

Reminiscence Arts and Dementia Care: Impact on Quality of Life, 2012-2015

An Interim Report of the Evaluation, December 2014



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This reports documents the activities and interim findings of an inter-disciplinary evaluation of *Reminiscence Arts and Dementia Care: Impact on Quality of Life* (RADIQL) designed and led by Age Exchange Theatre Trust. RADIQL is a three-year programme of creative activities funded by Guy's and St. Thomas' Charity, 2012-2015. This document reports findings from the first phase of the work from 2012-14.

The RADIQL programme responds to the challenges presented by the increased number of people living with dementia. The Alzheimer's Society predicts that by 2015 there will be 850,000 people with dementia in the UK, with a cost of £26 billion per annum.¹ In reply, there has been increased interest in the role of creative practice and the participatory arts with and for people living with different forms of dementia.

The RADIQL programme is developing and modelling a range of creative participatory practices which are potentially adaptable for use in other settings. It is clear throughout this report that the value of this work is demonstrable, and there are rich opportunities for collaboration between creative practitioners, artists, care staff and people experiencing dementia and other age-related conditions.

¹ www.alzheimers.org.uk/statistics



Executive Summary

1. Reminiscence Arts is a fusion of different art forms and reminiscence practices that is unique to Age Exchange. It responds to the interests, life-histories, abilities and needs of participants living with dementia.
2. Group Reminiscence Arts sessions create a social space for all those who participate, including artists, carers and people living with dementia. By including a range of art-forms, Reminiscence Arts creates the opportunity for a wide range of social, cultural and aesthetic interactions.
3. Group Reminiscence Arts sessions significantly improved the quality of life of people living with dementia in the first 50 minutes.
4. Engaging in Reminiscence Arts has the potential to enhance care home residents' lives by improving their connection to both the place they currently live and to spaces of memory and imagination.
5. Attending a Group Reminiscence Arts session steadily and significantly improves the quality of life of people living with dementia week-on-week over a 24 week period.



About the researchers

Research at Royal Holloway, University of London in the arts and social care is recognised as world-leading. This evaluation forms one element of Royal Holloway's wider research project into a cultural response to dementia and to the phenomenological and aesthetic qualities of dementia care.

Professor Helen Nicholson is Professor of Applied Performance at Royal Holloway, University of London. The author of several academic books and many peer reviewed articles, her research into the significance of the arts in community settings is widely read across the world.

Dr Frank Keating is Senior Lecturer in Social Work at Royal Holloway, University of London. His research and writing focuses on mental health, ethnicity and gender. Frank is particularly interested in addressing racial disparities in mental health.

The researchers on this project are **Jayne Lloyd** and **Dr Laura Cole**. Jayne Lloyd is a fine artist with extensive experience of artistic practice, research and evaluation in care settings and is currently completing her PhD on the role of Reminiscence Arts in dementia care. Dr Laura Cole is a social psychologist with over ten years of experience of working with people with dementia in multiple clinical and care settings. Her research has included evaluating the effectiveness of health and social care services, and investigating patient experiences and satisfaction of statutory services.



The research context

The evaluation of RADIQL exists in the wider context of several well-funded research projects into the efficacy of cultural participation and creative practice for older adults and people living with dementia. There is already significant evidence that participating in the arts and creative practice has positive benefits (Zeilig et al., 2014). This research falls into three broad categories:

- Analysis of the potential for the arts to deliver health and social care outcomes, often emphasising its cost-effectiveness (Buttrick et al. 2013; Cohen et al. 2006, 2007; Hanna and Perlstein 2008; Noice et al. 2013, Ramsey 2013).
- Analysis of creative approaches to living with dementia and dementia care based on sociological analyses of memory, citizenship, embodiment and selfhood (Katz, 2013; Twigg, 2013; Barlett, 2014; Barlett and O'Connor, 2010)
- Analysis of the effects of the arts on the mood and feelings of social isolation of people living with dementia (Guzma'n-Garcia et al. 2013; Eekelaar et al. 2012; McLean 2011; Smith et al. 2012).

