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Title: Educating a health service workforce about dementia: a qualitative study

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Abstract:

Purpose

People who are living with dementia are core health service users but there are ongoing concerns about the quality of their care and the need for improved education of healthcare staff. This paper reports on a qualitative study that investigated staff perspectives of an ethnodrama ('Barbara's Story') which was used to educate an entire health service workforce and promote a person-centred approach to care.

Design/Methodology/Approach

The study used a qualitative, longitudinal design with focus groups held with clinical (nurses, allied health professionals, medical) and non-clinical staff. In Phase 1 there were 10 focus groups (n=67 participants) and one individual interview. In Phase 2 there were 16 focus groups (n=77 participants) and three individual interviews.

Findings

Barbara's Story raised awareness of dementia, engaged staff emotionally and prompted empathetic responses and improved interactions. The project's senior leadership, whole organisation and mandatory approach were well-supported, with a perceived impact on organisational culture. The project helped to embed practice developments and initiatives to support person-centred care. Barbara's story is now well integrated into the organisation, thus supporting sustainability.

Originality/value

Whilst there are increasing resources for educating about dementia, there are fewer evaluations, particularly for large-scale initiatives, and there is a lack of focus on long-term effects. The study findings indicate that education about dementia can be delivered to a whole work force in a sustainable manner, to prompt empathy, raise awareness, support person-centred care and impact on individual behaviour and organisational culture.

Keywords: Dementia, awareness, education, healthcare, empathy, organisational culture, ethnodrama, person-centred care

Introduction

As the world population ages, there are growing numbers of people with dementia. In the United Kingdom (UK) in 2014, there were an estimated 835,000 people living with dementia, a figure expected to increase to 850,000 by 2015 (Alzheimer's Society, 2014a). The healthcare workforce must therefore be effectively prepared to meet the needs of people with dementia and their carers (Traynor *et al.*, 2011). As dementia primarily affects older people, most people with dementia have other health conditions too (Alzheimer's Society, 2014b). People with dementia are therefore core health service users but there have been ongoing concerns about the quality of their hospital care, with calls for improved education of hospital staff. This paper reports on a qualitative study that investigated staff perspectives of an initiative to educate the whole workforce in one UK healthcare organisation

Background

In the UK, one in four of all adult hospital beds is occupied by a person with dementia (Alzheimer's Society, 2009). Admission to hospital poses many challenges for people who have dementia (Chater and Hughes, 2012) with the presence of dementia affecting the person's treatment, care and recovery (Health Foundation, 2011) and usually their dementia worsens following hospitalisation (Dewing and Dijk, 2014). Wherever possible and appropriate, care at home, in a familiar environment, is preferable for people who have dementia (Department of Health [DH], 2015) but some acute health conditions will necessitate hospital admission. It is essential therefore for hospitals to effectively meet the needs of people with dementia who are often frail and have co-morbidities (Oliver *et al.*, 2014). However, previous research has highlighted poor experiences and outcomes for people with dementia who are admitted to hospital (Sampson *et al.*, 2009; Cowdell, 2010; Clissett *et al.*, 2013) and families have expressed discontent with hospital care (Jurgens *et al.*, 2012).

Kitwood's (1997) seminal work on person-centred care for people with dementia highlighted the uniqueness of each person. Brooker (2004) has since presented the VIPS framework for person-centred care, comprising: valuing people with dementia and carers (V), treating people as individuals (I), using the perspective of the person with dementia (P) and a positive social environment (S). Person-centred approaches for people with dementia are increasingly considered synonymous with best quality care (Edwardsson *et al.*, 2010) but hospital care has been found to be task-orientated with a lack of focus on the individual (Clissett *et al.*, 2013). Dewing and Dijk (2014) identified that person-centred care for people with dementia while in hospital is not widespread. Previous research has highlighted the contribution of psycho-social interventions for people with dementia: interactions that support cognition, emotion, meaningful activity, interpersonal relationships and a sense of control (Fox *et al.* 2013). However, busy acute hospital environments may pose barriers to building interpersonal relationships and meaningful activity for people with dementia. Recently nine UK NHS hospital Trusts took part in a nationally-led project to improve hospital care for people with dementia (Evans 2015). Positive improvements were reported but these were self-selected Trusts and it is too early to identify whether improvements were sustained.

