

Transforming dementia care through theatre



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Justine Schneider and **Tanya Myers** report on a bold creative effort to share findings from a landmark study with the very people who were the subjects of the study – health care assistants supporting people living with dementia

The quality of dementia care is a matter of urgent social concern affecting not just the economy, but also the ethical frameworks guiding interpersonal relationships, and indeed the very essence of human identity. Dementia remains incurable and it leads inevitably to degeneration and death. The effects are felt most directly by those with the diagnosis and their close relatives, of course. In addition there are many paid professional staff providing hands-on care for people with dementia who belong to different sectors: residential and home care, social work and the NHS. The scale of the issue is huge: 2.75 million paid workers in health and social care look after people with dementia on a day-to-day basis.

This task is physically and emotionally hard, stigmatised and relatively low paid. Yet most of these professional carers are relatively powerless in the hierarchies in which they work and, as the Francis Inquiry shows, with pressures of time and resources, the quality of care in many settings can be compromised.

Focus on dementia care staff

The study that underpins the play 'Inside Out of Mind' by Tanya Myers used 'participant observation', an approach based on the anthropological method of ethnography, to investigate staff working in challenging dementia care settings: what obstacles to good care they face, what they find stressful and how they cope, what promotes their well-being and what this means for person-centred care. It focused particularly on unregistered health care assistants (HCAs) who make up most of the NHS hands-on workforce.

Three researchers – Kezia Scales, Simon Bailey and Joanne Middleton – were employed to work as HCAs on different wards in the same Trust. They were all supernumerary, but otherwise worked half-time on all shifts in the rota. In their off time they wrote up their observations. After three months they met together to compare notes and formulated questions that arose from their experiences. These questions informed the next phase of the study when, in addition to continuing to work as HCAs, the researchers interviewed 30 members of staff and held focus groups with carers to bring in other points of view.

The study showed that HCAs for the most part disliked formal workplace training, lacked

confidence in classrooms and found online courses a chore. They appeared to have few opportunities to develop their skills. This was clearly related to the pace of work and the difficulty of releasing staff for anything other than mandatory training. Moreover, knowledge transfer in healthcare is complex because the learning process is essentially interpersonal; knowledge is modelled, generated and exchanged, rather than transmitted in a linear way from teacher to student. Therefore, the educational challenge seems to be to engage and empower dementia care staff; to increase their confidence and enable them to recognise and use the 'tacit' knowledge and skills that they already have – practice knowledge acquired through experience and reflection rather than through formal training.

The findings were reported to the funders at the National Institute for Health Research and are available in full online (see 'Challenging care: the role and experience of Health Care Assistants in dementia wards' by Schneider *et al* 2010). With hindsight the description 'dementia ward' is perhaps not entirely appropriate, because the treatment offered was for behavioural issues, rather than dementia as such. The researchers went on to publish academic papers as expected by their employers and funders. However, these publications were not very accessible to HCAs for the same reasons that educational opportunities were limited. We had masses of vivid, funny and poignant observations – too many to include in one report. We wanted to communicate our findings to the people we had observed, the direct care workers, both nurses and HCAs, so we opted to commission a play using our dissemination budget. Writer Tanya Myers then worked with the researchers to devise the play (see box/////)

Nottingham learning events

'Inside Out of Mind' was staged at Nottingham Lakeside Arts in June 2013 and was seen by over 2,000 people. Direct care workers (health care assistants and support staff) came to morning performances and in the afternoon attended workshops designed to reflect on the implications of the show for their own working lives (these were funded by the RCN Foundation). Up to 20 people attended each of the 62 workshops held following performances of the play: 1,109

participants in total. The workshop format was highly standardised in order to ensure that all participants had comparable experiences. It was led by a skilled trainer, while regional Arts Council funding (Grants for the Arts) permitted us to employ members of the show's cast to participate as well. In addition to their acting skills, each member of the cast brought relevant life experience to the workshops; two had mothers who were nurses, one had cared for a grandparent with dementia and so forth. This was made clear during the show and may have given them greater credibility in the eyes of the workshop participants, particularly when the emotional aspects of the caring job were discussed.

