

Executive Summary

Despite the high prevalence of people with a dementia who live in care homes, there is a lack of appropriate training for the workforce that provides their care. The DESCARTES project has developed and piloted arts-based workshops as a new and engaging form of education for the dementia care workforce. The aim of the workshop is to facilitate emotional learning, to empower care home staff and to encourage person-centred dementia care in line with current government recommendations. The development process used care home observation, storytelling and focus groups to explore the needs of care home staff and to help identify appropriate arts materials.

The resulting workshops are designed to be interactive and responsive to the needs of care home staff. Two pilot workshops were delivered to a range of care staff (senior care assistants, night staff and domestic staff) in a dementia-specialist care home. They were found to be useful, highly engaging and to provide new insights into and connections with the lives of those living with a dementia and to have relevance for people working with them.

The workshop materials helped staff to think creatively about people with a dementia and their own roles in providing care. The workshops offered a form of workforce education in dementia that can be:

- Experiential
- Replicable
- Scalable
- Cost effective
- Innovative
- Applicable to a wide variety of people (including families and GPs).

The indicative materials (arts resources and new materials) developed for DESCARTES are being examined for potential use by dementia courses at City College and by Norsecare.

The ideas and materials for DESCARTES arts-based workshops merit further development and much wider dissemination. A variety of funding sources to achieve this end is being examined.

Acknowledgements

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Structure of the report

This report comprises 4 main sections:

- 1) **Introduction** – the background to the project (its aims, objectives and rationale), details of key funders and the multidisciplinary team that led the work.
- 2) **Literature Review** – key findings from the research papers and government reports providing robust conceptual evidence to support the development of DESCARTES workshops.
- 3) **DESCARTES** – development, methods and delivery of the workshops.
- 4) **Discussion and conclusions** – a summary of the extent to which the project met its stated objectives and the future potential of arts-based workshops, their applicability for City College Norwich dementia courses and follow on applications for related knowledge mobilisation and research funding.

1. Introduction and background to DESCARTES

This is the final report detailing the development and delivery of innovative arts-based workshops for dementia care staff. The project was led by an expert multidisciplinary team comprising:

- ❑ Dr Hannah Zeilig, social and cultural gerontologist (AHP, UEA)
- ❑ John Killick, an internationally renowned innovator in dementia care
- ❑ Professor Fiona Poland, community sociologist and dementia research (AHP, UEA)
- ❑ Dr Chris Fox consultant old age psychiatrist (Norwich Medical School [MED], UEA) and Dementia Research Innovation Group (DRIG) Lead at UEA.

It was supported by an expert and stakeholder **Advisory Group** which comprised the following members:

- ❑ Hannah Zeilig (UEA, AHP, DRIG, DESCARTES Lead)
- ❑ Fiona Poland (UEA, AHP, DRIG)
- ❑ Anne Killeth (UEA, AHP, DRIG)
- ❑ Vicky Cowap (Norsecare)
- ❑ Clare Holmes-Urquhart (City College, Norwich)
- ❑ Dr Bridget Penhale (UEA, School of Nursing Sciences [NSC], DRIG)
- ❑ Chris Fox (UEA, MED, DRIG)
- ❑ John Killick (DESCARTES Consultant)
- ❑ Willie Cruickshank (NSDA)
- ❑ Juni West (Norfolk and Suffolk NHS Foundation Trust and NSDA).

The rationale for DESCARTES is based on three assertions that are well-supported by research:

1. The high prevalence of people with a dementia who live in care homes.
2. The lack of appropriate training for the staff that provide care to this vulnerable group of people and the need for well evidenced dementia care training.
3. The scarcity of work that explores the benefits that the arts might have if used in the training of dementia care professionals.

Each of these points is analysed in some detail in the literature review in relation to evidence from published research and government reports (section 1.1 below).

The originality of the DESCARTES project lies in bringing the arts into the education of the dementia care workforce.

DESCARTES is a pilot development project rather than a research project. However, there is a fine line separating research from development and the project was strengthened by the overview of national and international research contained in the literature review (section 2) and by the extensive contact time that the lead researcher (Hannah Zeilig) spent in the dementia care home, listening to the stories/narratives of both care staff and residents. Hannah Zeilig (HZ) is an experienced qualitative researcher and drew on ethnographic techniques of observation and field notes during her time in the dementia care home to inform the project. The methods underpinning the project are discussed below (section 3).

The main aim of the project was to develop and deliver a way of training dementia care home professionals (direct care staff, managers, domestic staff) in a single care home, which uses cultural resources (film, fine art, music, memoirs, novels, poetry). The care home staff were closely involved with the development of the workshops. The intention was that these workshops would therefore be directly engaging and responsive to the needs and concerns of participants.

The objective of the arts-based workshops was:

- i) To encourage emotional and reflective learning around dementia care.
- ii) To engage care home staff in a re-consideration of 'dementia' by critically examining representations of this condition.
- iii) To empower care home staff to recognise the skills they already possess.
- iv) To provide, through reference to the arts, multiple perspectives on what 'dementia' can be and how it might be experienced.
- v) To engage participants' imagination in re-considering dementia through the arts and challenge stigma and prejudice about dementia.

