

Impact case study (REF3b)

Institution: University of Nottingham
Unit of Assessment: 22 (Social Work and Social Policy)
Title of case study: <i>Inside Out of Mind: Bringing research findings to life to influence dementia care</i>
<p>1. Summary of the impact</p> <p>The findings of an innovative ethnographic study of Health Care Assistants (HCAs) who care for dementia patients were used to create a stage play, <i>Inside out of Mind</i>, which was performed to audiences of HCAs, NHS managers and the general public.</p> <p>The performances raised awareness with NHS managers and healthcare policy makers, of the role and importance of HCAs; their working environment, the skills they need and the difficulties they encounter. It enabled HCAs to reflect upon their practice and to identify specific areas upon which they would focus to improve care.</p>
<p>2. Underpinning research</p> <p>The key researcher for this case study is Professor Justine Schneider, School of Sociology and Social Policy, University of Nottingham, December 2004 to present.</p> <p>The research was commissioned in 2008 by the UK National Institute for Health Research (NIHR) under the Service Delivery and Organisation programme (SDO) (6). The research was intended to raise the quality of care for dementia patients through greater understanding of the working practices and conditions for NHS unregistered Health Care Assistants (HCAs). Prior to this innovative participant observation study, in which researchers worked as HCAs in hospital dementia wards, immersing themselves in the role, very little empirical research into the role of HCAs had been conducted. The full report is available on-line (1), and the methodology (2), interdisciplinary issues (3) and the emotional impact (4) have also been reported in peer-reviewed papers, with one article in a journal for HCAs (5). The project has been short-listed for the 2014 Times Higher Research Project of the Year.</p> <p>The five key findings of the research are outlined below:</p> <ol style="list-style-type: none"> Motivations and environment: The research identified that HCAs undertook their work with warmth, empathy and commitment and derived considerable satisfaction from improving patients' quality of life even in small ways. However, it also revealed that the dementia ward can feel a closed environment where the odd and disturbing are every-day. HCAs recognise that to outsiders some of the things that occur must seem shocking, and therefore difficult to share with friends and family. It is important for policy makers and managers to understand the motivations of staff and the effects of the working environment on them. Managing the emotional climate: HCAs manage the emotional climate on the ward, stimulating patients when the atmosphere is dull and calming things down when stress levels rise. The importance of this function and the capability of HCAs in this regard may have been underestimated and unacknowledged in previous research. Working with families: The interface between HCAs and informal carers and/or patients' families is vital and is an aspect of care that deserves further attention and research. Whilst nurses provide clinical information the HCAs provide minute detail about the patient's care and condition. Communication with patients' families/informal carers could be problematic, often guarded and strained, because of the potential for misunderstanding. Stress and coping: An essential requirement for an effective HCA is to be able to achieve selective desensitisation in order to cope with unpleasant tasks and personal abuse. While the newcomer is bewildered by some of the surreal situations that arise, experienced staff demonstrate coping strategies, including the use of humour to cope with stressful aspects of the job.

5. **Team identity:** The research found that **belonging to and participating in the team was a fundamental part of the HCA role**. The team empowers its members to manage their complex, changing and stressful role; it compensates for limited recognition from outside, and supports them emotionally. However, if staff prioritise the team over patients, e.g. focussing on completing feeding efficiently during busy periods, or if the team's self-reliance inhibits communication with the rest of the multidisciplinary team, this clearly presents a risk to care quality.

3. References to the research

The quality of underpinning research is evidenced by the fact that the following outputs have been published in peer-reviewed journals or are the result of a peer-reviewed funding process.