A recurring theme is that hospital staff lack knowledge and skills to care for people with dementia so improved education is necessary (Sampson *et al.*, 2009; Cowdell, 2010; Chater and Hughes, 2010, Gladman *et al.*, 2012, Calnan *et al.*, 2013; Clissett *et al.*, 2014). In addition, negative attitudes towards older people generally but particularly for those with dementia have been identified amongst hospital staff (Gladman *et al.*, 2012; Calnan *et al.*, 2013). How professionals view people with dementia influences the care that they provide (Jonas-Simpson *et al.*, 2012). Negative perceptions about dementia are still prevalent in society and are a barrier to people living well with dementia (Alzheimer's Society 2014b). It is

argued that the ageism and stigmatisation of people with dementia that is embedded in society is reflected in UK healthcare provision too (Chan and Chan 2009). In 2014, the UK's Care Quality Commission (CQC) concluded that care is improving but there was variable or poor care present in many hospitals and care homes and staff lacked knowledge and the right values for good dementia care.

Various reports and guidelines have recommended that hospital staff are educated to be able to recognise dementia and care for people with dementia when they are admitted to hospital for other conditions (National Institute for Health and Clinical Excellence, 2010; Health Foundation, 2011; Royal College of Psychiatrists, 2011; All Party Parliamentary Group, 2014). Alzheimer's Society (2014b) argued for high quality mandatory training for all staff who provide formal care to people who have dementia, a message supported by England's Department of Health (2015). Recently, Surr et al. (2016) reported that a half day person-centred care training course for hospital staff (mainly nurses) positively influenced attitudes towards people with dementia while a longer more in-depth course also improved staff satisfaction and feelings of caring efficacy. In another example, a pilot training programme for clinical and non-clinical staff on two hospital wards was evaluated well through pre and post questionnaires (Robinson et al. 2015). Whilst both studies indicate benefits of training, small numbers of staff were involved and large health care providers are challenged by the need to train all staff who are in contact with people with dementia.

Cowdell's (2010) study revealed that although hospital staff worked hard and attempted to deliver 'good care', they showed little empathy for people who had dementia. She argued that educational methods that engage staff on an emotional level are more likely to successfully prompt staff to be empathetic and become more person-centred. Little is known about how best to teach empathy and many study designs have been methodologically weak (Reynolds et al. 1999). An ethnodrama is the dramatisation of information (Saldaña 2010), through which human experience is communicated to an audience, providing a way for healthcare professionals to immerse themselves in the lives of people with dementia and their families (Kontos and Naglie 2006). A review of studies of empathy education in nursing included none where ethnodrama was specified; most used experiential learning (Brunero et al. 2010). Mitchell et al (2011) reported on the development and immediate responses to an ethnodrama about people and families living with dementia and seven patterns of engagement with the drama emerged with powerful emotions, insights and meaningful learning. The evaluation using focus groups indicated a transformation of healthcare professionals' understandings, images and intended behaviour towards people who live with dementia and their families (Jonas-Simpson et al. 2012). However, the long-term effects of this educational approach appear unreported.

Method

The Barbara's Story initiative and healthcare setting

The setting was a large National Health Service (NHS) system ('Trust') in London, England that included two large hospitals and community services. In 2012, the Trust launched a project to improve dementia awareness across all staff. As the aim was to engage the staff emotionally in the experience of people who have dementia and access healthcare, the Trust adopted an approach similar to ethnodrama (Kontos and Naglie 2006) by developing a filmed drama: 'Barbara's story'. The film shows the experience of an older woman (Barbara) in the early stages of dementia (undiagnosed), as she attends a hospital appointment and is then admitted for cardiac investigations. Barbara's perspective is the focus of the film and whether she is treated as a valued person and as an individual clearly affects her experience, thus highlighting principles of person-centred care (Brooker 2006). The film was mandatory for all Trust staff and 11,054 clinical and non-clinical staff attendances were recorded. The sessions were multidisciplinary and consistently led by the chief nurse and

safeguarding adults team, who facilitated discussion after the film. Each attendee was provided with a resource pack. Barbara's Story was subsequently embedded into the corporate induction programme for all new staff.

