

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

Quantitative Evaluation Final Report, November 2015



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CONTENTS

EXECUTIVE SUMMARY	2
ABOUT THE RESEARCHERS	3
THE RESEARCH CONTEXT	3
AIMS OF THE QUANTITATIVE EVALUATION	4
RESEARCH METHODS	4
RESULTS	7
DISCUSSION	11
REFERENCES	12
APPENDIX A	13
APPENDIX B: CHALLENGES	14
APPENDIX C: RECOMMENDATIONS FOR FUTURE RESEARCH PROJECTS	16
APPENDIX D: GLOSSARY OF STATISTICAL TERMS	16

EXECUTIVE SUMMARY

This reports documents the findings of a quantitative 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 and should be read in conjunction with the overall evaluation report.

The quantitative evaluation aimed to assess:

- a. What difference, if any, does Reminiscence Arts practice make to the quality of life and well-being for people with dementia?
- b. How successfully have Reminiscence Arts practice reached its specific intended outcomes for people with dementia?
- c. What difference does Reminiscence Arts practice make for frontline paid carers for people with dementia?

The quantitative research measured 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; Brooker 2006). This part of the evaluation, therefore, measures the extent to which Reminiscence Arts (RA) practice impacts on individuals' psychological and emotional well-being. The project aims were achieved through a comparative and time series design, which gathered evidence from residents and staff in care homes for people with dementia. Age Exchange selected 12 care homes, and assigned six to the intervention arm of the research and six to the waiting list i.e. treatment as usual (TAU) or hold

group. Those care homes in the intervention arm received a Reminiscence Arts group session once a week, over a 24-week period. Those in the TAU groups received usual care over a 24-week period; with a view that these care homes would receive the RA group sessions after six months, although quantitative evaluation of these groups would not be conducted.

Key findings from the study are:

1. During sessions, positive behaviour and quality of life increased and peaked at 50 minutes;
2. After each session there was a sustained positive effect on positive behaviour for 30 minutes;
3. Every 3 weeks, the behaviour and quality of life was more positive than at the start of the previous session;
4. After each session had finished, quality of life returned almost to baseline levels.
5. Quality of life for participants in the intervention group improved over the whole period of the study, but dropped to slightly above the baseline at follow up.

In brief, these trends are statistically significant, except for number 5, which suggests that Reminiscence Arts groups would produce similar results if replicated for the wider population of people with dementia living in care homes. The study found that Reminiscence Arts practice did make a positive difference to the quality of life of people with dementia in residential settings. Overall, this evaluation supports, builds and strengthens the evidence base for Reminiscence Arts practice for people with dementia living in continuing care homes.



ABOUT THE RESEARCHERS

Dr Laura Cole is a social psychologist with over ten years 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.

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.

Robert Grant, who conducted the statistical analyses, is a Senior Lecturer in Health and Social Care Statistics at Centre for Health and Social Care Research, Kingston and St Georges University of London. He is a medical statistician, contributing to a variety of research projects and postgraduate teaching in research methods and statistics.

Acknowledgements: Helen Nicholson and Jayne Lindsay (in particular for background information and the images in this report)

THE RESEARCH CONTEXT

The RADIQL programme responds to the challenges presented by the increased number of people living with dementia. The Alzheimer's Society predicts that over the next few decades there will be a steady increase in the numbers of people with dementia in the UK, with a cost of £26 billion per annum¹. In response, 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 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). The quantitative component of the RADIQL evaluation is small in scale and the

findings reported here should be viewed in light of this.

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.

In dementia studies, quality of life can be measured using three different approaches: self-rating, proxy rating and observational methods. As Algar et al (2014) 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. Quantitative researchers often use the terms 'quality of life' and 'wellbeing' rather interchangeably, 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 (QOL) 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 on page 5), and is based on models of person-centred care.

In Reminiscence Arts group sessions that normally lasted between one to two hours. Creative Reminiscence Arts Practitioners (RAPs) trained in different arts disciplines co-facilitated activities with people with dementia, thus enabling participants with complex and diverse abilities to engage imaginatively in their environment in different ways. Reminiscence Arts recognises and values embodied and sensory memories as well as verbal or narrative recall. The arts activities

¹ www.alzheimers.org.uk/statistics

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.

The quantitative evaluation of RADIQL is concerned with the effectiveness of Reminiscence Arts practice for people with dementia living in care homes, and aims to provide evidence that will lead to an understanding of the relationship between quality of life and Reminiscence Arts.