Evaluation

The events were evaluated using two principal methods: a focus group held after the run in which the actors discussed their impressions of the workshops, and anonymous questionnaires distributed to participants in which they evaluated the show and workshops together. This had some pre-coded questions and invited comments both positive and negative. In addition, to explore the longer-term impact on their working role, respondents were given the opportunity to make a resolution or set themselves a goal that they felt would improve dementia care within their workplace.

Focus groups

In the quotations below the actors are coded by their gender (F or M) and a unique number. The workshops were used by participants to give the actors feedback about their performances. In turn, the actors sometimes had to point out that the script was not intended to be too literal, despite the fact that it was based on serious research. The characters portrayed on stage were sometimes slightly exaggerated for effect.

F3: We had a few discussions about characters, because they said, "We don't do that," and I said, "Yes, and I can understand that... but it is sourced." And we are dealing with theatre, which is characters, so we do have a certain range of different approaches – you know, Grace was the example of like a very, very good nurse, and I think Brenda is a brilliant H[earth] C[are] A[ssistant]. I mean, her approach might not be everybody's, but they loved her because they recognised her.

F2: Everybody said they loved Brenda.

F3: She says what she bloody thinks, you see, and I think that's why they responded to her.

Most participants (85 per cent) had not been to the theatre in the past year, while some told us that they had never before been to the theatre. Yet their appreciation of the acting was based on their own knowledge of the job:

M1: ... There was this one lad who, watching Anna doing her acting, was going, "I can't believe that,



that's too good, that's too real, that's fantastic." And he was just fascinated by this person who could do this role and play the patient so well, so believable. And he's in contact with these types of patients every day and, he said, "That's so real."

The staging of the show uses a lot of effects in the first half (surreal sounds, flying objects and sudden changes of pace) and this could present a challenge even to frequent theatre-goers.

F2: There was kind of a lot of people who said that they found the first half really confusing and really disorientating and then the second half they really, really loved and enjoyed... And they said that, when they realised that the first half was very patient-orientated and the second half very staff-orientated, they could really indulge and appreciate what the writer had done. And I hadn't even realised until they said it.

The play uses 'doubling' throughout – the same actors play both patients and family carers or ward staff, often with rapid changes of costume and role.

M1: [One] woman... she said, "I didn't understand why they were walking about in different costumes all the time, because I know they're the same people." And her comment was, "Then I realised what they were trying to say was that all of us in the end will either be a dementia patient or a carer." So this person hadn't been to theatre, didn't get the fact that actors play different characters – which is fine, but then she interpreted it in that way, interpreted a piece of art in a way that I don't think any of us could have claimed.

The audience members in workshops reinforced for the actors the issues that make dementia care more stressful: lack of staff, lack of recognition, stigma and fear of a disease that robs individuals of their identity. The cast also came directly to understand how undervalued some unregistered dementia care staff can feel and also how passionate they are about dementia care.

F3: In every workshop there was quite a strong

Reference

Schneider J, Scales K, Bailey S, Lloyd J (2010) *Challenging care: the role and experience of Health Care Assistants in dementia wards*. Report for the National Institute for Health Research Service Delivery and Organisation programme. Queen's Printer and Controller of HMSO. This is available to view at http://panicoa.org.uk/sites/assets/challenging_care.pdf

The writer's viewpoint

The researchers entrusted me with their field notes and asked for them to be transformed into a play. 'Why theatre?' one might ask. To care requires an ability to empathise, and I would suggest imagination is a prerequisite for empathy. Acting and ethnography have much in common: ability to imagine oneself into the mind, heart, shoes of another human being, to feel how that person might feel, are all essential to caring. This imagination is a common ability most of us share as human beings – perhaps one of the prevailing forces that potentially define our common humanity and underpin society's core value systems. However, if a situation becomes too painful or frightening, we tend to try to avoid or ignore it – hiding behind the sofa, crossing to the other side of the street or turning the page.