In the next stage of the project, a series of films was developed, 'Barbara's evolving story', which shows Barbara's health deteriorating and her care in hospital and community settings. After each film there was a facilitated discussion that highlighted key learning points and principles of person-centred care. Attendance was not mandatory at this stage; there were 4190 attendances from a wide range of clinical and non-clinical staff. The whole series of Barbara's Story was then made available on the intranet and is now delivered through the Trust's longer dementia training courses.

Study design

The study's aim was to investigate staff perspectives of the effect of Barbara's Story on themselves, their colleagues and the organisation. The study was qualitative and took a social constructionist approach, with the view that people together create social phenomena (Berger and Luckman 1996), a perspective that aligned well with the development and delivery of Barbara's Story across the Trust. Focus groups were used as they link individual and group interactions and subjective views are seen within a fuller social context (Burr 1995). Focus groups also enable exploration of processes as well as outcomes (Barbour 2007) and prompt the gathering of rich data about experiences (Plummer-D'Amato, 2008). The interactions between the participants stimulate more ideas for discussion; these data created through interactions are a fundamental component of focus group methodology and can provide insights into public discourse (Kitzinger, 1994).

A longitudinal design was used, comprising focus groups in two phases. Barbara's Story was launched in September 2012 and to enable all Trust staff to attend, the sessions were delivered regularly from September 2012 to April 2013. The Phase 1 data collection took place in August-September 2013, approximately one year after the initial launch but before the second series of films 'Barbara's Evolving Story' started. One new episode, with multiple viewings, was shown each month, completing in March 2014. The Phase 2 data collection started in April 2014 and completed in September 2014. The data collection period was extended due to challenges with focus group attendance, resulting from the increasing busyness of the Trust, especially on one hospital site.

Participants and data collection

Purposive sampling was used to include participants from different professions (clinical and non-clinical) and settings and the aim was for group sizes of 6-10 people. In practice due to the acute nature of the Trust, the facilitators had to be flexible and group sizes ranged from 2-14 participants (see Table 1). In groups with only two staff, there was still rich discussion between them. The larger groups occurred because facilitators did not wish to turn away staff who had managed to attend. An individual interview with a Facilities manager was conducted during Phase 1, in order to access views from a non-clinical and non-patient contact perspective. At Phase 2, three individual interviews were conducted with nursing staff who could not leave their wards to attend a focus group. The use of some interviews within an overall focus group design has been previously recognised as a pragmatic decision (Barbour 2007).

Nursing staff included registered nurses of varied seniority and non-registered nursing assistants. Non-clinical staff included porters, housekeeping/catering staff, receptionists and training staff. Each focus group (or interview) was assigned a unique identifier, which are used to attribute data extracts in the results. The focus group topic guides were developed from the project aims, in discussion with the Trust project team. Open questions with follow-

up probes were used to explore: recall and views about Barbara's Story, personal experiences and observations of care delivery since Barbara's Story launch, any changes within the organisation, sustainability and further developments. Focus groups were conducted in seminar rooms in varied sites across the Trust and interviews in ward offices. Each focus group was audio-recorded, lasted 35-60 minutes and was facilitated by two research team members, with one taking notes about non-verbal communication (for example, nodding). The individual interviews lasted 15-30 minutes and were conducted using the topics in the focus group guide.

[Table 1 here]

Data analysis

The focus group/interview audio recordings were transcribed. The data were analysed using the framework approach, which is a 5 stage process (Ritchie and Spencer 1994): 1) familiarisation with the data; 2) development of a thematic framework; 3) systematic application of the thematic framework to all data; 4) charting of coded data; 5) reviewing charts and searching for patterns. The Phase 1 data were analysed following completion of data collection. Firstly, the transcripts were read through to gain familiarity and themes were noted. At Stage 2, the thematic framework was developed from the focus group topics and the themes noted in Stage 1. The framework was then applied to each transcript through line by line data coding (Stage 3). Charts were then developed to display the data (Stage 4), and these showed the application of the codes for each focus group, with data summary or extracts within the cells. At Stage 5, the research team critically reviewed the charts, clustering codes into categories and then overarching themes were identified. The Phase 1 thematic framework was used as the basis for the Phase 2 thematic framework but additional codes were added after familiarisation, to ensure inclusivity of Phase 2 data. Finally, the themes were critically reviewed across Phase 1 and 2 and a coherent set of themes was adopted, to enable comparisons across the project's timescale.