AIMS OF THE QUANTITATIVE EVALUATION

This project aimed to evaluate Age Exchange's Reminiscence Arts groups to provide quantitative evidence for the efficacy and effectiveness of Reminiscence Arts for people living with dementia living in care homes. It specifically aimed to answer the following questions:

1. What difference, if any, does Reminiscence Arts practice make to the quality of life and well-being for people with dementia?
2. How successfully have Reminiscence Arts practice reached its specific intended outcomes for people with dementia?
3. What difference does Reminiscence Arts practice make for frontline paid carers for people 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.

RESEARCH METHODS

The project aims were achieved through a comparative and time series design, which gathered evidence from residents and staff in care homes for people with dementia. Age Exchange selected 12 care homes, and assigned six to the intervention arm of the research and six to the hold or TAU group. Those care homes in the intervention arm received a reminiscence arts [RA] group session once a week, over a 24-week period. Those in the hold arm received usual care over a 24-week period; with a view that these care homes would receive the RA group sessions after six months, although quantitative evaluation of these groups would not be conducted.

We used statistical modelling to look at how QOL and behaviour changed over time, and how this differed between the 'hold' homes which did not have RA sessions, and the 'intervention' homes which did. This took each individual's severity into account (a so-called 'multilevel model') and looked for average trends over time.

ETHICS & REGULATORY APPROVALS

The study protocol and other documentations were submitted to National Health Service [NHS] Research Ethics Committee at Queen Square, London and gained favourable approval.

Permissions from relevant local Research Governance Committees were also sought, and approvals were obtained from Guy's and St. Thomas' (GST) NHS Foundation Trust.

SAMPLE

PEOPLE WITH DEMENTIA

Care staff or activities coordinators working in the care home identified residents living in the care home with a diagnosis of dementia or memory impairment. The researcher then approached potential participants to introduce the project, outline what it would entail for them and asked whether they would like to be involved in the research. If the person had mental capacity to understand the research and the implications it had for them, in accordance with the Mental Capacity Act (MCA, 2005), they were given a participant information sheet and asked to sign a written consent form. However, if the person did not have mental capacity to understand the research and the implications this had for them, then their next of kin was asked to act as their consultee. If the consultee confirmed that the person with dementia would have agreed to take part in the study, then they gave their written assent for the person with dementia to be involved in the study. In the absence of a next of kin, the care home manager signed the consultee declaration. Please refer to Table 1. for the inclusion / exclusion criteria for people with dementia.

Table 1. Inclusion Exclusion Criteria

Inclusion	Exclusion Criteria
Older adults with dementia in care homes	People who do not have a diagnosis of dementia
Informed written consent or approval from consultee	Lack of consent or consultee
	Residents receiving palliative care

Each of the 12 groups, whether in the intervention or hold arm of the study, aimed to include six to eight participants. The size of the group was dependent on the number of residents in the care home with dementia, and potential participants' stage of dementia. If the majority of the people with dementia were in the later stages of the illness then the group size was ideally six; however if participants were in the early stages of dementia then the group could include eight participants. These numbers were guidelines set out by Age Exchange and made for practical reasons so that care staff and RAPs were able to safely and effectively support all participants in the group.

CARE HOME CARE STAFF

Care staff directly responsible for one or more of the participants in the intervention or hold groups (e.g. keyworkers) were approached and asked if they would participate in the study. The two care staff supporting the RA group every week (one usually being the Activities Coordinator), were also approached and asked if they would be willing to participate in the study. Staff were given a study information sheet, and if they wished to participate in the research sign a consent form. As some care staff usually keywork for more than one person, it was expected that there would be between 4-6 staff members participating per care home.



DATA COLLECTION PROCEDURES

DEMOGRAPHICS

Demographic information was gathered for each of the 12 care homes, people with dementia, and care staff. These details were used to describe the samples and to ensure that the two arms of the research did not differ significantly from each other.