2. Dementia care training and the Arts: Key Findings from the Literature Review

The literature review was completed prior to the start of the practical developmental work for DESCARTES; it was carried out in October 2012. This review of policies, practice and evidence was undertaken as a means of framing the DESCARTES project, providing essential background and a clear conceptual focus for the subsequent practical work.

The main points arising from this review in relation to the rationale for the project noted above (section 1) are:

2.1 The high prevalence of people with a dementia in care homes

In the UK, a third to one half of all people with dementia live in a care home (Knapp, Prince et al., 2007; Macdonald and Cooper, 2007; CQC, 2011) and almost three quarters of people in residential homes have dementia (Macdonald and Carpenter, 2002). Moreover, care homes tend to be dominated by people with dementia who have the highest needs in terms of behavioural difficulties and physical co-morbidity (Banerjee, 2009). The numbers of people with dementia in care homes is likely to increase with considerable economic and social implications (Bond et al., 2012; Wild and Nelson, 2010). In addition, as residents age their health needs generally increase leading to considerable overlap in the roles played by nursing homes and residential homes (Wild and Nelson, 2010). It is noteworthy that in Australia and in the USA residential settings for lower levels of care, such as hostels and assisted living, also have many residents with a dementia (noted by Fossey, 2010).

2.2 Training for the dementia care workforce

Government, NHS and academic research in the last five years has repeatedly emphasised the urgent need for workforce training for those who provide care for people with a dementia. There has also been concern expressed about the level of stigma and prejudice even amongst those professionals who provide care. In addition, an 'important skills gap' amongst the dementia care workforce has

been highlighted by many studies (see for example, Hussein & Manthorpe, 2012). In the last four years, there has been a repeated emphasis on the need for adequate workforce training for professionals who care for people living with dementia (Banerjee, 2009; National Dementia Strategy, 2009; APPG on dementia, 2009, 2011; DH: Skills for Care and Skills for Health, 2010; Ministerial Advisory group on dementia, 2011). A recent report by the CQC (2011) reflects the findings of the APPG on dementia (2011) – both of which highlight problems in the quality of dementia care and connect this with a lack of staff training. In addition to this, higher perceived levels of quality by users were positively associated with a highly trained workforce (among other factors) (Health, 2012b).

Training then, is clearly linked with a higher quality of care. The APPG report (2011) further stresses that a failure to ‘invest in a well trained and supported workforce’ has resulted in the waste of ‘significant amounts of money’. It is perhaps in recognition of this that the government’s recent ‘Challenge on Dementia’ initiative (2012a) includes the assertion that the workforce will be supported through training:

“Via Skills for Care, the Department of Health has a fund of £2.4 million for social care employers and providers who support people with dementia, including those who employ their own support staff, to build the skills of their employees by completing relevant accredited qualifications.”

(2012a,p.16)

The ‘Delivering Dignity’ report from Age UK and the NHS confederation (June 2012) provided a number of recommendations for care homes. These also stressed the importance of investing in support and regular training for staff. The report highlighted the need to foster positive attitudes towards ageing through training and emphasised the centrality of compassion. Research has demonstrated that staff who provide care for individuals with Alzheimers and other dementias are at risk of burnout (Ballard, Lowery, & Powell, 2000; Hallberg & Norberg, 1995). Research that focused on a number of factors associated with staff burnout has suggested that training programmes or interventions aimed to

increase levels of self-efficacy for managing challenges at work could assist in reducing burnout (Duffy, Oyebode and Allen, 2009).

Additionally, research suggests that a well-trained dementia care workforce will create a virtuous cycle of care. If adequately trained, their confidence will increase and this will encourage positive interactions with clients (Moyle et al., 2011). Research evidence amply supports this sense of the self-propagating advantages of training for the dementia care workforce. For instance, studies have demonstrated that appropriate training can significantly improve staff morale (Popham and Orrell, 2012; Train et al., 2005) and sense of hopefulness towards people with dementia and can also improve their sense of competence at forming relationships with residents (Goyder, et al., 2012: .8). The STAR (Staff Training in Assisted Living Residences) training implemented in the UK and assessed by Goyder et al (2012) resulted in reduced depression, anxiety and behaviour problems amongst residents as well as encouraging reflective behaviour amongst staff (p.8). This ameliorated relationships between staff and residents. Good training then, is likely to help staff as well as those they are caring for and can have a multiplicity of benefits.

Clear evidence (Bannerjee, 2009) also suggests that good training is likely to help reduce the use of antipsychotic medications, which can have serious health effects when given to people with dementia.

However, there is a lack of training initiatives, especially of training that has been robustly assessed as appropriate, being of high quality and effective for this workforce. This is surprising given the widespread political and public concerns about how to care for a growing population of older people with dementia. There is a lack of clarity at the level of national policy concerning the exact skills necessary for the dementia care workforce. Although there is some requirement by CQC for registered homes to ensure that the workforce has a fundamental level of awareness and training about dementia (supported by Skills for Care), there is no direct specification about the courses that people should undertake. Care home providers are thus able to choose dementia care training that they deem appropriate for their workforce.