Ethical considerations

Ethical approval was obtained from the University's Research Ethics Committee. The study was registered with the Trust's Clinical Governance Department. The participants were invited to take part on a voluntary basis. Invitation letters and information sheets were distributed. Participants were reminded that the discussion should remain confidential to the group. They were assured that they would only be identified by professional group and no individual would be identifiable.

Results

The findings are presented in four themes:

- Barbara's Story as an educational device and its delivery;
- Effect on individual staff: emotional engagement, awareness, interactions and behaviour;
- Practice developments and improvements;
- Organisational culture and sustainability.

These themes are presented next; data extracts are identified by phase (P1=Phase 1; P2=Phase2) as well as the focus group/interview participants (see Table 1).

Barbara's Story as an educational device and its delivery

Staff expressed that Barbara's Story had gained a high profile: '*She's the most famous name in the Trust!*' (P1-AHPs1) and by Phase 2, Barbara had become a way of communicating about dementia: '*You say Barbara's Story, everybody knows exactly what you mean*' (P2-Non-clinical1). There was now a Trust-wide awareness: '*You can see the massive difference of how they've increased awareness of dementia*'. (P2-Nurses9).

The films prompted staff to reflect on their practice, viewing healthcare and everyday practice through a different lens. The technique of showing Barbara's perspective was considered effective:

I think it's seeing it from Barbara's perspective the whole time, that's what makes the difference [...] it helped you to get a richer understanding of how people perceive an environment that we're very familiar with. (P2-Nurses2)

The second series helped staff to '*get more context to that patient's journey [...] I think it makes me think that there is more going on*' (P2-Non-clinical1). Comments such as these implied that Barbara's Story had helped staff to appreciate that during the hospital attendance they see only a brief snapshot of a person's situation. The films highlighted home circumstances and wider social factors and illustrated that all older patients are individuals who have a history: '*behind any patient there is a person with family, with interests, with a past and memories*' (P2-Medical). The films gave insights into family perspectives too, as Barbara's daughter's perspective is shown in the second series and staff also commented positively on seeing an individual's whole healthcare experiences across hospital and community care.

The chief nurse's leadership of the project was perceived to confirm the topic's importance: '*I think it carried a lot of weight*' (P2-AHPs1). There was unanimous support for the interprofessional delivery and for the mandatory initial Barbara's Story session, which was considered unifying: '*a shared experience across the Trust*' (P2-Nurses2). Staff expressed that the mandatory nature of the first film sent an important message, showing that the Trust took dementia very seriously (P1-Non-clinical2). The second, non-mandatory series, however, was seen by fewer staff and some expressed difficulties in leaving a clinical environment for non-mandatory training:

With the best will in the world, none of our wards, they wouldn't not want their staff to go but on the day, when it's ten to one and the film is being shown at one and lunches aren't finished etc., then you're not going to leave 'Barbara' to go and watch Barbara. (P2-Nurses2)

Some staff however had, since the initial showings, accessed the series through the intranet or by attending the Trust's dementia training programme, highlighting the value of different options being available to increase accessibility.

Effect on individual staff: emotional engagement, awareness, interactions and behaviour

Many staff gave examples of their emotional responses and of how they connected to the films personally and professionally; some staff recalled that the films had moved them to tears. Staff remembered Barbara being '*lost*', '*confused*', '*vulnerable*', '*scared*' and '*worried*'. Empathetic responses were expressed, such as:

What we take for granted every day, doing something – all the simple things – can, for some people, be very, very difficult. (P1-Community)

Staff appreciated that many people attending hospital for other health issues could have dementia as well and dementia was now considered to be of equal importance to a patient's other health condition that had prompted referral (P2-Nurses3). At the Phase 2 focus groups, staff discussed their increased awareness of delirium, which was shown in 'Barbara's evolving story'.