DEMENTIA CARE MAPPING (DCM)

The primary outcome measure for this evaluation was Quality of Life (QOL) assessed using Dementia Care Mapping [DCM] (Bradford dementia Group, 2005). There is a range of tools to measure QOL, but DCM was chosen because it is dementia specific, adopts a person centred approach and is focused on gaining an understanding of the subjective experience of the person with dementia. DCM was originally developed as a clinical tool to improve care and inform service development, but is increasingly being used as a research tool. Brooker (2005) suggested that DCM is suited to small-scale within-subjects or group interventions. DCM is a reliable research

tool as recommended by Fossey, et al (2002) who found that it has internal consistency and is a useful tool for intervention studies for people with dementia in residential settings. Sloane et al (2007) suggested that DCM might be a good assessment of QOL, because it is rated from the perspective of the person with dementia.

DCM (see Sloane et al, 2007 for a more detailed explanation) is an observational tool that involves continuous observation during which a trained observer (mapper) tracks five to eight individuals for a dedicated period. Two main coding frames are used to code behaviour and to rate QOL in five-minute periods. The first coding frame is the behaviour category code (BCC) that consists of 24 behaviour categories. The second coding frame is the mood and engagement (ME) score that consists of a scale of numerical values ranging from -5 (severe ill-being) to +5 (positive well-being).

An example of a completed fictional DCM data sheet can be found in appendix A.

The behaviour codes, dichotomised into high (A, D, E, F, G, I, J, K, L, O, P, R, S, T, V, X, Y) and low (B, C, N, U, W), provide us with a proportion of time in positive behaviour codes for each participating resident. This was determined by calculating the frequency of occurrences of positive behaviours.

For the intervention arm, DCM was conducted for one hour at baseline (non-RA activity) and every third week that the RA group took place (e.g. weeks 3, 6, 9, 12, etc.). DCM was conducted 30 minutes prior to the RA group session, during the group session (that could last up to two hours) and 30 minutes after the group session. A three-month one hour post intervention DCM (similar to baseline DCM i.e. no RA activity) was also conducted to assess for any sustained affect.

For the hold arm of the research, DCM was used to observe one hour of non-RA activity at baseline and at 24-week follow-up. We did not deem it appropriate to observe the TAU groups at 3 months post the interventions.

To reduce bias, the two researchers (LC and FK) conducted inter-rater reliability test for the DCM data. This was evaluated during a series of pilot mapping sessions where the two researchers observed the same individuals for a one-hour period calculating concordance by dividing the actual agreements score by the maximum possible score for the one-hour period. The concordance coefficient was at 90%.

STAFF MEASURES

Staff in all the 12 care homes were surveyed to assess their levels of well-being, stress, and burnout using standardised measures at baseline and at 24 weeks. Wellbeing was assessed using the short version of the General Health Questionnaire (GHQ-12; Goldberg et al. 1997); stress at work was measured

using the Work Environment Scale (WES; Moos, 1994); and staff burnout was evaluated using the Maslach Burnout Scale (MBS; Maslach, Jackson, and Leiter, 1996).

The GHQ-12 was a subjective health questionnaire which required the participant to answer 12 questions regarding physical and mental health using a four-point Likert scale (e.g. Have you recently been losing confidence in yourself? Not at all, no more than usual, rather more than usual, much more than usual). Scores ranged from 0-12 where higher scores indicate well-being and lower scores indicate ill-being.

The WES was a subjective questionnaire, which required the participant to place true or false next to each of 90 statements. Statements were regarding the participants' workplace (e.g. People seem to take pride in their organization). There are ten subscales within this questionnaire which cover: relationships dimensions (involvement, peer cohesion, supervisor support), the personal growth or goal orientation dimensions (autonomy, task orientation, work pressure), and the system maintenance and system change dimensions (clarity, control, innovation, physical comfort).

The MBS was a subjective questionnaire containing 22 statements regarding the participants' job (e.g., I feel that I treat some recipients as if they were impersonal objects). Each statement required a response using a seven-point Likert scale i.e. never, a few times a month, once a month or less, a few times a month, once a week, a few times a week, and every day. There are three subsections when scoring: emotional exhaustion, depersonalization, and personal accomplishment. High scores indicated. The overtime approach to this research study is displayed in Table 2.

Table 2. Quantitative evaluation over time

Time Week		Screening Visit	Baseline	T1 W3	T2 W6	T3 W9	T4 W12	T5 W15	T6 W18	T7 W21	T8 W24	3 months Post Intervention
Intervention Group	Resident and Staff information and informed consent	✓										
	Resident, Staff and Care-home demographics	✓										
	Resident and Staff DCM observations		✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
	Staff measures		✓								✓	
Hold Group	Resident and Staff information and informed consent	✓										
	Resident, Staff and Care-home demographics	✓										
	Resident and Staff DCM observations		✓								✓	
	Staff measures		✓								✓	

RESULTS

DEMOGRAPHICS OF PARTICIPANTS AND CARE HOMES

DEMOGRAPHICS OF THE CARE HOMES

Six care homes were initially allocated to the intervention arm and six to the TAU arm. Due to a lack of engagement with the evaluation team, one care home was withdrawn and replaced by a new care home.