Interest in developing psychosocial approaches to dementia care is quite recent (since the mid-1990s) but a major obstacle is the lack of investment in this compared with pharmaceutical interventions. Despite the many positive effects associated with training, this sector relies on workforce that has very few and low qualifications. Above all, this should be addressed to improve the lives of people with dementia in care homes. As stated by Banerjee (2009):

'Building skills in care home staff (nurses and care staff) is also vital if we are to improve the quality of care provided for people with dementia and their carers in care homes.' (p.46).

2.3 The arts in dementia care

Very little use has been made of the arts in the education or training of the dementia care workforce. This is surprising given the expansion in the medical humanities, which stress the value of using cultural texts (film, novels, poetry, theatre amongst other media) for educating healthcare professionals and others. In 2004 the Arts Council published a review that included 385 references from medical literature related to the positive effect of the arts and humanities in healthcare. It offers strong evidence of the influence of the arts and humanities in achieving effective approaches to patient management and to the education and training of health practitioners. Several studies have demonstrated the tangible benefits of using the arts in training doctors, these benefits include an increase in the humane treatment of patients (Anderson and Schiedermayer 2003). Film has been shown to be an effective teaching tool in psychiatry; especially when dealing with sensitive issues (Dave & Tandon, 2011) and in order to effectively combat subtle prejudices (Raingruber, 2003).

In addition, arts-based research methods have gained in popularity over recent years and offer an alternative approach to the positivistic stance of much health and social care research (Foster, 2012). These approaches have also tended to be aligned with marginalised groups in society (as noted by Foster, 2012: 743). The emphasis of the arts is on experience, feeling, imagination and meanings that lie to the side of our vision, that may be masked and cannot easily be measured. In the hyper-cognitive culture in which we live, older people with dementia are

doubly marginalised. The emphasis on emotions that is integral to the arts is of particular relevance for people with dementia and their carers.

Despite the general neglect of the arts for dementia workforce education, some work has begun to explore the usefulness of the arts in this context. Reflective narratives have been investigated as a means of helping dementia nursing staff think about the patient as a whole person (Graham-Pole and Lander, 2009). Fiction has also been used as a means of contextualising the lived experiences of dementia and encouraging the development of imaginative empathy (Morris, 2012) in the education of health care professionals.

This indicates that the arts are likely to have an important role in illuminating the lived experiences of someone with dementia, that they can encourage empathy and an understanding of the holistic nature of care-giving (rather than the task-oriented medical model that tends to dominate much dementia care). The arts have also proved effective in knowledge production and in stimulating critical reflection about personal care-giving practices. Although it is important to be cautious about the efficacy of arts-based approaches (they cannot offer a single 'catch-all' solution and have not been adequately assessed and evaluated) there is reason to expect that as part of a training module, reference to the arts will help alleviate the existing boundaries between service providers and people with dementia and open up new ways of communicating and interacting with individuals with dementia.

The literature review therefore provided ample support for the rationale, aims and objectives of the DESCARTES workshops.

3. DESCARTES: development, methods and delivery of workshops

3.1 Project development

The project was developed in partnership with one dementia care home in North Norfolk and started in October 2012. Dr Hannah Zeilig (HZ) spent several hours

on consecutive days prior to the formal start of the project discussing its aims and objectives with the care home manager. This was to ensure that the manager was fully aware and supportive of DESCARTES. The project was structured in 4 stages and each stage was linked with a specific strategic objective and output. All the strategic objectives were met in strict accordance with the time lines of the project. In addition, all the outputs were presented to members of the advisory group for their consideration. Advisory group meetings were organised at regular intervals to facilitate a credible accountability mechanism and also to provide a forum in which the project leaders received advice and substantive input from key members.

Stage 1: October – December 2012

In the first 3 months, HZ spent 7 days in the pilot care home and set up and conducted 3 in-depth focus groups, which 22 members of staff attended (there are 35 members of staff in total at the care home including night and relief staff). John Killick attended 1 focus group and was instrumental in helping to analyse the transcripts from all of the focus groups (which are discussed in some detail below, section 3.2).

In November 2012, HZ presented DESCARTES development concepts at a research seminar series at a key dementia centre in Sweden (CEDER, Linkoping University). This trip was funded by AHP (UEA) and forged strong links between the DESCARTES team and international colleagues who are investigating similar approaches to dementia workforce education.

The output from stage 1 of the project was an overview of the main findings from the literature review (section 2.1) and initial focus group findings on care home staff needs (these findings are discussed in more detail below, section 3.2).

Stage 2: January – March 2013

In stage 2 of the project the DESCARTES team concentrated on the analysis of the focus group findings, the development of an evaluation questionnaire for staff and above all the careful preparation and selection of arts material that could be incorporated into the workshops. John Killick and HZ collaborated closely during this process. In addition, HZ spent several days negotiating with Norsecare to ensure staff attendance at the workshops and to confirm that the care home floor would be covered during the workshops. HZ continued visiting the care home to maintain good communication and strong links with both staff and residents.