Within this burgeoning research field, many studies are relatively small-scale and address specific audiences of funders and stakeholders. Some are written to persuade, and the lack of a major research project that analyses the social experience of dementia is often noted (Zeilig et al., 2014). It is anticipated that the major inter-disciplinary research project at the University of Bangor will address this gap. *Dementia and Imagination* is part of a research programme that has been awarded in excess of £7 million to investigate the ways in which people with dementia experience community engagement. With a budget of £1.2 million dedicated to researching the role of art in the lives of people with dementia, the results are eagerly anticipated.² By comparison the RADIQL evaluation is small in scale (£140,000), but whereas the research at Bangor University is exclusively focused on the visual arts, Age Exchange's practice also includes music, drama, dance and creative approaches to reminiscence.

² www.alzheimers.org.uk/statistics

RADIQL takes place in a research context in which models of care are subject to critical scrutiny. Person-centred care for people with dementia was conceived in the 1980s as an alternative to the medicalisation of the condition. Critical dementia researchers have demonstrated that models of research that focus solely on brain function tend to isolate individuals from the wider social environment (Dumit, 2004; Whitehouse and George, 2008). Person-centred care offers an alternative to care that was primarily task-centred, and recognises the social and personal implications of the condition. According to Brooker (2006), person-centred care aims to:

- treat people as individuals;
- look at the world from the perspective of the person with dementia;
- regard ‘personhood’ as way of informing a moral vision of care in which the person living with dementia can experience relative wellbeing.

More recently, relationship-centred care has also gained currency, as outlined by Michael Nolan (Nolan et al., 2006). Relationship-centred care has many similarities with person-centred care, but stresses the following qualities of caring relationships:

- Sees the care home as a community, where quality of life for everyone in that community is valued, including care staff, family, friends, residents and visitors;
- Values the network of relationships that exist within care environments, and the reciprocity and inter-dependence of caring relationships (Bartlett and O’Connor, 2007)
- Understands that the body is a source of selfhood that ‘does not derive its agency from a cognitive form of knowledge’ (Kontos, 2004)
- Recognises that everyone involved in care needs to have a sense of security, sense of continuity, sense of belonging, sense of purpose, sense of achievement and sense of significance. This is described by Nolan (2006) as the ‘Six Senses Framework’, and argues that good care will nurture these ‘senses’ with everyone.

The RADIQL evaluation drew on both theories of person-centred care and relationship-centred care. These theories are inter-related with many cross-overs, but differ in that the former places the emphasis on the individual needs of the person being cared for, whereas the latter focuses on the reciprocal relationships involved in the caring process.

In dementia studies, quality of life can be measured using three different approaches: self-rating, proxy rating and observational methods. As Algar et al. point out, observational methods can provide robust evidence for the effects of creative participation on the quality of life for people with dementia who are unable to self-rate their levels of wellbeing. (Algar et al., 2014) The terms ‘quality of life’ and ‘wellbeing’ are often used rather interchangeably by quantitative researchers, but they derive from very different perspectives. Quality of life is widely regarded as a social project, associated with relationality and mutual responsibility. The World Health Organisation defines quality of life as:

The product of the interplay between social, health, economic and environmental conditions which affect human and social development. It is a broad-ranging concept, incorporating a person’s physical health, psychological state, level of independence, social relationships, personal beliefs and relationship to salient features in the environment. As people age, their quality of life is largely determined by their ability to access needed resources and maintain autonomy, independence, and social relationships. World Health Organization, 2004, p.48)

‘Wellbeing’ individualises quality of life and it is, broadly speaking, based on a set of behaviours and moods, and suggests that wellbeing can often be improved by self-discipline and positive habits (interactivity, exercise, diet and so on). In this study, we have defined quality of life in the terms advocated by the World Health Organisation. We have recognised wellbeing as part of the measures of behaviour delineated by Dementia Care Mapping where activities are rated according to 24 behavioural category codes (described in more detail below), and is based on models of person-centred care.