Twelve care homes were involved in the study, from the London Boroughs of Lambeth (n=7) and Southwark (n=5). Nine care homes were private and three were NHS run (GST and SLAM). Three of twelve care homes were faith-based (please refer to table 3. for a summary).

Table 3. Care home details

	Intervention Group	Hold Group	Total
Type of care home			
Private	4	5	9
NHS	2	1	3
London Borough			
Lambeth			7
Southwark			5
Faith care home?			
Yes	1	2	3
No	5	4	9
TOTAL			12

DEMOGRAPHICS OF PEOPLE WITH DEMENTIA

Seventy five people with dementia participated in the study. The majority (76%) were female. Participants' mean age was 86 years and ranged between 69 and 100 years. Although nearly half of the participants were White British (49%), there was some diversity in the group, as other ethnicities included white Irish (5%), white other (8%), Asian other (3%), black Caribbean (8%), and black African (3%). Most had English as their first language (73%); however other languages included (French, Gujarati, Vietnamese). Concerning dementia diagnoses, nearly a third of participants had Alzheimer's disease (29%), but 42% had an unspecified memory or cognitive problem (See Table 4 for an overview)

Intervention arm: The number of participants in each of the groups at baseline ranged from five to eight with the mean number being seven. Attrition was observed over time as at week 24 group sizes ranged from four to eight with a mean group size of six. Reasons for attrition were: death (n=3), move to another care home (n=1), and disengaged from the RA group (n=4).

Table 4. People with dementia demographics

	Intervention Group N=39	Hold Group N=32	Total
Age (years)			
(Range) mean	(69-98) 85	(71-100) 87	(69-100) 86
Gender			
Female	73%	78%	76%
Male	27%	22%	24%
Ethnicity			
White British	50%	47%	49%
White Irish	3%	6%	5%
White Other	3%	16%	8%
Asian Other	3% ^a	3%	3%
Black Caribbean	13%	9%	8%
Black African	5%	0%	3%
Other / missing	25%	19%	
First language (7 missing data)			
Yes	83%	86%	73%
Type of dementia			
AD	36%	16%	29%
VD	18%	16%	18%
Mixed	5%	6%	5%
Mobility (2 missing data)			
Walk unaided	38%	30%	35%
Walk assisted	38%	50%	43%
Able to stand	8%	7%	7%
Unable to stand	15%	13%	14%

The only notable difference between the two groups was in the prevalence of recorded Alzheimer's disease as the type of dementia. We do not know if this reflects more thorough diagnosis or a true difference in the groups, and the difference is not large enough to be incompatible with chance variation (it is not statistically significant, $p=0.35$ by chi-squared test).

DEMOGRAPHICS OF CARE STAFF

Thirty nine care staff participated in the study. Their ages ranged from 22 years to 60 years of age, with a mean age of 45 years. Only 11% of care staff were men. Nearly half of the staff were black Caribbean and only 15% were white British. 81% had English as their first language. The experience of the staff varied, with some only working in care homes and with people with dementia for a few months, to others who had over 20 years of experience. Please refer to Table 5 for a summary of staff demographics.

Table 5. Care staff demographics

	Intervention Group N=14	Hold Group N=17	Total
Age (years)			
(Range) mean	(22-55) 46 (4 missing)	(24-60) 45 (2 missing)	(22-60) 45
Gender			
Female	14 (100%)	13 (76%)	23 (89%)
Male	0 (0%)	4 (24%)	3 (11%)
Ethnicity			
White British	2	3	4 (15%)
White Other	0	2	2 (8%)
Mixed Caribbean	2	0	2 (8%)
Asian Pakistani	1	0	1 (4%)
Asian Other	0	1	1 (4%)
Black Caribbean	5	8	12 (46%)
Black African	1 (3 missing)	2 (1 missing)	3 (11%)
First language			
Yes	11 (92%) (2 missing)	12 (75%) (1 missing)	21 (81%)
Years worked at care home			
(Range) mean	(1-20) 6	(0-25) 6	(0-25) 6
Years worked with people with dementia			
(Range) mean	(1-20) 7	(1-29) 12	(1-29) 10

The only notable difference is in the length of time staff had worked with people with dementia in any setting. There is no difference in the length of time working at the current care home, so this reflects previous work experience. The age is barely different, so it is not a reflection of that. However, this difference is not statistically significant ($p=0.17$ by Mann-Whitney test) and could plausibly arise purely by chance.