At both phases, staff discussed how their interactions with patients and their behaviour had changed:

A bit more patient with people, I always talk really quickly but if it's someone who has got dementia or is a bit older I'll speak slower and I'll make sure they understand what I'm saying rather than just saying my piece then leaving. (P1-AHPs1)

The changes discussed included: giving more time to patients, improved communication, better explanations, offering help to people who look lost or confused, listening, reassurance and attentiveness. Staff also recognised the value of building relationships:

You are the person that they're going to remember, that they recognise as being the person that makes them feel safer, can comfort them at a certain point, looks after them. (P2-Nurses8)

Staff expressed that Barbara's Story had given them confidence to offer help to people visiting the Trust but several staff had offered help to people who seemed confused when they were outside work too, for example, while out shopping. Reflecting a person-centred approach, staff expressed the need to understand individuals' situations and consider reasons for behaviour, for example, why a patient might not attend an appointment and so they were more proactive in following this up (P2-AHPs1). At both phases, indicating a sustained effect, staff discussed changes they had observed in others, particularly non-clinical staff, for example, porters and housekeepers were engaging more with patients and explaining what they were doing (P1-AHPs2; P2-AHPs1).

Practice developments and improvements

At the Phase 1 focus groups, staff identified various dementia-related initiatives (such as the forget-me-not symbol to indicate a person has dementia) and how these were:

Being used more now than before Barbara's Story, it was more on the shelf there, and you had to prompt people. (P1-Nurses3)

The second series of films showed these initiatives in practice and the Phase 2 data indicated that the project had helped in embedding these further. The initiatives discussed most were: 'This is me' (a short patient profile, developed by Alzheimer's Society), improvements to food provision (e.g. pictorial menus, snacks), trained nursing assistants to provide one-to-one person-centred care, dementia champions, and environmental changes, such as improved signage and décor. Staff who had used 'This is me' were vocal about how the document enabled them to approach people as individuals, for example:

It just made the care you gave so personalised and I remember the patient and it said in the notes, loves Coronation Street and EastEnders. So at 7.30pm I'd go and put on Coronation Street, just because I knew about it. (P2-Nurses4)

At Phase 2, discussions indicated increased awareness of: dementia screening with a perceived increase in referrals, the Dementia and Delirium team, and the Trust's care pathways for people with dementia or delirium.

Organisational culture and sustainability

At both Phase 1 and Phase 2 focus groups, staff perceived there had been a culture change within the Trust so that they felt able to spend longer with a patient:

Before people might have had a bit of a pop at you for spending too much time, [now] it may be a bit more acceptable. (P1-Nurses4)

Staff described a culture where they could put patients' needs first, feeling able to stop to help a person who was confused, even if this meant being late for a meeting (P1-Community). Similarly, non-clinical staff discussed:

It's a culture change so you're less nervous now of approaching people and saying, do you want help, can I help you. [...] I think they're bringing out the human part of us a little bit more rather than the paperwork bits. (P2-Non-clinical1)

However, lack of time, due to staffing shortages and workload, was raised as a barrier to giving more time at some Phase 1 and Phase 2 focus groups.

Staff discussed that Barbara's Story had set an expectation for staff to challenge care and there was reference to standard setting, starting at induction:

It's almost creating a new norm, isn't it? [...] I think it's increased or raised the bar. I think that's why it's quite good, doing it in the induction programme, because it's creating an ethos as to how we're expected to behave (P1-AHPs2).

There were similar comments at the Phase 2 focus groups and staff expressed that dementia was now seen as 'everybody's business' with Barbara's Story establishing the role that all staff were expected to play in improving patients' experience.

At the Phase 1 focus groups, staff recognised the need to sustain the impact of Barbara's story, for example, through regular reinforcement (P1-Medical) and raising it at appraisal (P1-Non-clinical1). At the Phase 2 focus groups, further suggestions included updates, further training and newsletter items. It was also identified that dementia champions, who were established across the Trust, had an important role in sustaining the impact of Barbara's Story (P2-Nurses5, P2-Medical).

Discussion

Educational resources to improve care for people who have dementia are increasingly available but there is a lack of formal evaluation and especially long-term follow-up (Dewing & Dijk, 2014). A strength of the current study is that it was longitudinal and gained staff perspectives over time, for example, at Phase 2, focus group discussions indicated momentum building and an increased profile of the project and awareness of dementia. The study involved staff from a range of disciplines and the focus groups led to rich data from the interactions. However, some staff participant groups, in particular medical staff, were small in number. Whilst there were many examples of improvements to individuals' practice following Barbara's Story implementation, these are perceptions and a limitation is that the study did not include observation and nor was it possible, within the project timescale, to collect baseline staff views prior to launching Barbara's story. Including the views of people with dementia who had experienced care in the Trust would have also strengthened the study.