The unique perspective that the evaluation of RADIQL brings to the research community lies in its emphasis on defining, developing and modelling the affective and aesthetic qualities of Reminiscence Arts practice. Using this knowledge and quantitative evidence of the effects of Reminiscence Arts, Age Exchange aims to influence the culture of care by training care staff to work creatively with people with dementia, and alongside skilled creative practitioners. The evaluation of RADIQL provides evidence that will lead to an understanding of the relationship between the quality of life and the qualities of Reminiscence Arts.

Aims of the evaluation

This report documents interim findings that address two aims of the RADIQL the evaluation:

1. To define, develop and model Reminiscence Arts

Reminiscence Arts has been developed intuitively by highly skilled creative practitioners. In order for different models of practice to be developed into a pedagogic framework for training purposes, implicit or tacit knowledge needs to be turned into explicit knowledge, skills and understanding (Polanyi, 1998). Royal Holloway researchers are contributing to the programme by providing a strong theoretical underpinning for Reminiscence Arts that is informed by ethnographic and practice-based research. This will provide a clear conceptual framework for Reminiscence Arts that will sustain high quality practice and develop models of training.

2. To provide quantitative evidence for the efficacy and effectiveness of Reminiscence Arts on people living with dementia

The quantitative research measures the improvement RADIQL brings to the quality of life of older people living with dementia against the criteria of a person-centred care approach. Person-centred care is defined as care that 'respects others as individuals and is organized around their needs' (Department of Health, 2001). This part of the evaluation, therefore, measures the extent to which Reminiscence Arts practice impacts on individuals' psychological and emotional well-being.

A third aim, to analyse how the environment and culture of care is affected by the RADIQL programme, will be included in the final report.

Research methods

The evaluation was undertaken from two distinct academic disciplines: social psychology and the creative arts. These disciplines complement each other. Research methods drawn from the arts provide a context for the quantitative study by critically engaging with the 'how' and 'why'; a process of questioning that clarifies and defines the specific artistic, aesthetic and communitarian qualities of Reminiscence Arts.

The social scientific research provides statistical evidence of the effects of Reminiscence Arts on individuals living with dementia. Importantly, these statistical results demonstrate clearly the effectiveness of Age Exchange's practice, and



document the extent to which individuals are engaged in the activities. The evaluation, therefore, captures robust evidence from multiple perspectives.

Ethics and regulatory approvals

The study protocol and other documentations for the care home observations were submitted to National Health Service [NHS] Research Ethics Committee at Queen Square, London and gained favourable approval on October 23, 2013. A subsequent amendment to the original application was made and given favourable opinion by the same Ethics Committee on November 6, 2013.

Ethical Approval was also sought from Royal Holloway, University of London's Ethics Committee. Approval for the qualitative arts-based research was given on October 22, 2013.

Royal Holloway's policy on ethical conduct can be found at: www.royalholloway.ac.uk/iquad/collegepolicies/documents/pdf/research/codeofgoodresearchpractice.pdf

Following the receipt of favourable opinion by the NHS Ethics Committee, Research and Development (R&D) approval was sought for the three NHS care homes in South London and Maudsley NHS Foundation Trust (SLAM) and Guy's and St. Thomas' NHS Foundation Trust (GSTT).

Our findings

Defining Reminiscence Arts

Reminiscence Arts describes Age Exchange's unique approach to working creatively with people living with advanced dementia and related conditions. Reminiscence Arts recognises and values embodied and sensory memories as well as verbal or narrative recall. This creative approach to working with people with dementia is built on Katz' neurocultural analyses of ageing that demonstrate that memory is not only a passive cognitive function but, importantly, a creative act of imagination. The arts activities extend reminiscence practices, which often rely on verbal discussion, by involving all the senses and enabling participants to communicate non-verbally through mark making and movement. This multi-sensory approach develops a practice that is responsive to the needs of the participants in RADIQL, particularly those with advanced dementia. Age Exchange is developing an increasingly clear identity of the potential for Reminiscence Arts through their work on the RADIQL programme.

Reminiscence Arts are always reciprocal and relational, affecting everyone involved, not just the people living with dementia. Analysis of creative practice is, therefore, best supported by methodological models of relationship-centred care that recognises 'the uniqueness of each individual, but also the interdependence that shapes our lives' McCormack (2001).