ANALYSIS OF DCM WELL/ILL-BEING SCORES

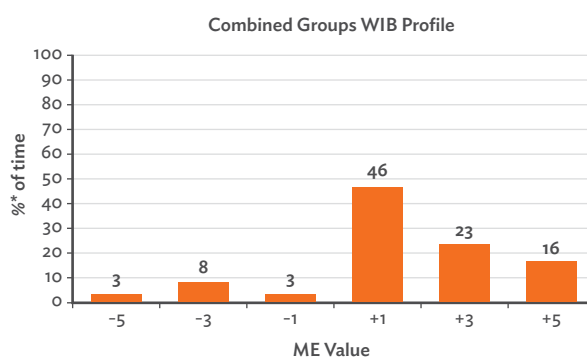
Seventy-five residents contributed to a total of 385 person-sessions. Measurements on DCM were recorded every five minutes, with a total of 6429 measurements.

ANALYSIS OF CARE HOME A'S DCM DATA

The following analysis provides a summary of findings from one of the care homes, (care home A), from the intervention group.

Baseline (graph 1): combined mood and engagement (ME) scores for the participants in the study were distributed across the six different scores (i.e. -5, -3, -1, +1, +3, +5). This shows that at baseline participants experienced both ill-being and well-being. Nearly half of the well/ill-being scores were attributed to ME +1. According to the scoring of DCM, +1 is a neutral ME value, which meant that the majority of participants were not particularly engaged in activity and were neutral in mood.

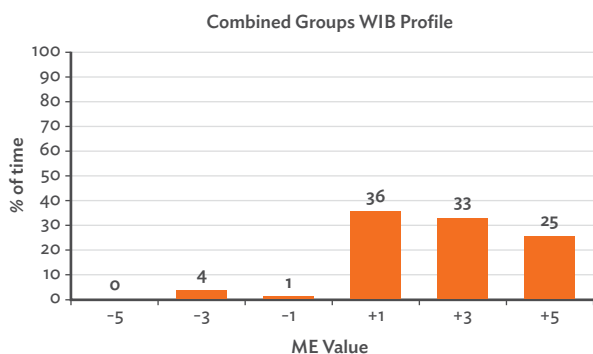
Graph 1: Care home A at baseline



* % indicates the number of times a particular ME value was observed during a session for all participants in the group, which was aggregated and calculated as a percentage of all the ME values observed during that session.

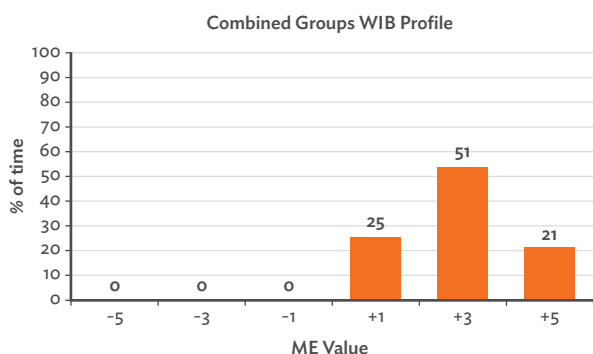
Week 3 (Graph 2): the combined group WIB profile has shifted towards the higher end of the scale. This indicates that during the RA group, participants experienced well-being more often. In addition, negative ME values are fewer than baseline, and higher positive ME values (e.g. +3 and +5) have increased.

Graph 2: Care home A at 3-weeks



Week 24 (graph 3): at the end of the intervention the combined groups WIB profile shows that no participants experienced ill-being (poor quality of life) whilst taking part in the RA group. Positive ME scores are observed throughout. In addition, +1 ME values have decreased and +3 values account for over half of all the total ME values recorded for the group. This means that the majority of the participants in the group experienced high well-being (good quality of life) when in the intervention group.