In February 2013 HZ presented work stimulated by the DESCARTES project at a well-attended knowledge exchange seminar in UEA. It was titled ‘What do we mean when we talk about dementia?’ A version of this presentation has subsequently been published in the peer-reviewed journal ‘The Gerontologist’ (Zeilig, 2013).

The output from stage 2 of the project was a brief report on the selection, structure and use of arts materials for the workshop (see section 3.3 below for more detail).

Stage 3: April – June 2013

The focus for this stage of DESCARTES was on the final preparations and delivery of the arts-based workshop in the dementia care home. HZ spent 2 days with an IT specialist (John Thompson, UEA) cutting clips from the films and music that had been selected at stage 2 of the project. These were subsequently embedded in power-point slides and a presentation was carefully structured including a diversity of images and some text.

HZ also met with Clare Holmes-Urquhart (who is responsible for designing the new HE course on dementia at City College Norwich) to discuss potential links with the material being developed within the DESCARTES project.

Between April and June, HZ and colleagues also started considering ways of securing further funding to develop the workshops, deliver them more widely and disseminate their impact.

The arts workshop was delivered twice in the dementia care home, on 13th and 14th June to a group of 15 staff members in total (the delivery of these workshops is discussed in more detail below, in section 3.2).

Output 3 was an interim report on findings from the workshop delivery on the feasibility and acceptability of training and ideas for a web-based resource that provoked an enthusiastic discussion at the subsequent advisory group.

Stage 4: July – September 2013

This is the final stage of this phase of the DESCARTES project and it focuses on writing up the final report, exploring the potential for training resources emerging from the arts workshop (including web-based resources) and submitting applications for further funding and development.

HZ and John Killick have disseminated the project at one national conference (Innovations in Dementia Care: July 17th, University College Suffolk 2013) and one international conference (British Society of Gerontology: September 11th-13th 2013).

3.2 Methods

Familiar methods were used to construct something essentially novel in orientation.

These aimed to encourage fresh perspectives on and creative engagement with people living with a dementia. The workshops were designed to explore the complex and contradictory emotions involved in dementia care. The methods have specifically included:

- ❑ A **literature review** (as outlined section 2): this has provided conceptual focus and robust evidence for initiation of the project.

- ❑ The collation of a **wide range of cultural media** that focus on dementia. The lead researcher (HZ) has accumulated arts resources that articulate and explore different aspects of the experiences of living with or caring for someone with a dementia. This is a collection that has expanded with the help and guidance of John Killick. However, DESCARTES has also benefitted from:
 - The support of colleagues in the BBC who have allowed us access to a wide range of TV and film that portray different aspects of dementia
 - The support of Chris Boicos the curator of William Utermohlen's work.
 - The resources at the Poetry Library (London)
 - From the interest of colleagues in literature departments who shared texts and knowledge about representations of dementia.

- ❑ HZ and John Killick spent several days reviewing the **arts resources** to identify through detailed discussion which films and other texts would be most appropriate. These discussions were guided by the combination of a need to use a cross section of types of materials as people respond differently to different stimuli and pragmatic considerations about the feasibility of using particular resources.

- ❑ The use of a **comic** to communicate quickly and concisely with dementia care home staff. HZ realised after spending several weeks in the care home that communicating clearly about the project was difficult due to the time pressures that staff face to complete their rounds. HZ collaborated with TenFiveTen (a small medical communication company) to produce a comic that succinctly described the aims and objectives of DESCARTES. This was well received by both the staff and the residents of the care home. (*See appendix*) The use of comics in medical education is well established but has not been explored in dementia care settings. HZ and colleagues are pursuing possibilities for extending this work.

- ❑ **IT technical help** (from a UEA-based technician) was enlisted to download appropriate films and then cut selected scenes from them in order to incorporate them into the presentation (powerpoint slides) for the final workshop.

- ❑ **Three focus groups** were held with care home staff, each group lasted an hour. A total of 22 members of staff (including care assistants, senior care assistants, kitchen staff, domestic and night staff but not management) attended the focus groups (this represents 63% of the total staff who work in the care home). The groups were recorded, transcribed and analysed by HZ, John Killick and Professor Poland. The groups were carefully planned to elicit the feelings that staff had about their jobs in dementia care and the particular difficulties that they experience (*See appendix*). The recurrent themes emerging from the discussions formed the basis for structuring the workshops. The themes were: - identity (as a carer and when living with a dementia), - awareness, - difficulties with language and communication (between care home staff as well as between staff and residents), - the work of caring.

- ❑ In addition, **observational data** about emotional and affective aspects of care home work has been gathered and analysed. HZ spent a total of 5 hours in meetings with the manager of the home and with overall managers of Norsecare. She therefore gained a clear sense of some of the practical issues (i.e. funding, staff cover, difficulties with families and so forth) and some of the strategic priorities (i.e. future for small dementia care homes, changes to staff structure etc) that are an essential part of the care home culture. HZ also spent c.40 hours in the dementia care home with both residents and staff. She therefore gained a well-informed sense of the complexity of emotions that accompany the work of caring for people living with a dementia and the difficulties of providing care that is properly 'person-centred' whilst also satisfying the task-oriented demands of the job to feed, medicate, dress and clean residents. In addition, there were several deaths during the 12 months that HZ spent in the care home and profound resultant difficulties for residents and staff were apparent; the staff had little time to grieve and the news was often not shared with residents.

