC has served as a catalyst for a range of developments to ensure</p>

improved quality of care and quality of life for people living with dementia.

2. References to the research (indicative maximum of six references)

1. Kitwood T. (1997) *Dementia reconsidered: the person comes first*. Buckingham: Open University Press.
2. Kitwood T. (1997) The experience of dementia. *Ageing and Mental Health* 1(1): 13-22.
3. Brooker DJ. (2003) What is person-centred care? *Reviews in Clinical Gerontology* 13: 215-222.
4. Brooker DJ, Woolley RJ, Lee D. (2007) Enriching opportunities for people living with dementia in nursing homes: An evaluation of a multi-level activity-based model of care. *Ageing and Mental Health* 11(4): 361-370.
5. Clare L, Rowlands J, Bruce E, Surr C, Downs M. (2008) 'I don't do like I used to do': A grounded theory approach to conceptualising awareness in people with moderate to severe dementia living in long-term care. *Social Science and Medicine* 66(11): 2366-2377.
6. Clare L, Rowlands, J, Bruce E, Surr C, Downs M. (2008) The experience of living with dementia in residential care: an interpretative phenomenological analysis. *Gerontologist* 48(6): 711-720.
7. Clare L, Whitaker R, Quinn C, Jelley H, Hoare Z, Woods B, Downs M, Wilson B. (2012) AwareCare: Development and validation of an observational measure of awareness in people with severe dementia. *Neuropsychological Rehabilitation: An International Journal* 22(1): 113-133.

Evidence of the quality of the research is demonstrated by the award of the following research grants:

National Institute for Health Research Health Technology Assessment, 2007-2010, *Reminiscence groups for people with dementia and their family care-givers: pragmatic 8-centre trial of joint reminiscence and maintenance versus usual treatment*, £1.4m. Investigators – Woods, Bruce, Edwards, Hounsome, Keady, Moniz-Cook, Orrell, Russell.

National Institute for Health Research Programme Grant, 2007-2012, *Management of challenging behaviour in dementia at home and in care homes*. £1.6m. Investigators - Moniz-Cook, Mason, Mozley, Woods, Russell, Jones, Markova, Campion, Hilton, Stokes, James, Downs.

National Institute for Health Research Programme Development Grant, 2011-2012, *Developing an evidence-based intervention to improve health care for, and prevent avoidable hospital admission of, older care home residents with frailty or dementia*. £97,238, Investigators – Downs, Sampson, Clare, Young, McCormack, Nurock, Woodward-Carlton, Robinson, Katona, Green, Bowman, Wright, Koopmans, Ouslander.

National Institute for Health Research School for Social Care Research, 2012-2014, *Can participatory video (PV) enhance social participation and well-being for people with dementia in long-term social care?* £101,102, PI Capstick in collaboration with Methodist Care Homes.

National Institute for Health Research Service Delivery and Organisation, 2013-2015, *A multi-site evaluation of the Person, Interactions and Environment (PIE) tool to improve person-centred care for people with dementia admitted to acute hospital wards*. £442,979, Investigators – Young, Woolley, Godfrey, Brooker, Surr, Hoyle, Hood, Manley, Arrojo, Padilla-Lamb.

National Institute for Health Research Health Technology Assessment, 2013-2017, *Evaluating the effectiveness and cost-effectiveness of Dementia Care Mapping (DCM) to Enable Person-centred*

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Care for people with dementia and staff: A UK cluster randomised controlled trial in care homes (DCM-EPIC trial) £2,403,888, Investigators – Surr, Downs, Edwards and Wallace in collaboration with researchers from Leeds University; Kings College, London; University of Technology, Sidney, Australia; Oxford NHS Trust and Newcastle University.

4. Details of the impact (indicative maximum 750 words)

Bradford's research on Person Centred Care (PCC) and Dementia Care Mapping (DCM) has had far-reaching impact on the quality of dementia care by providing an alternative conceptualisation of dementia care and a tool by which PCC can be developed and measured.

In the area of policy, BDG's research was heavily cited by the National Institute for Health and Clinical Excellence (NICE) in its 2006 guidelines on supporting people with dementia, and their support for the use of PCC in practice was reiterated in the 2012 revision of the guidelines. They state that, "*There is broad consensus that the principles of person-centred care underpin good practice in the field of dementia care and they are reflected in many of the recommendations made in the guideline*" (a). The National Audit Office (2010), in their interim report on *Improving Dementia Services in England* (b), recommend DCM as a measure of quality of life and the same report highlights Bradford's research on the importance of meeting psychological needs. Bradford's research on PCC has also had a significant influence on international policy, most notably in Norway, where PCC and DCM informed the focus of national strategy, and in Germany where DCM is recognised as an indicator of quality care by the long term care insurance system (c).