Graph 3: Care home A at 24 weeks



REGRESSION MODELS

(Please see Appendix D for a glossary of terms used in this section)

The multilevel linear regression for ME demonstrated a significant non-linear effect of time within each activity period, but not for longer-term trends over the weeks. The variation (random intercept) between participants was significant, with standard deviation 0.51, 95% CI 0.35 to 0.73.

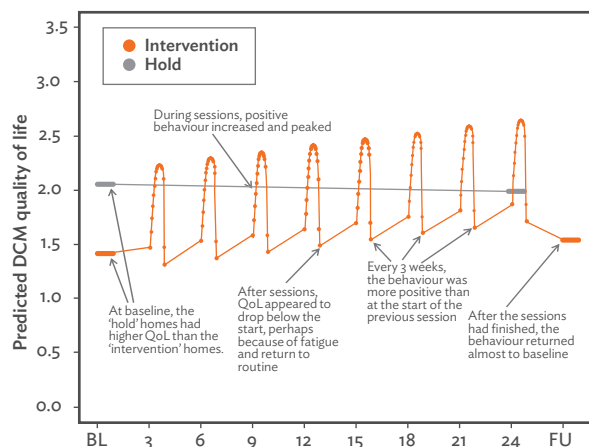
The hold group had a significantly higher quality of life at baseline by a mean of 0.64 points (95% CI 0.28 to 1.00, $p < 0.001$). During each intervention, the quality of life of residents rose and levelled off according to the formula:

$$0.148t - 0.007t^2$$

where t is the time counted in measurements since the intervention began (5-minute increments). Both coefficients are statistically significant; the linear has 95% CI 0.126 to 0.171, and the quadratic -0.009 to -0.006, both have $p < 0.001$. This suggests that the benefit peaks after about 50 minutes and perhaps declines, although the exact shape of the curve is not precisely known. After each activity, the quality of life dropped to 0.157 points below the pre-intervention level on average (95% CI -0.271 to -0.043, $p = 0.007$).

Each activity (spaced three weeks apart) in the intervention group saw a steady increase of 0.019 points on average (95% CI 0.014 to 0.024, $p < 0.001$). At 24 weeks, the hold group were not statistically significantly different to baseline, with an average change of -0.077 (95% CI -0.308 to 0.153, $p = 0.51$). At follow-up, the intervention group were not significantly different to baseline (mean change 0.130, 95% CI -0.066 to 0.325, $p = 0.19$). Graph 4 shows the model's predicted values over time.

Graph 4: Graph showing the model's predicted DCM quality of life values over time.

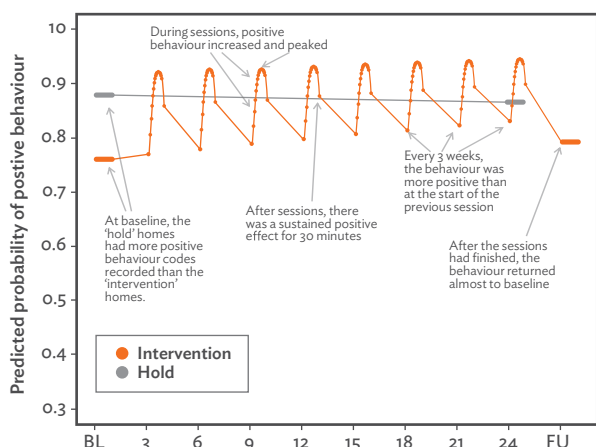


The multilevel logistic regression for positive behavioural codes showed the same pattern of change over time as that for quality of life, with one exception: the behaviour codes after the activity had ended in the intervention homes was significantly higher than prior to the activity (OR 1.84, 95% CI 1.47 to 2.30, $p < 0.001$). The hold group had significantly more positive behaviour at baseline (OR 2.32, 95% CI 1.27 to 4.25, $p < 0.001$). Behaviour improved and plateaued within each intervention period with odds ratio relative to the start given by:

$$e^{(0.232t - 0.011t^2)}$$

Both linear and quadratic coefficients are significant with $p < 0.001$. The increase over weeks was significant (OR 1.02, 95% CI 1.01 to 1.03, $p = 0.001$), but the difference between baseline and 24 weeks in the hold group, and between baseline and follow-up in the intervention group, was not (respectively, OR 0.88, 95% CI 0.52 to 1.49, $p = 0.63$ and OR 1.20, 95% CI 0.85 to 1.69, $p = 0.29$). The random intercept for inter-participant variability had standard deviation of 1.07 on the log-odds scale (95% CI 0.85 to 1.34). Graph 5 shows the model's predicted values over time.