Research outputs

1. **Schneider, J.**, Scales, K., Bailey, S., and Lloyd, J. (2010) *Challenging Care: The Role of Healthcare Assistants in Dementia Wards*, Report for the National Institute for Health Research Service Delivery Organisation Programme (Project Number 08/1819/222), Southampton: NCCSDO. http://www.netscc.ac.uk/hsdr/files/project/SDO_FR_08-1819-222_V01.pdf
2. Lloyd, J., **Schneider, J.**, Scales, K., Bailey, S. and Jones, R. (2011) 'In-group identity as an obstacle to effective multidisciplinary teamworking: Findings from an ethnographic study of healthcare assistants in dementia care', *Journal of Interprofessional Care*, 25(5): 345-351. <http://informahealthcare.com/doi/full/10.3109/13561820.2011.567381>
3. Scales, K., Bailey, S. and Lloyd, J. (2011) 'Separately and together: Reflections on conducting a collaborative team ethnography in dementia care', *ENQUIRE*, 6: 24-49. <http://enquirenottingham.co.uk/images/edition%206%20-%20scales.pdf/>
4. Bailey, S., Scales, K., Lloyd, J., **Schneider, J.** and Jones, R. (2013) 'The emotional labour of health-care assistants in inpatient dementia care', *Ageing and Society*. 'Firstview' article published online: August 21 2013. http://journals.cambridge.org/abstract_S0144686X13000573
5. **Schneider, J.** (2010) 'Research: Support workers play vital role in dementia care,' *British Journal of Healthcare Assistants: For HCAs and assistant practitioners*, 4(10): 498-501. Available on request.

Research grant

6. PI: Professor Justine Schneider, NIHR/SDO Programme 08/1819/222, 2008-2010, £291,197. <http://www.nets.nihr.ac.uk/projects/hsdr/081819222>

4. Details of the impact

The research has influenced healthcare policy makers, changed practice and raised awareness through conventional dissemination and the innovative use of a play, *Inside out of Mind*, to communicate the research findings directly to stakeholders.

The full report had been **downloaded from the SDO website by researchers and policymakers 369 times** by 31 March 2012 (when counting ceased). Schneider also spoke about the findings within the 'Delivering better health services' session at the 2010 SDO network. The Royal College of Nursing hosted a webinar (web based seminar), 'Re-evaluating the role of the Health Care Assistant in dementia care' on 13 May 2010, which was **attended by 40 nursing managers**, workforce planners, those involved in planning care for people with dementia and their managers. The study has influenced commissioners of research who have used its findings as the basis of further NIHR HS&DR calls for research into the delivery of care, e.g. (A).

In addition to reaching policy makers, it was felt important to **disseminate the research findings directly to HCAs** themselves in order to reach those to whom they are most relevant. The research findings were therefore also **published in** The British Journal of Health Care Assistants (5) which is **the only UK journal intended for healthcare assistants**. The journal has a circulation of 5,000 and an estimated readership of some 25,000.

Inside out of Mind was conceived of as a way of portraying the key research findings vividly and

in an accessible way to the widest possible audience. For example, the play's soliloquy of a nurse going off duty after an exhausting night: "I take all these voices home with me ..." powerfully presents the effects of the working environment on staff. The challenge of the emotional climate is shown in the responses of patients to noise and bustle, often seen through the eyes of the ethnographer character, playing the role of the original fieldworkers. A scene featuring a ward visit from a supercilious doctor, characterised as a 'tour de farce', humorously portrays to the audience many of the 'us and them' issues that are commonplace amongst unregistered staff including HCAs.

The Institute of Mental Health (IMH) at the University of Nottingham funded a Managed Innovation Network (MIN) (7) which brought together NHS providers, research and arts leaders to explore production possibilities, leading to a theatre workshop performance of excerpts from the script to an invited audience in July 2011. Financial support from the University's Science, Technology and Society Research Priority Group and the School (8) enabled the production of a **10-minute documentary** (B) about the development of the workshop performance. This film has been **presented to 12 conference audiences totalling 800 people**. The MIN used the positive feedback on the workshop performance to seek financial support (9), together with a great deal of support in kind from the NHS and University of Nottingham to **develop a full production**. Funding was secured from Comic Relief (10) for a **video trailer** (C) for the full production. ***Inside Out of Mind* had its premiere run at the University's public arts centre, Lakeside, in June, 2013, with 15 public performances, 8 of them reserved for local HCAs released by their employers. These performances included a discussion between the artistic team and the audience.**

1,109 HCAs attended the play (D) and participated in discussions and activities about dementia. Ninety-three per cent of participants judged the day as 'good', 'very good' or 'excellent', while **92% of the participants who work with people with dementia felt that the experience would have a positive impact on their work** (E).