This study indicated that a filmed ethnodrama can engage a workforce emotionally, prompting empathetic responses, thus supporting recommendations for more interactive and engaging methods for educating staff about dementia (Cowdell, 2010; Commission on Dignity in Care, 2012). However, our findings did not reflect all seven patterns of engagement in an ethnodrama previously identified (Mitchell et al 2011). It is possible that four of these patterns (participants seeing the familiar in a new way; their connection with the truths presented in the film; placing themselves in the scenes, and sensing a physical impact while watching the film) were experienced through Barbara's Story. However the other three tenets (experiencing meaningful learning; expanding understanding of the entire journey of dementia and affirming personal knowledge about dementia) were not revealed explicitly. Although the measurement of meaningful learning and increased knowledge about dementia were not the main focus of our study, evaluation of these aspects would be worthwhile in future research. Reports about education to increase empathy have mainly focused on nurses (Brunero *et al*, 2009, Williams and Stickley, 2010) and medical staff (Pederson 2010). However, the whole of the healthcare team (clinical and non-clinical) affect patients' care experiences and the current studies' findings highlighted the value of including non-clinical staff, supporting results from a pilot training programme's evaluation (Robinson et al. 2015). A book chapter exploring how Barbara's Story evoked empathy, using data extracts from Phase 1 of the study only, has been previously published (Authors, 2015).

Embedding person-centred care in acute hospital settings is complex (Webster 2011) and there are continued reports of task-orientated hospital care, with tensions between prioritising acute care and providing person-centred dementia care and a resulting lack of focus on individuals (Dewing and Dijk, 2014; Oliver *et al.*, 2014; Clissett *et al.*, 2013). Recent research indicated that a person-centred training programme for hospital staff can improve attitudes, but impact on care delivery was not included in the design (Surr *et al.*, 2016). 'Barbara's story' illustrated how principles of person-centred care could be integrated into practice even in busy, acute settings. The films helped staff to focus on one person and her perspective, thus highlighting the importance of understanding the perspective of the person with dementia, one of the principles of person-centred care (Brooker 2004). Staff recognised the importance of getting to know individuals with dementia and building relationships, supporting previous research (Edvardsson *et al.* 2010; Dewar and Mackay, 2010; Bridges and Wilkinson, 2011; Fox *et al.* 2013). At most Phase 2 focus groups staff discussed use of the personal profile 'This is me', which the films showed applied with Barbara, and they gave examples of how knowing personal information about patients benefitted care delivery. The CQC (2014) found that 'This is me' was used with variation even within the same hospital so showing its use across the Trust, as in Barbara's story, could increase consistency.

Edwards *et al.* (2014) emphasised the need to address negative attitudes associated with dementia, suggesting that using the term 'dementia' more frequently will promote its acceptance. The current study's findings support this view as Barbara's story's delivery across the whole Trust raised awareness of dementia and its relevance to all staff across the organisation. McPhail *et al.* (2009) conducted an evaluation of a project to educate a whole workforce about dementia but the setting was a very small hospital. There are few published examples of educating a complete workforce about dementia, particularly with the inclusion of non-clinical staff and across such a large organisation. As the initial Barbara's Story was mandatory, its importance to the organisation was conveyed and ensured that staff had to be released to attend. Previous studies have highlighted difficulties in staff being released for non-mandatory training and the need for organisational support and prioritisation (Smythe *et al.*, 2014; Coffey *et al.*, 2014). In the current project, the chief nurse's leadership of Barbara's Story confirmed its high priority in the Trust. However, attendance, though considerable, was much lower for Barbara's evolving story and some staff expressed that attendance for non-mandatory training could not be prioritised over clinical care.

A positive social environment is a dimension of person-centred care (Brooker 2004) but acute care hospital environments are considered generally unsuitable for people with dementia (Dewing and Dijk, 2014). However, in the current study, staff were aware of dementia-friendly environmental improvements within the Trust and practice developments and innovations in the Trust was a key theme that emerged. Study participants, at Phase 2, reported that the inclusion of initiatives to improve care for people with dementia, showing positive effects for Barbara, supported the embedding of changes in practice. The Trust's Dementia and Delirium team were concurrently supporting staff to improve care and the study findings revealed the value of their role, supporting suggestions for specialist nurses for dementia in acute hospitals (Chater and Hughes, 2012).