Researchers working within the arts have questioned creative practices that rely primarily on memory, suggesting that reminiscence activities based on cognitive recall can re-enforce a sense of failure (Harries et al., 2013; Basting, 2009). Age Exchange has responded to this research context by developing new forms of creative participation and relational arts practice. Reminiscence Arts is a creative practice that integrates different art forms and finds ways to recognise and value embodied and sensory memories as well as verbal or narrative recall. As Stephen Katz points out, 'memory is an act of agency and imagination, not simply a passive cognitive process, and can be expressed through the body' (Katz, 2013: 311).

In Reminiscence Arts creative practitioners trained in different arts disciplines co-facilitate activities with people with dementia, thus enabling participants with complex and diverse abilities to engage imaginatively in their environment in different ways. Reminiscence Arts draws on the best practice of person-centred care by valuing the experiences and memories of people with dementia, and also builds on

the dynamic and embodied practices of relationship-centred care that recognises that the care home is a community that includes care staff, family, friends, residents and visitors. Led by skilled practitioners, Reminiscence Arts encourages improvisation, creativity and engagement in the community of care, and invites people with advanced dementia to draw inspiration from the past, to develop meaningful and reciprocal relationships in the present, and to look to the future.

This strand of the evaluation addresses the following questions:

a) Innovation - How is the practice of Reminiscence Arts artistically innovative as well as socially and personally beneficial?

Reminiscence Arts is at its most innovative when reminiscence activities are integrated with different art forms. Highly skilled Reminiscence Arts Practitioners find ways to merge or move fluidly between their art forms, and this enables participants to engage in multiple ways. For example, there was a high level of engagement when dancers supported participants to develop movement that was based on verbal reminiscences triggered by reminiscence practices based on narrative re-call.

b) Participation - How does the presence of artists encourage social interaction, aesthetic engagement and a culture of participation with older adults?

Reminiscence Arts groups encourage participants to join in activities and to share their memories and interests with each other. Different art forms support different types of interaction and create a range of social spaces and interactivity. During the music and movement activities, for example, group interaction was highly visible and there were many instances of participants with dementia interacting with each other as well as Reminiscence Arts Practitioners and staff.

An example might help to illustrate this. When participants and Reminiscence Arts practitioners threw a large balloon to each other, they evoked a lot of laughter and playfulness. Building on this warm-up, when participants mirrored each other's dance movements and gestures the group came together, enabling their actions to be reinforced, shared and celebrated. Visual arts activities often resulted in one-to-one work, a process that enabled two people to work closely together. For example, one participant demonstrated how to weave strips of paper to a member of care staff whilst talking about how she used to weave rugs when she lived in India. All the activities were opportunities for staff to spend time with the people in their care, where they could learn more about their interests and abilities.

When Reminiscence Arts involves the whole care community, it has the potential to improve relationships and change the social interactions outside the hour-long weekly sessions. This creative approach to relationship-centred care will be evaluated in more depth during the second year of RADIQL.

c) Environment - How does the on-going presence of artists transform the social space of care settings, and does it introduce creativity into the everyday lives of carers and residents?

Reminiscence Arts often evokes memories of experiences that happened in places and times outside the care home. It is important to remember, however, that the sessions take place within the physical, social and aesthetic space of the care setting. This means that Reminiscence Arts often enhances participants' lives by improving their connection both to the place they currently reside and to their memories and imaginations. An experience of something beyond the walls of the care setting can be evoked through the senses. The sounds of birds chirping, the crunch of autumn leaves, smell of scented spring flowers and the dance and music heard in dance halls can inspire participants to imagine themselves in a world outside the care setting. These multi-sensory interventions often triggered a feeling of 'leaving of the home' that was often evidenced by verbal reminiscences, embodied movements or facial expressions. For example, one participant closed her eyes and smiled whilst listening to a soundtrack of bird sounds and another participant looked straight ahead whilst walking on the spot in a purposeful manner that suggested she was imagining going somewhere special.