Graph 5: Graph showing the model's predicted probability of positive behaviour values over time.



In summary, the analyses presented above show the following:

During the group Reminiscence Arts sessions our observations showed that the positive behaviour and quality of life of participating care home residents increased. After the sessions we observed a sustained positive effect for 30 minutes.

This pattern was sustained over the whole study and was found to be statistically significant. In each group session positive behaviour and quality of life peaked at 50 minutes. This could be explained by the way sessions were planned. Most of the sessions were very energetic but wound down towards the end with slower less demanding activities. Most sessions did not end abruptly but transitioned back into

the daily life of the care home, for example, tea was served at the end of many sessions whilst some residents and the Reminiscence Arts Practitioners began to leave. However, this is only an explanation for those groups that were held for an hour (three of the six intervention groups). For the remaining three groups, the length of the groups were not previously determined, and could continue for two hours. Consequently, the results of the study suggest that the maximum benefit for participants may be at 50 minutes and therefore longer sessions would provide no further gains. However, this cannot be concluded from this study and further larger studies would be required to ascertain this.

The positive behaviour and quality of life of care home residents participating in group Reminiscence Arts sessions increased as the 24 week projects progressed.

We observed at three weekly intervals that the participants' quality of life and behaviour was more positive than the previous session. This pattern was sustained over the period of the study and was statistically significant. However, it has to be noted that at three month follow-up participants' quality of life and positive behaviours dropped, but not below the baseline.

ANALYSIS OF STAFF QUESTIONNAIRES

In table 6 below, the staff results for General Health Questionnaire, Work Environment Scale, and Maslach Burnout Inventory are given. Out of 31 respondents, up to 27 provided answers at baseline, but only 11 at follow-up. In both time points, the answers dwindled with progress through the questionnaire. The poor response at follow-up makes any conclusions from those data unreliable and they are not considered further. The table below shows baseline measures.

Table 6: Table showing results from staff measures

	Intervention group (range) mean (N)	Hold group (range) mean (N)	Total (range) mean (N)
GHQ *	(2-12) 9.4 (n=10)	(7-12) 11.1 (n=15)	(2-12) 10.4 (n=25)
MBI emotional exhaustion *	(0-44) 21.0 (n=12)	(0-28) 12.1 (n=15)	(0-44) 16.0 (n=27)
MBI depersonalisation *	(0-6) 1.3 (n=10)	(0-7) 1.1 (n=14)	(0-7) 1.2 (n=24)
MBI personal accomplishment	(24-48) 41.6 (n=12)	(17-48) 37.9 (n=13)	(17-48) 39.7 (n=25)
WES I	(37-65) 52.5 (n=11)	(32-65) 52.5 (n=8)	(32-65) 52.5 (n=19)
WES PC	(32-62) 48.7 (n=12)	(26-57) 46.9 (n=7)	(26-62) 48.0 (n=19)
WES SS	(40-68) 53.8 (n=11)	(26-63) 53.3 (n=7)	(26-68) 53.6 (n=18)
WES A	(37-63) 49.3 (n=11)	(42-58) 47.9 (n=7)	(37-63) 48.7 (n=18)
WES TO	(19-60) 47.4 (n=10)	(50-60) 56.4 (n=7)	(19-60) 51.1 (n=17)
WES WP	(30-63) 50.5 (n=12)	(39-63) 51.3 (n=7)	(30-63) 50.8 (n=19)
WES C	(39-65) 49.2 (n=11)	(39-60) 51.9 (n=7)	(39-65) 50.2 (n=18)
WES Ctl	(27-65) 54.9 (n=12)	(49-65) 56.3 (n=9)	(27-65) 55.5 (n=21)
WES Inn	(36-67) 53.8 (n=12)	(45-67) 54.6 (n=8)	(36-67) 54.2 (n=20)
WES Com	(30-71) 55.7 (n=9)	(39-66) 54.8 (n=8)	(30-71) 55.2 (n=17)

* - a high value indicates a poor outcome for the staff member

DISCUSSION

The findings from this evaluation shows that participants in the intervention benefited by engagement in structured activity such as Reminiscence Arts practice. We found that well-being rose incrementally over the course of the intervention. At baseline we noted evidence of ill-being as can be seen in the Graph 1 (page 8), but during the course of the intervention there was an incremental increase in positive well-being scores.