- ❑ **Folders of arts resources.** Folders titled 'Tell me about Dementia' were compiled: these include some of the poetry and excerpts from the memoirs that were discussed during the workshop sessions. Research has demonstrated that staff can be reinforced by 'tip cards' and posters

(Broughton *et al.* 2011, Gould and Reed 2009, Moyle *et al.* 2010) a function that we expect will also be fulfilled by continued use of the folders in the care home.

- ❑ **Specific evaluative questionnaires** were developed for the project workshop and all workshop participants completed these. The results are reported in section 4 (below) (*See appendix*)
- ❑ **Advisory group meetings.** The advisory group consisted of representatives from all key stakeholders involved with supporting and funding DESCARTES (including members of UEA's dementia research interest group, Norsecare, City College Norwich and NSDA). Each meeting was well attended and linked to one of the stages in the project. HZ reported on a specific output at each meeting and received substantial input from key members that helped to shape the project. For instance, detailed discussions amongst the advisory group helped to determine the structure and size of the evaluation questionnaire.

3.3 Delivery of workshops

The information supporting the themes that emerged from the focus groups and from assembling the arts resources has great potential for developing a series of workshops to use the principles piloted here. However, time constraints and practical considerations (fundamentally the need to provide staff cover in the dementia care home) led to one 2-hour workshop being created that was delivered to a total of 15 care home staff over a 2-day period. The workshop was built from arts resources, structured around the care home staff focus group themes (identity, awareness, language and communication, the work of caring). The workshop included two interactive games: one that explored ideas of identity (and what is true or false in relation to our identity); and another that invited participants to consider difficulties relating to language and communication.

The workshop is organised in two halves separated by a coffee break. Each half includes 10 separate but connected extracts (from film, music, poetry, memoirs or art) that are discussed after they are presented. HZ and John Killick introduce the workshop by stressing that no information or statistics about 'dementia' will be presented, rather that the focus is to feel our way into some of the situations that

people living with a dementia may experience and also to re-consider the work of caring for those with a dementia. The workshop is **experiential** rather than fact-giving and was created to prompt self-reflexive reflection about the nature of emotional work of dementia care.

The use of arts resources to explore themes in dementia care

Identity and awareness was explored via music, theatre and poetry. The workshop opened with music by Elvis Costello (Veronica), an interactive 'ice-breaker' game and an excerpt from the play 'An Evening with Dementia'. In addition, the poem '13 snapshots of Maisie' was read in which a woman with a dementia introduces herself. All these texts were discussed in terms of the personhood of people living with a dementia. The extent to which an individual is aware that they are living with a dementia was also discussed. In particular, who we think we are and the ways in which we present ourselves to others provoked animated discussions in both workshop sessions as did the notion that people with a dementia might have to work hard in order to appear 'normal'. Issues of personhood and identity were also explored in the interactive game in which all participants were invited to share one true thing and one false thing about himself or herself with everyone present – others then had to guess which was true and which was false.

Communication and language were introduced by presenting poems, art, a clip from the film 'Away from Her', an excerpt from a memoir and by playing an interactive game designed specifically for this workshop, entitled 'word salad'. All participants could empathise with the difficulty of finding appropriate words and with the struggle that people living with a dementia care often face as their language and vocabularies are diminished. However, the excerpts also highlighted the creative and playful ways in which people with a dementia often use language to communicate with others.

The work of caring was examined through poetry, several clips from the film 'Lost for Words' and the film 'Ex-Memoria' and was designed to address some of the practical issues highlighted by care staff. For instance: the physical work of

lifting people out of bed, or taking them to the toilet and bathing people. These are all essential tasks but can also be times of conflict and distress both for residents and care staff. The particular world of a care home and the relationships within these settings was also discussed by presenting a clip from 'Away From Her'; this clip was also used to consider the role of care home staff in relation to residents' families. The session ended on a positive note about the importance of good caring and how valuable this can be for families as well as people with a dementia.

The workshop was carefully timed and lasted exactly 2 hours on both mornings. The relative brevity of the workshop was to ensure that there would be few difficulties with staff coverage in the care home and to ensure that the staff were not emotionally overwhelmed.