Other activities that Reminiscence Arts Practitioners facilitated enabled the participants' to become increasingly aware of their sensory engagement in the room. Near the start of some sessions Reminiscence Arts Practitioners asked participants to stretch their limbs and become aware of each part of their body and how it connected with the space. For example, they were asked to feel where their feet made contact with the floor and to be aware of their body's contact with the chair. This prompted many participants to look at their hands and feet, and to experiment with moving them in creative ways, often extending the movements they made habitually. Activities such as these grounded the memories and imaginations evoked by the Reminiscence Arts in the present, and thus avoided becoming purely escapist by enabling participants to see themselves and their environment in new ways.

Quantitative evidence for the efficacy and effectiveness of reminiscence arts

Dementia Care Mapping

For the qualitative study, the primary method of data collection was Dementia Care Mapping (Bradford Dementia Group, 2005). Dementia Care Mapping is a quantitative methodological approach that measures a range of types and levels of wellbeing of participants. It is an observational tool that assesses behaviour and well/ill-being. It was used in this study as an indicator of the quality of life of the person with dementia.

Dementia Care Mapping was used to observe participants with dementia and record their behaviour using one of 23 behaviour category codes [BCC], and their mood and engagement in an activity using a mood-engagement [ME] value. Observations were recorded before, during and after each Reminiscence Arts session at three-weekly intervals. The qualitative evaluation used a Person Centred Approach to care (Kitwood, 1997).

Behaviour Category Codes describe the activity in which the participant is taking part (e.g. eating, talking, dancing, praying). Dementia Care Mapping uses a letter of the alphabet to distinguish between the 23 different Behaviour Category Codes.

The mood-state of a participant is determined by observing facial expressions, verbal and non-verbal interactions. Levels of mood are assessed in terms of degrees of happiness, contentment, comfort, relaxation and pleasure. According to the *Dementia Care Mapping 8 Manual* engagement is 'about how connected a participant is with people, activities or objectives around them' (Bradford Dementia Group, 2005, p. 11). Engagement can be on a sensory, social or occupational level.

Positive mood-engagement (ME) scores are +1, +3, +5 where +5 is recorded for the most engagement or / and positive mood. Negative ME scores are -1, -3 and -5. -5 is recorded for very distressed mood.

This methodology enables researchers to ascertain whether their perception of the participants' engagement in Reminiscence Arts causes a statistically significant difference in their wellbeing. This strand of the evaluation addressed the following questions:

- a) What difference, if any, does Reminiscence Arts practice make to the quality of life and well-being for people living with dementia?
- b) How successfully has Reminiscence Arts practice reached its specific intended outcomes for people living with dementia?

From the Dementia Care Mapping there are four significant findings

1. Participants' quality of life significant improved during Group Reminiscence Arts sessions. This effect plateaued after 50 minutes into the group session.

Participants' quality of life (as measured by Dementia Care Mapping's mood- engagement scores) significantly improved during Group Reminiscence Arts sessions from the start of the session. This meant that participants became more involved in the activities as the sessions continued. In addition, the mood-engagement scores were found to peak 50 minutes into the session, which is taken as an indicator of improved quality of life. After 50 minutes mood and engagement started to decline. Explanations for this plateauing may indicate a transition phase in the activities as the group winds down towards ending the session, or a point at which participants fatigued.

2. Participants' quality of life steadily and significant improved during the Group Reminiscence Arts session, week-on week, over the 24 week period.

There was a week-on-week significant improvement in mood-engagement scores for participants receiving the Group Reminiscence Arts session over the 24 week period. Consequently, the mood-engagement scores indicated an improved quality of life at each subsequent Group Reminiscence Arts session. One explanation for this finding is that participants were building on interactions, connections and associations from previous weekly Group Reminiscence Arts sessions.

3. Group Reminiscence Arts sessions did not have a sustained impact on participant's quality of life.

Post-session quality of life reverted to pre-session levels of mood-engagement. In addition, twelve weeks after the last Group Reminiscence Arts session, the quality of life was similar to that recorded at the baseline point before the programme began. Therefore, Group Reminiscence Arts sessions did not have a sustained impact on participant's quality of life over time. This means that once the Group Reminiscence Arts sessions stop, their mood-engagement scores (quality of life) begin to decline.