In terms of practice, PCC is now a widely used term in the UK and has changed the focus of care for people with dementia. The Department of Health's Good Practice Compendium on Living Well with Dementia (2011) showcases examples of good practice in care for people with dementia from across England. DCM is highlighted in two examples demonstrating its use in care homes, acute hospitals and across the health and social care community (d). Inspection reports for care homes provide evidence of the impact of our training in PCC and DCM on practice (e). Testimonials from care providers to whom we have introduced PCC refer to improvements in bed occupancy, staff turnover and care practice in care homes (f) and in staff knowledge and practices in NHS settings (f). Commissioned by Bupa Care Services, BDG has provided cascade training in PCC to 400 Person First Coaches and developed cascade materials that have been delivered to over 10,000 staff in 300 care homes. This training was specifically mentioned as exemplary practice in Bupa Group's feedback on achieving 'Investors in people' status in 2012 (f). Four Seasons Health Care, which runs 180 care homes in the UK, had trained 500 staff in DCM by April 2010 (g) as part of their Pearl model of specialised dementia care. Their 2013 report on the impact of introducing Pearl at 16 of their care homes clearly states the value of DCM as part of this process (g). The social care regulator, the Care Quality Commission (CQC) re-adopted the Short Observational Framework for Inspection (SOFI) on its formation in 2010: SOFI was first adopted in 2006 by the CQC's predecessor, the Commission for Social Care Inspection (CSCI). It was retained by CQC as integral to capturing the experiences of people who may be unable to report their experiences due to conditions such as dementia. All CQC inspectors (1000+) are trained in the use of SOFI and are expected to use it in inspections where service users have communication difficulties. "*SOFI is a tool developed with the University of Bradford Dementia Group and used by our inspectors to capture the experiences of people who use services who may not be able to express this for themselves*" (h).

Bradford's research on PCC has had significant impact on care practice internationally including in the USA, Australia, Spain, Germany, Norway and Denmark. The influence of Kitwood's PCC on care home residents in an Arizona care home was so noteworthy as to form the basis of an article in the *New Yorker* (i). The positive impact of PCC and DCM on staff morale and practice internationally has been empirically demonstrated. A cluster RCT study conducted in Australia, published in *The Lancet* in 2009, demonstrated decreased falls and agitation in care homes that used DCM (j). BDG has contracts with over 12 international organisations (e.g., voluntary sector organisations such as Alzheimer Catalunya in Spain) for the delivery of courses in *Learning to use DCM*. DCM has been licensed by University of Bradford for training in countries including Australia,

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Denmark, Germany, Japan, the Netherlands, Germany, Singapore and Switzerland. The DCM tool is available in a range of languages including Catalan, Spanish, German, Japanese, Italian and Danish. Since 2008, 3189 practitioners have been trained internationally. Our Japanese DCM partner reported in their 2013 annual report that the government has implemented a project to improve the quality of dementia care and dementia care leaders were supported to attend the BDG's *Learning to use DCM* course (k). We have recently signed a contract with Australian Aged Care Standards Accreditation Agency Ltd. (the national accrediting body for care homes) to train their inspectors in the use of the SOFI tool (l).

5. Sources to corroborate the impact (indicative maximum of 10 references)

- a. NICE/SCIE guidelines – web link to 2006 guidelines and 2012 review (quote on page 6): <http://publications.nice.org.uk/dementia-cq42/person-centred-care>
- b. National Audit Office 2010: <http://www.nao.org.uk/wp-content/uploads/2010/01/091082.pdf>
- c. Norwegian Directorate for Health and Social Affairs (2007) *Glemsk-men-ikke-glemt (Forgetful but not forgotten)*. Norway pre strategic plan document.
Brüggemann J, Brucker U, Eben E, Fler B, Gerber H, Kurzmann K, Ziegert S, Lübke N (2009) *Gundsatzstellungnahme: Pflege und Betreuung von Menschen mit Demenz in stationären Einrichtungen* (General Statement: Care and Support of people with dementia in nursing homes). MDS:Essen, Germany.
- d. Department of Health (2011) *Living well with Dementia*. (<http://tinyurl.com/o6mwckg>)
- e. CQC reports on Thornfield Cannon Care Home in Devon before (<http://tinyurl.com/ng5hcgq>) and after (<http://tinyurl.com/p6k5s88>) training in PCC and DCM.
BBC/OU TV programme “*Can Gerry Robinson fix dementia care*” featuring DCM used in Cannon Care Homes facilitated by one our team Paul Edwards.
- f. Testimonial from the CEO, Nightingale Hammerson Care Homes.
Testimonial from Consultant in Psychiatry and Old Age on the impact of BDG training and expertise within the Northumbria Healthcare NHS Foundation Trust
Testimonial from BUPA Care Services re outcomes associated with our training in PCA.
- g. 2013 Report by Four Seasons Health Care on the implementation of Pearl and DCM in 16 of their care homes: <http://www.communitycare.co.uk/2010/04/22/best-practice-in-dementia-care-home-staff-training/>
- h. Care Quality Commission use of SOFI – described on their web site: <http://www.cqc.org.uk/taxonomy/term/8581/0>
- i. Mead R (2013) The sense of an ending: A new direction in dementia care. *New Yorker*, May 20, 92-103.
- j. Chenoweth L, King MT, Jeon YH, Brodaty H, Stein-Parbury J, et al. (2009) Caring for Aged Dementia Care Resident Study (CADRES) of person-centred care, dementia-care mapping, and usual care in dementia: a cluster-randomised trial. *Lancet Neurology*, 8: 317–325.
- k. Japanese Dementia Care Mapping: International Implementation Group Report 2013 –BDG template completed on behalf of Japanese strategic partner Imaise Mental Care Centre by Dr Yutaka Mizuno.
- l. Australian inspectorate contract with BDG for use of SOFI assessment tool and e-mail from the General Manager of Aged Care Standards and Accreditation, NSW, Australia