I believe that we put our future in peril if we ignore distressing realities, such as dementia. Theatre creates a safe space for profound exploration of such pain and joy and what it is to be human. Given no rules, my remit was to respond with emotional honesty to the researchers' vast body of documentation, transcend its academic purpose and create a theatre experience that would touch the heart and emotions of a wider public audience.

As weeks turned into months I submerged myself in an ocean of research data, and I also read widely about dementia. Characters evolved – people with past and present lives, who balanced personal issues, both inside and outside their working environments. I could hear them, smell the ward, deafened by the constant noise, alarm bells and institutionalised chaos. And I tried to imagine what happened when they left the ward: what happened to their feelings when they went home and who did they talk to?

This challenge has been and continues to be an extraordinary creative journey. The research material was poetic at source and I encouraged the three researchers who undertook the participant observation (Kezia, Joanne and Simon) to acknowledge their own voices. The lead character in the play became a young ethnographer called 'Youth' – she is our Everywoman entering dementia worlds on behalf of the wider audience. Youth has to earn the trust of her working colleagues and her questions are driven by what she experiences immersed within the carers' working world.

I saw my job as to communicate the emotional legacy carried by the health care workforce into wider public awareness. I became aware of themes that seemed to be seldom discussed in the public domain, for instance it is common for staff to become attached to patients and often there is a real sense of loss when a patient dies – how this bereavement is managed (or not) on the ward is something that the script explores.

During the writing process, I met and promised a woman who was caring for her husband with Alzheimer's disease that the play would resist solemnity and worthiness. She said to me, "If we couldn't

laugh we'd go mad. Please give us permission to laugh!" So right from the start the challenge was to find humour driven by character or situation; humour that enables us to laugh 'with' and not 'at' vulnerabilities. On taking their seats in the theatre the audience enter the world of the play through the eyes and ears of our central protagonist – a person in hospital living with Lewy body dementia called Mr P. Although this is a rather surreal cacophony of sound, colour and shapes, we discover that his world is woven with logic.

Gradually as the play develops there is 'seepage' of storytelling and we move in and out between naturalistic routine medical worlds of nurses and the subjective worlds of the patients. As Maurice Reeves, who plays Mr P, has stated, the actor has to find his logic moment by moment – to search deeply for the cause and effect of each action. Likewise, there is a logic to each character's unique narrative – past, present and future. The audience identify with Youth and become 'dream detectives', searching for clues as to why a person might be doing these 'odd things'. Many of Youth's realisations are formed from hunches and quiet observations. I would call this 'intuitive listening'.

'Inside Out of Mind' is a creative fugue, a layering of worlds within worlds. On the ward with no name we witness a fusion of love stories criss-crossing time and space, where walls turn into forests, thunder to gunfire and books to birds. 'Never forget the person,' echoes down its corridors. Each handover, nurses come, nurses go, carrying, folding, trying their best to deliver person-centred care, to see the person not the dementia. Onstage, nurses transform into patients and patients into nurses and the audience gasps in recognition that 'there go I but for the grace of ...'.

None of us could have known how deeply the emotional impact of the play would hit. Many people have told me that the play helped them to articulate feelings of loss or frustration, to share stories, concerns or to encourage one another. In fact the post-show dialogues seemed to empower audiences to express their feelings in response to the play. Those people whose working lives the show portrays – now with the objective distance of spectators – could talk about the play and relate its themes to their personal experiences. For audiences to feel secure enough to reflect and learn from the messages of the show, it was crucial that this post-show dialogue space be intimate and non-judgemental.

Touching on profound themes such as identity, loss, relationships, power and death, the aim of the show is to impact positively on the care of people with dementia, to highlight the skills and compassion of basic-grade staff, and to use the medium of theatre with all its scope for illusion and magic to engage the audience's emotions, fostering empathy for staff and patients, while giving pause for reflection and intuitive listening.

Tanya Myers





feeling of resentment that they were doing all the work, the work, the hands-on work, with the patients, knew the patients, weren't asked about the patients by the doctors, when they felt they knew more about them than the qualified staff. And that the qualified staff spent far too much time in the office.