The impact of the play in stimulating HCAs' analysis and reflection of their work is evident in their comments:

I have been working in dementia for some time and today's play gave me more insight into dementia, quite inspiring... fantastic. (25/1/4)

Now have a better understanding of dementia. Brilliant day. (25/4/14)

It has been an amazing day. I have learnt that people with dementia have feelings and I have learnt to appreciate how they must feel. (25/4/18)

Wonderful, knowledgeable play, excellent for giving an insight to people unaware of dementia and what can be experienced. Should be shown nationwide. (26/2/07)

Participants were invited to specify how they **intended to apply their new insight** to improve dementia care within their workplace, and 481 took up this opportunity, for example, to set themselves a goal:

Take time to look into their background to get a better understanding of that person. (17/6/8)

To try to make less noise and to remember each patient as an individual and treat them accordingly. (18/1/7)

To be understanding more and step back to evaluate the situation more, we got to do this watching the play. (18/3/18)

The testimonies of HCAs can be found in a YouTube documentary, seen 799 times in the period 9 July-14 October 2013 (F).

The programme for the production was also designed with the needs of family carers in mind so that it would provide information about where to turn for help and advice. A **free on-line resource** (G), funded by a philanthropic donation to the University's Impact campaign (11), was created to bring together information about dementia care. The **site receives 100 new visits per week and has registered 500 users in the first four months since it was launched in June 2013**. Many of the nearly 1000 people who came to the public performances had some connection with health or social care, and the blogs posted by Francois Matarasso, former chair of the Arts Council East Midlands (H), and Eileen Shepherd of the Nursing Times (I), **illustrate the impression made by the play on an informed audience**.

This original approach to research dissemination and the scope of the play in working across the arts, health and academia, was highlighted in an edition of the **PM programme** (J) and was featured on **BBC TV East Midlands Today** (K). **BBC Radio Nottingham** interviewed Professor Schneider and the director of the play, Tanya Myers twice: first trailing the production, and then, during the run, they were joined by a carer, Meryl, in a longer interview about the issue of dementia (L).

Plans are in hand for a **national tour in 2014**, in partnership with the University of Nottingham, RCN Foundation Trust and NHS employers, conditional on a Strategic Touring Fund grant from The Arts Council. A **digital recording is also planned** which, in addition to use in care homes and domestic settings, can be broadcast to cinemas and therefore widen audience access, especially in remote and rural areas.

Funding

7. Institute of Mental Health, University of Nottingham: £5000
8. University of Nottingham Science, Technology and Society Research Priority Group: £2,200; School of Sociology and Social Policy: £800
9. Royal College of Nursing Foundation Trust: £52,000; The Arts Council: £10,000; NHS partners: £84,000.
10. Comic Relief: £3,000
11. University of Nottingham Impact Campaign: £120,000

5. Sources to corroborate the impact

- A. NIHR HS&DR Commissioning Brief - Supporting Information 13/07 - After Francis: Research to strengthen organisational capacity to deliver compassionate care in the NHS.
http://www.netscc.ac.uk/hsdr/files/adhoc/13_07-supporting-doc%281%29.pdf
- B. Documentary about the development of the workshop performance. <http://vimeo.com/32860587>
- C. Video trailer for *Inside out of Mind* <http://www.institutemh.org.uk/x-research-/managed-innovation-networks/inside-out>
- D. Audience figures for both public and NHS performances are available.
- E. A report on the NHS audience evaluations of the play is available.
- F. Documentary on learning event. <http://www.youtube.com/watch?v=Kbir0cCQPYM>
- G. Improving Dementia Education and Awareness. <http://idea.nottingham.ac.uk/>
- H. Francois Matarasso, 19 June 2013: There's No Insurance Against Life, Parliament of Dreams. <http://parliamentofdreams.com/2013/06/19/theres-no-insurance-against-life/>
- I. Eileen Shepherd, 18 June 2013, Practice blog for The Nursing Times. <http://www.nursingtimes.net/opinion/practice-team-blog/how-do-you-get-hospital-staff-to-walk-in-the-shoes-of-people-with-dementia/5060004.blog>
- J. PM Programme, Radio 4, 13 May 2013.
- K. East Midlands Today, 26 May 2013, 6.30 and 10.30.
- L. Andy Whittaker show, BBC Radio Nottingham, 7am 14 June 2013; Mark Dennison, BBC Radio Nottingham, 9am 25 June 2013.