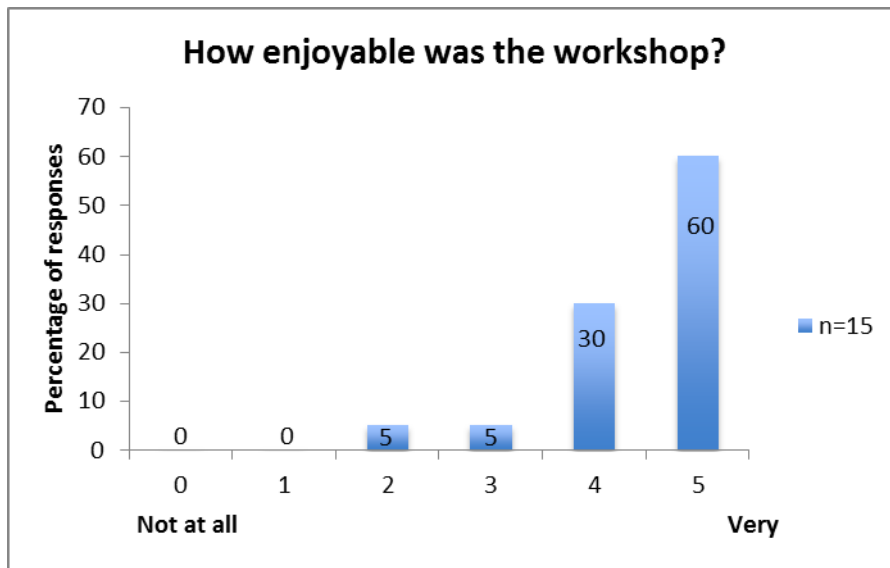
As this workshop was in development rather than a final product, a great deal of material was presented. The recurrent comment from successive evaluations was that participants would have valued more time for discussion.

The evaluation of the workshop

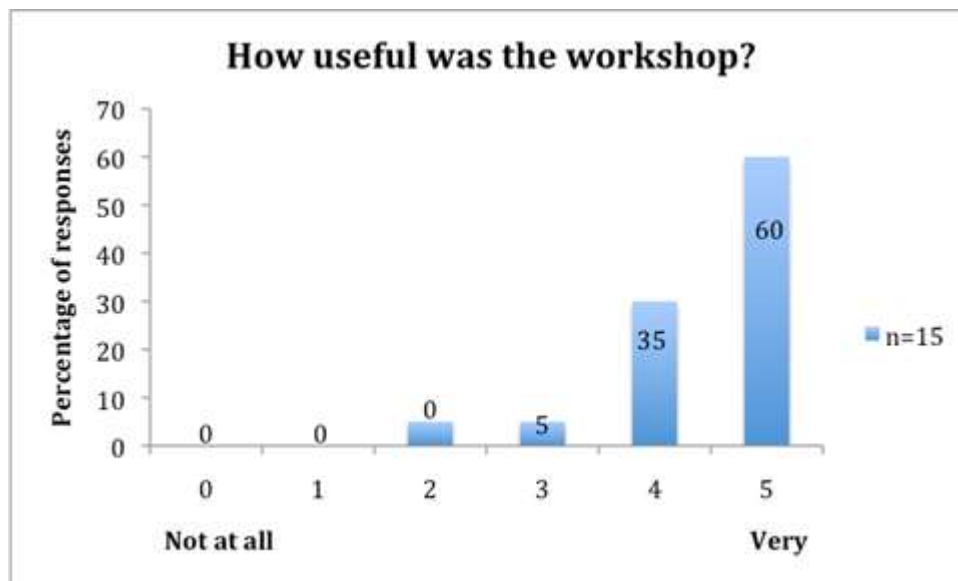
The evaluation questionnaire was brief and was completed at the end of the workshop. A total of 15 care home staff attended and they all completed the evaluation. They were asked:

1. How enjoyable the workshop was.
2. How useful it was.
3. Which sections that worked well (ticking all those that were relevant).
4. Free comments on sections that worked well.
5. Which sections could be improved and how.
6. What they will remember about the workshop.
7. Any other comments about this workshop or dementia care training in general.

The findings from the questionnaire are summarised as follows:



Thus **90%** of those who participated found the workshop enjoyable or very enjoyable. Nobody who took part reported that it was not at all enjoyable.



95% of those who took part in the workshop found it useful or very useful. Nobody who participated felt that the workshop was not at all useful. This indicates that a workshop that enables care home staff to reflect upon their experiences caring for people with a dementia might be extremely useful despite not overtly providing information (such as distinguishing between the different types of dementia, giving statistical summaries of the prevalence of the illness and so forth) or imparting new skills (such as how to lift or feed or provide end of life care to individuals with a dementia).

**Please indicate sections that you felt worked particularly well?
(Tick all appropriate):**

USE OF FILM CLIPS

All of the 15 participants felt that using film clips worked well.

USE OF POETRY

The use of poetry was considered to work well by 12 of the 15 participants.

USE OF AN EXCERPT FROM PLAY

14 of the total participants liked the use of an excerpt from the play.

DISCUSSION ABOUT ART

The use of art was perceived to have worked well for 12 of the 15 participants.

DISCUSSION ABOUT GOOD CARE PRACTICES

Discussion about good care practices worked well for 13 of the 15 participants.

Comments on sections that worked well:

The film clips and poetry really made me stop and think about how dementia makes people feel

The art moved me!

It was nice to hear views from family members about carers and what they believe a skilled carer can bring to a service user

Other comments include the observation that all the sections had relevance to someone experiencing and living with dementia and the pleasure of hearing music at a workshop for dementia: *'because music has mapped my whole life and I respond to music the most'*.