Participants largely rated the event positively, despite some logistical hitches on the first day and a handful of criticisms overall. Clearly, with a total of 15 different leaders running the workshops, the experience was sometimes not up to par:

I believe the workshop needs to be more interactive and elicit more ideas and reflections from participants.

I didn't feel that we were taught about dementia and our discussion group was not well structured. I didn't really learn anything.

Although some participants were mistakenly expecting facts and figures rather than experiential workshops, the facilitation was crucial to the success of the afternoon.

Questionnaires and resolutions

The questionnaire results show that of 856 responses, 93 per cent rated the day good, very good or excellent. The novelty of the approach to education through theatre was appreciated by many:

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

The best training day I have been on for a long time.

Moreover, the experience seemed to reach people at an emotional level as well as at a cognitive one:

Excellent play – laughed and cried. A wonderful day throughout.

Even though I have extensive knowledge and understanding of dementia this day has made me think that even if I'm rushed off my feet I must make

more time for dementia patients. This production should not only be for clinical staff but it should be nationwide to raise awareness to the general public.

However, not everyone was inspired by the workshops:

The play was great and I did get more of an insight into 'ward life', but workshop really I didn't find useful. Sorry.

How far did seeing the show and participating in the workshops 'engage and empower'? The fact that the vast majority of participants were satisfied is evidence of the show's effectiveness at engaging, while the resolutions may be taken as promising indications of empowerment. In the 481 resolutions recorded, participants expressed intentions to improve their own practice, to listen more, to give patients more time or to implement person-centred practices:

To be understanding more and step back to evaluate the situation more, we got to do this watching the play.

The actors reported that performances gained from their encounters with the real-life care workers in the workshop settings, and in correcting aspects of the performance, some participants clearly enjoyed an opportunity to play the part of the director themselves.

Excellent day, please, please roll this out to all carers of dementia patients, they would value the opportunity to see this! As a community health care assistant it was good to feel appreciated, because there is such negative press in the media about health care in general.

This quotation illustrates how the show could influence the participants' self-esteem and perception of how they are seen by others. While it would be naïve to expect radical change in response to the events described alone, our impression is that seeing this play, combined with a period of time for dialogue, did permit busy care staff to reflect on several levels: from their contribution to society and their place in the public sector, to the ways that the norms of hospital life (such as buzzers) can help or hinder patient care and the rich rewards that successful communication with a person with dementia can deliver.

National roll-out

The play is on tour in February and March 2015, thanks to support from Arts Council England. Daytime shows are intended mainly for health and social care workers and are followed by post-show dialogues, as is the opening performance at each venue. A film of the production will be made for subsequent distribution to cinemas in other parts of the country, translating the work into a new medium and engaging a more widespread audience. ■

'Inside out of Mind' on Tour 2015

Derby Theatre
01332 593939
Wed 18-Sat 21 February
Wed 18: 7.30pm
Thu 19: 10am & 2.30pm
Fri 20: 10am & 2.30pm
Sat 21, 7.30 pm.

Nottingham Lakeside Arts
0115 846 7777
Tue 24-Sat 28 February
Tue 24: 7.30pm
Thu 26: 10am & 2.30pm
Fri 27, 10am & 2.30pm
Sat 28, 7.30pm

Canterbury Gulbenkian Theatre
01227 823494
Tue 3-Fri 6 March
Tue 3: 7.30pm
Wed 4: 10am & 2.30pm
Thu 5: 2.30pm
Fri 6: 2.30pm & 7.30pm

Warwick Arts Centre
0247 615 0930
Tue 10-Fri 13 March
Tue 10: 7.30pm
Wed 11: 10am & 2.30pm
Thu 12: 2.30pm & 7.30pm
Fri 13: 10.00am

Exeter Northcott Theatre
01392 493493
Tue 17-Fri 20 March
Tue 17: 7.30pm
Wed 18: 10am & 2.30pm
Thu 19: 2.30pm
Fri 20: 2.30pm & 7.30pm

Leicester Curve Theatre
0116 242 3570
Tue 24-Fri 27 March
Tue 24: 7.45pm
Wed 25: 10am & 2.30pm
Thu 26: 2.30pm & 7.45pm
Fri 27: 10.00am