4. Some Reminiscence Arts activities consistently encouraged high levels of mood-engagement

For participants in the Group Reminiscence Arts sessions, the five top ranked behaviour category codes (or activities) in accordance to Bradford's Dementia Care Mapping mood-engagement categories were: verbal reminiscence; exercise; flirtatious expression; prioritising intellectual abilities (e.g. completing jigsaws); and creative activities (e.g. dancing).

Reflections on interim findings

The findings from the social psychological and the creative arts research suggest two key points. Firstly, Reminiscence Arts is most effective when it employs a range of creative activities in the sessions because this engages people with dementia in different ways. Secondly, in order for the Reminiscence Arts sessions to have a sustained impact on the participants' quality of life beyond the weekly one hour sessions, care staff need to be involved in the creative activities.

The importance of using a range of arts and reminiscence activities was evident throughout the evaluation. The group Reminiscence Arts sessions were most innovative and engaging when they combined and moved seamlessly between a range of creative activities. The Dementia Care Mapping measures showed that high positive mood-engagement scores (and thus higher levels of quality of life) for participants were provoked by a wide range of activities such as verbal reminiscence; throwing and catching a balloon; dancing; reciprocated friendly or interactive body language, such as winking, and puzzles or reminiscence quizzes that





were centred around objects. Verbal reminiscence produced the highest mood-engagement scores when they were used in conjunction with creative activities.

Some participants responded better to some Reminiscence Art forms than others. For example, participants with impairments to their verbal communication often responded more actively to embodied forms of reminiscence such as music, dancing or non-verbal gestures. The differing modes of participation demonstrates the importance of Age Exchanges' varied and responsive approach, as this allows people with a range of abilities, needs and interests to participate in the activities.

The evaluation demonstrates that the interactions and connections between those involved in the group Reminiscence Arts sessions increased during the course of the project. As the weeks went on the Reminiscence Arts Practitioners got to know the participants, and they were increasingly able to plan sessions in response to their interests, life stories, abilities and talents. Participants' engagement increased from week to week and their wellbeing scores went up. However, the Dementia Care Mapping did not show any affect on the participants' quality of life outside the session. This suggests that engagement in Reminiscence Arts activities needs to be sustained in order to maintain any benefit.

This finding has an impact on future projects and staff training. Age Exchange is delivering training for care staff, and the Reminiscence Arts sessions themselves are intended to offer learning experiences for staff who attend. As we pointed out earlier in this report, the sessions give care staff an opportunity to learn more about the interests and abilities of the people in their care and to spend time with them. Through care staff involvement, there is more potential to embed Reminiscence Arts into the culture of care, and to sustain some of the benefits of Reminiscence Arts activities beyond the sessions.

Next stages

In the final year of RADIQL, the evaluation will address three main aims:

1. To deepen understanding of Reminiscence Arts through a doctoral study. Jayne Lloyd is a practice-based PhD student in the Theatre and Drama Department at Royal Holloway, University of London under the supervision of Professor Helen Nicholson. Her practice-based PhD involves desk-based research; observation of Age Exchange's Reminiscence Arts practice and facilitating Reminiscence Arts sessions herself. Analysing the experience of facilitating these sessions forms an important part of understanding Age Exchange's Reminiscence Arts practice. The PhD thesis will be completed in December 2015 and will include chapters covering three areas of Age Exchange's practice; the inter-disciplinary relationship involved in the co-facilitation of Reminiscence Arts sessions; the relationship between the care setting environment, particularly the physical space, and Reminiscence Arts; analysis of the various types of reminiscence practice.
2. To analyse how the environment and culture of care is affected by the RADIQL programme. This part of the evaluation is two-fold. It will analyse the impact of the RADIQL programme on care staff, providing evidence of how the programme has impacted on their working lives. Reciprocally, it will assess how Age Exchange has changed as a charity as a result of the RADIQL programme, addressing areas such as the quality of management of the RADIQL programme, and how the Reminiscence Arts Practitioners have developed their working practices as a result of the programme.
3. To present an end of project report in Autumn 2015. This will document findings, reflect on how the project has developed, as well as identifying ways forward for future Reminiscence Arts provision.

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