The CQC (2014) reported that being treated with care and compassion and high quality of care were most important for people with dementia and their families in UK hospitals and care homes. However, with reference to care homes, Sheard (2014) asserts that transformation of organisational culture is necessary for delivering compassionate care and he argues that focusing on individuals, rather than the organisation, is flawed. Indeed, previous investigations of poor care in the UK have highlighted how organisational culture impacts on care quality (Francis, 2013). The current study's findings indicated that, from staff perceptions, a Trust-wide educational approach can impact on organisational culture, for example, staff expressed that they felt able to give more time to patients when needed, despite a very busy environment. The findings also indicated that there had been a cultural

shift in attitudes, with older people with dementia recognised as being core health service users, in line with recommendations from previous researchers (Gladman et al. 2012). The influencing factors were the senior leadership of the project, the involvement of the whole organisation – all staff at every level, its roll-out over a lengthy timeframe (September 2012-March 2014) and permanent integration into the organisation within induction, dementia training courses and the intranet. Whilst there is always a risk that the impact of any project can diminish over time, the concept of ‘Barbara’ is now well embedded with many related initiatives to improve care for people with dementia.

When considering the transferability of the study findings, other settings would need to appreciate that for maximum effectiveness, Barbara’s Story needs strong leadership, consistent facilitation by a committed team, and commitment to improving dementia care through educating all staff within an organisation. A key factor in the project’s success was that the initial Barbara’s Story was seen by all Trust staff (clinical and non-clinical) so there was a shared experience and a common awareness and understanding gained.

Conclusion

The requirement for effective education of healthcare staff to provide high quality care for people who are living with dementia who access healthcare is now embedded in UK guidelines and policy but the best way of achieving this in practice remains a challenge for many organisations. This study presented qualitative findings about the use of an ethnodrama to engage a whole large workforce of clinical and non-clinical staff with an individual’s experience, providing insights into her perspective and supporting person-centred care. The study findings indicated that this approach can be used successfully with large groups of staff, thus ensuring wide scale reach and feasibility of delivery, whilst also leading to a perceived culture change through the shared experience. Senior leadership of the project was a key feature and sustainability has been promoted through integration with induction and within intranet resources, local Dementia Champions, support from a dedicated Dementia and Delirium team and the continued embedding of initiatives to improve care.

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Table 1 Focus groups/interviews participants

Phase 1 focus groups/interview		
Identifier	Discipline	Attendees: n
P1-Nurses 1	Nursing staff	2
P1-Nurses 2	Nursing staff	6
P1-Nurses 3	Nursing staff	6
P1-Nurses 4	Nursing staff	3
P1-Nurses 5	Nursing staff	6
P1-Community	Community staff	6
P1-AHPs1	Allied health professionals	14
P1-AHPs2	Allied health professionals	8
P1-Medical	Doctors and dentists	4
P1-Non-clinical 1	Non clinical staff with patient contact	12
P1-Non-clinical 2	Facilities manager	1
Total participants		68
Phase 2 focus groups/interviews		
Identifier	Discipline	Attendees: n
P2-Nurses 1	Nursing staff	3
P2-Nurses 2	Nursing staff	3
P2-Nurses3	Nursing staff	2
P2-Nurses4	Nursing staff	5
P2-Nurses 5	Nursing staff	10
P2-Nurses 6	Nursing staff	13
P2-Nurses7	Nursing staff	8
P2-Nurses8	Nursing staff	2
P2-Nurses9	Nursing staff	2
P2-Nurse10	Registered nurse	1
P2-Nurse11	Registered nurse	1
P2-Nurses12	Nursing staff	2
P2-Nurse13	Registered nurse	1
P2-Community	Allied health professionals and district nurse	6
P2-AHPs1	Allied health professionals	2
P2-AHPs2	Allied health professionals	5
P2-Medical	Doctors	2
P2-Non clinical1	Non-clinical staff with patient contact	7
P2-Non clinical2	Non-clinical staff, mainly non-patient contact	5
Total participants		80