Comments on sections that could be improved:

No

The course to be longer as it was a little bit rushed although I know you were under pressure

None it was extremely well presented

More time to cover the whole course

What will you remember about the workshop?

Everything

The feelings, the video, poems etc gave from a person with Alzheimer's point of view

Seeing the things we deal with everyday from a different point of view

It was emotional at times but that just reinforced how complex dementia is

Any other comments about this workshop or dementia care training in general?

This workshop would benefit anyone who works with dementia

This was the best dementia course I've done in 4 ½ years in this job. It was REAL. Well done. I feel totally emotionally frazzled.

Training like this makes us think more about the way in which we care and not focus on the task based part of the job!!!

Everyone who works in a care home should attend one

4. Discussion and conclusions

This section presents a summary of the extent to which the project met its stated objectives and outputs (4.1), the future potential of arts-based workshops, their applicability for City College Norwich dementia courses (4.2) and a brief discussion of developing applications for related knowledge mobilization and research funding (4.3).

4.1 Did DESCARTES fulfill stated objectives and outputs?

There were 5 stated objectives for the DESCARTES project and 5 outputs. These are discussed in some detail below. However, overall (and given the limited evidence base of 2 workshops provided in a single care home with a total of 15 care staff) the use of arts resources for dementia care education was exceptionally successful. The rationale underpinning the project – that the arts and humanities, which have been so successfully used in other health care settings might also form an integral part of dementia care education – was wholly substantiated by this project. The outputs for the project were also all achieved according to the project’s timelines. Indicative material concerning how the arts might be used in dementia care training was developed and this constitutes the substance of the workshop; a workshop was also developed and evaluated by care home staff, a peer review paper emerging from this work has been drafted, dissemination has been initiated via presentations at several conferences and work is currently underway to secure follow-on funding.

□ Objectives

1. To encourage emotional and reflective learning around dementia care

Many of the comments from the evaluation questionnaire completed following completion of the workshop indicate that the workshop encouraged reflective thought about the condition ‘dementia’, about individuals living with a dementia and about the ways in which care staff provide care to residents living with a

dementia. In addition, the interactive games created a non-threatening, safe space in which participants were encouraged to think about the construction of their own identities and their own occasional difficulties with language. This is apparent from the following comments:

“When talking about word salad it’s important to remember the frustrations people suffer, not many residents have humour when struggling to find words.”

“The way people try to cover not knowing words by describing things...”

“They all help to open your eyes regarding feelings, mixing of words (word salad)”

The word salad game demonstrated the time it can take to find alternative words for the clear communication of basic tasks. Clearly the experience of playing this game in a light hearted and humorous environment prompted reflective thought for several care home staff.

Other comments that were written on the evaluation also indicate that this objective was fulfilled, these include:

“Discussion about good care practises. I felt I should more listen and not try to take over conversations.”

“It was emotional at times but that just reinforced how complex dementia is.”

Clearly the workshop had a practical impact on one participant who realised that s/he should listen to residents with a dementia more. The comment about the emotional nature of the workshop re-enforces the value of emotional learning, which could prompt people towards deeper insights about the complexities of living with a dementia.

However, it is important to note that there were many comments about the need for more time after each section to discuss the feelings provoked and reflect more fully on the issues raised. It is likely that arts-based workshops, which are longer

in length or cover less material more thoroughly would be even more effective in provoking reflective learning.

2. To engage care home staff in a re-consideration of 'dementia' by critically examining representations of this condition

Each of the arts-based resources were carefully chosen to illustrate alternative ways of considering what 'dementia' might be and how it affects those who live with it and their families. The discussions that were gently directed by the workshop facilitators (John Killick and Hannah Zeilig) prompted participants to re-consider their own prejudices about what 'dementia' involves, albeit that these were somewhat limited by time. Thus, several poems written from the words of those living with a dementia and the art of William Utermohlen gave unique insights into the feelings of people who are living with this condition. In addition the film clips provided insights into the perspectives of individuals who live with a dementia. The extent to which some participants were prompted to re-consider the category 'dementia' was reflected in the following comments:

"The film clips and poetry really made me stop and think about how dementia makes people feel"

"The art moved me !!"

"Interesting poems. How individuals cope with dementia their feelings and thoughts"

3. To empower care home staff to recognise the skills they already possess

The underlying intention of the project was to honour the experiences of care home staff whose work in dementia care is often undervalued and who are rarely given the opportunity to express their emotional needs as carers. In a discussion following the first workshop, a care assistant took the time to talk to the project

team (Hannah Zeilig, John Killick and Fiona Poland) to express her relief and gratitude that the workshop was not patronizing and that it treated the care staff with respect. This was a pertinent exchange because as she acknowledged herself, she had been very skeptical about many of the dementia courses she had attended previously. Several of the comments made on the evaluation questionnaire stressed the importance for staff of feeling that their skills had been recognized by the workshop:

“It was nice to hear views from family members about carers and what they believe a skilled carer can bring to a service user.”

