PSSRU LSE Literary Festival discussion

"Who is it who can tell me who I am?" Understanding Dementia through Art and Literature

Melvyn Bragg
Award-winning author and broadcaster. Books including Grace and Mary.

Dr Andrea Capstick
Lecturer in Dementia Studies, University of Bradford

Professor Justine Schneider
Professor of Mental Health and Social Care, University of Nottingham

Professor Martin Knapp
Chair, LSE

Suggested hashtag for Twitter users: #LSElitfest
Justine Schneider
Researcher

Tanya Myers
Writer, Director
Challenging care: role of HCAs in dementia wards

Joanne Lloyd, Kezia Scales, Simon Bailey
Observations

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<th>Observation</th>
<th>Reflection</th>
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<td>The last patient we bathed was P11, one of my favourites.</td>
<td>I know I shouldn’t have favourites but – guiltily – I find that I do.</td>
<td>Attachment, loss, grief when patient dies</td>
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Focus Groups

Researcher: Does it take a certain kind of person to do this job?

HCA: No, all you need is patience.

Researcher: Any other personal kind of traits?

HCA: Just got to be able to give them the love and attention what they need, and respect. It’s always somebody’s mother or father or grandparent. Show them the respect as though they’re yours, they’re no different form anybody else.
Reflections

It makes me sad to see a new patient on the ward – not just because they’re there at all but also because there’s no apparent mechanism for easing the transition – how can we expect them to instantly assimilate into this crazy context?
The emotional labour of health-care assistants in inpatient dementia care

SIMON BAILEY*, KEZIA SCALES†, JOANNE LLOYD‡, JUSTINE SCHNEIDER† and ROB JONES†

Ingroup identity as an obstacle to effective multiprofessional and interprofessional teamwork: findings from an ethnographic study of healthcare assistants in dementia care

Joanne V. Lloyd¹, Justine Schneider², Kezia Scales², Simon Bailey² and Rob Jones³

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• Motivations and rewards of dementia care
• Stress and coping
• Managing the emotional climate
• Working with families
• Team identity
• Dignity
• Death
Production Planning and Performance
World premiere Lakeside Arts Centre Nottingham 13 – 27 June 2013

2,200 people saw the play, more than half HCAs released by their employers to attend one of 8 day-long learning events

Discussions chaired by NHS managers workshops co-facilitated by the actors.

Local press, TV & radio coverage increased public awareness
There will be those who believe that nothing produced in this way can be anything but worthy and dull or—in the ultimate insult that some in the arts world reserve for what they neither value nor understand—instrumentalised art. They could not be more wrong. *Inside Out of Mind* is a memorable, clever and moving theatre performance, enjoyable even its hardest moments. What it achieves in developing understanding of dementia and dementia services it achieves because it is excellent theatre.

Francois Matarasso,
former chair Arts Council East Midlands
Acknowledgements

The research received funding from the National Institute for Health Research (SDO 08/1819/222). We are grateful to the people we observed, their managers and their employing Trust.

The production has received support to date from the Institute of Mental Health, University of Nottingham, Lakeside Arts Centre, Nottingham University Hospitals Charity, NUH Trust, Nottinghamshire Healthcare Trust, Comic Relief, CLAHRC-NDL, The Arts Council East Midlands and the RCN Foundation Trust.
Acknowledgements – contd.

**Cast**
- Anna Mottram
- Holly-Robin Harrison
- Jarrod Cooke
- Jim Findlay
- Joanna Wells
- Lily Lowe Myers
- Maurice Roeves
- Maxine Finch
- Rebecca DeSouza
- Ulrike Johansson

**Creative team**
- Barret Hodgson
- Christine MacSween
- David Wilson
- Jo James
- Keziah Serreau
- Martin Hinkin
- Nettie Scriven
- Richard Statham
- Sean Myatt
- Shona Powell
- Stephen Lowe
- Vanessa Rawlings-Jackson
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Participatory video in long-term social care

Dr Andrea Capstick
Bradford Dementia Group
Participatory video

- People who are prone to social marginalisation make films about matters of concern to them (Milne et al 2012)

- The study aims to find out whether participatory video can be adapted for use by people with dementia (Capstick 2012)
Background

- 18-month study funded by NIHR School for Social Care Research
- 15 people with dementia living in long-term social care
- 12 women and 3 men: age range 76-99 years.
- Each participant is helped to make a short 5-10 minute film/digital story on a subject of their own choice.
Nora: born 1927, Jarrow, Tyneside

- Wanted to make a film about the place where she grew up, Tynemouth: ‘Heaven to me’
Key themes in Nora’s film

- Local history/’place memory’ (Chaudhury 2008)
- Social justice/injustice
- Love of birds and animals
- Strong bond with her mother
The process:

- **Flickr/Creative Commons** to search for preferred images
- **Photostory 3** to import the images into a slide show
- **Audacity** for editing in the participant voice
- **Freesound** for additional sound effects.
References and Disclaimer


• NIHR-SSCR disclaimer: This presentation presents independent research commissioned by the NIHR SSCR. The views expressed are those of the author and not necessarily those of the NIHR-SSCR or the DH, NIHR or NHS.
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