“Making us think more about people’s feelings emotions and well-being and the impact we as carer’s have on their day to day living”

4. To provide, through reference to the arts, multiple perspectives on what ‘dementia’ can be and how it might be experienced

The workshop does not offer conventional training or education about people with a dementia. On the contrary, it is structured in such a way that expectations are slightly unsettled, for instance the workshop opens with a slide featuring Elvis Costello holding a camera and asking participants to guess who he is. This is followed by a slide of images relating to the content of the workshop (purposely without words or statistics: neither are there slides of brain scans or other biomedical information). The workshop focus then shifts back to Elvis Costello talking about his grandmother who lived in a care home and singing his song about her, entitled Veronica. The workshop also includes the voices of those living with a dementia who have written poems with John Killick and the painful insights offered by the self-portraits of William Utermohlen. The film clips provided multiple perspectives and encompassed the views of spouses/partners and other family members involved in caring as well as the individual’s perspective and the crucial role played by good nursing. In the words of one respondent, the workshop allowed him/her to see

“...the things we deal with every day from a different point of view”

It is very likely that if future versions of the workshop allowed more time for discussion and reflection, then the multiple and often conflicting perspectives that the arts can provide about living with and caring for someone with a dementia could be more fully and actively explored by participants.

5. To engage participants' imagination in the consideration of dementia through the arts and challenge stigma and prejudice about dementia

The workshop was entirely structured to appeal to the imaginations of the participants. This was achieved through the use of interactive imaginative games and by constant reference to relevant plays, artwork, poetry, music and film. The success of this approach is evident in the numbers of participants who felt that all these resources were useful (responses to the question about sections that worked well are provided above in section 3.3). Whether the workshop was able to challenge stigma and prejudice about dementia is difficult to measure as we could not directly ascertain the prejudices or stigma that the participants may have had prior to participation in the workshops. However, the discussion that followed the presentation about William Utermohlen's artwork concerning the potential of someone living with a dementia to continue creating important art and to express their feelings seemed to indicate that the care staff were surprised that someone with a dementia was still capable of making and creating and expressing their personhood. This suggests some potential for diminution of stereotypes, if not direct prejudice.

4.2 Limitations of the DESCARTES work to date

Despite the successful reception given to the arts-based workshop developments to date, several limitations to the work should be acknowledged.

Although a cross-section of the home's dementia care staff were included, its management did not take a direct part in the focus groups or the delivery of the workshop. The workshop could not therefore include the views of those who

manage the care home although other staff members who did take part felt that the managers would also benefit greatly from taking part. Another limitation was the lack of time for discussion and reflection following each of the arts-based activities. As the time for the workshop could not be more than two hours to ensure staff could cover, there was not enough time to develop discussions in any depth. Also, the very small sample of 15 care home staff within one, small care home (although HZ had spent much time with them to deepen her insights into their working experience) means that the study findings though based on intensive activity cannot be seen as representative. Although it has subsequently been warmly received by other groups of professionals who work in dementia care (at regional and national conferences) the approach needs to also be developed and tested in other environments.

To strengthen the study these limitations need to be addressed through further work to establish whether:

- this approach would work as effectively in other environments (types and size of home, or other institutional care settings)
- other materials that the DESCARTES team have gathered during the course of this phase would work as well or even better
- more time for discussion would increase the efficacy in practice of the approach.

4.3 Future potential and next steps for DESCARTES workshops

The literature review (set out in section 2) demonstrates the value of using the arts in health care settings. This review also demonstrates a scarcity of work exploring the benefits that the arts might have in the training of dementia care professionals.

The development and provision of the DESCARTES workshops further substantiate the importance of facilitating education about dementia that engages participants' imagination and empathy. The use of arts materials is one effective way of doing this. The arts-based materials illuminated a number of issues some

of which were connected with attitudes to people living with a dementia and others that were more practical such as the work of caring.

Despite valid hesitations expressed by Norsecare managers about the possible dangers of encouraging care home staff to explore their emotions, no negative comments were made about this from the participants themselves. On the contrary, many participants seemed to welcome being enabled to express their feelings. In addition, all the participants reacted with surprise and enjoyment to their encounters with the materials that allowed them to think creatively about people living with dementia and about their roles as care home staff. Above all, the workshops were found to represent a form of workforce education in dementia that can be:

- Experiential
- Replicable
- Scalable
- Cost effective
- Innovative
- Applicable to a wide variety of people (including families and GPs).

The indicative materials developed for DESCARTES (a selection of the arts-based resources and some of the material from the folders) will also be examined by those responsible for establishing dementia courses at City College Norwich and possibly integrated into their curricula.

4.4 Follow on applications for related knowledge mobilisation

Being involved in the success of the first, developmental stage of DESCARTES has been inspiring. Further funds will next be sought to deliver the workshop in other settings, to build incrementally on the workshop model to create other related workshops and also to introduce mentoring as a way of ensuring that the arts-based material can continue to resonate with participants within practice settings. The DESCARTES team envisages that a fundamental part of any further future project will be to develop an e-learning resource or app. to make the arts workshops available to wider audiences. Funding streams that will be applied to include: ESRC, Wellcome Trust and NESTA.

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