The hold groups showed more positive behaviours and higher quality of life at baseline than the intervention group and the difference was statistically significant. Explanations for this are not clear, but we are aware that there have been other activities taking place in those homes such as quizzes, singing, dancing and outings.

We were not able to assess whether the severity or the type of dementia was a predictor for improved well being given that over half of the intervention group had a diagnosis of unspecified dementia. Given that the age range is small, we were unable to reach conclusions about the possible effect of age on quality of life. However, we were interested to see whether the intervention worked for people with dementia in care homes and can conclude that our findings show that quality of life improved from the start of the session and peaked at 50 minutes and that there was an upward trajectory over time.

It was unfortunate that we were unable to achieve a more comprehensive data set for the staff measures due to a range of issues identified in the appendices.

We have noted that that follow up there was a drop in QOL to near the baseline for the intervention groups, but not below it. The quality of life for the hold groups dropped below baseline at 24 month follow up. Even though the differences were not statistically significant, it is an important finding, because we can conclude that at follow up the hold groups were slightly worse and the intervention groups were slightly better in terms of quality of life. In a degenerative condition, this is potentially quite positive.

This study supports findings of previous research that demonstrated that regular engagement with Reminiscence Arts activities is positively associated with higher levels of well-being and QOL for people with dementia (Mowlam, et al, 2014). We however, still need to develop ways of capturing and exploring the views of people with dementia in care homes on the value of arts and reminiscence (Roe, et al, 2014). We also need to find ways to overcome the methodological challenges to evaluate the effectiveness for Reminiscence Arts for people with dementia as identified by Zeilig, et al (2014).

Overall, this evaluation supports, builds and strengthens the evidence base for the use of reminiscence art groups for people with dementia in continuing care homes.

STRENGTHS OF THE STUDY

1. Evaluation was conducted independently by experienced health and social care researchers with expertise in dementia research.
2. DCM is an established and validated observational tool for recording the quality of life and behaviour activity of people with dementia living in care homes.

3. Having the hold group enabled a comparison of those receiving usual activities in a care home activity to be compared to those receiving specific Reminiscence Arts activities.
4. The study confirms that DCM is a valid observational tool to capture QOL for people with dementia living in care homes.

LIMITATIONS OF THE STUDY

At the outset it has to be noted that this was a small scale pilot study and the results, although significant should be viewed in light of this fact. There were very little other non-Reminiscence Arts structured activities in the intervention homes, which meant that we were limited to observe the participants in everyday activities such as watching television, chatting to a friend, etc. This means that we cannot make conclusive statements about the impact of Reminiscence Arts groups on quality of life.

The way in which participants were identified for inclusion in the study may have introduced a level of bias in that staff may have been preferential in their selections. However, we compensated for this during the consent seeking process and prospective participants who did not meet the inclusion criteria were excluded from the study.

Another limitation of the study is that we were examining QOL by using just one measure and work of this nature should benefit by self reports, particularly from people with mild to moderate dementia. This also meant that were not able to evaluate to what extent the intervention enhance the overall quality of care. Further challenges regarding the methods used for conducting this study are highlighted in Appendix B along with some suggestions as to how these challenges could be addressed for future research projects investigating the use of reminiscence arts groups for people with dementia living in care homes presented in Appendix C.

There is a need to assess in much greater depth to the association between QOL and Reminiscence Arts practice. This will provide a stronger evidence base on the effectiveness of Reminiscence Arts practice. Moreover, to arrive at firmer conclusions from a quantitative study, we need to compare non-standard activities with iterative standardised activities – this is the challenge for work in this field of study. We also need further work to explore to what extent Reminiscence Arts practice can contribute to the overall quality of care for people with dementia.

CONCLUSION

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. There is scope for future research that compares Reminiscence Arts activities with non reminiscence arts activities for people with dementia on a larger scale.

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APPENDIX A:

Blank raw data sheet

Date:	09/01/14	Time period:	09:30 -10:30	Place:	BLOOM LODGE CARE HOME .
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Total number of service users:	6	Number of staff:	2	Observer:	LC .
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Participant name	Time	09:35	09:40	09:45	09:50	09:55	10:00	10:05	10:10	10:15	10:20	10:25	10:30											Total ME			
																											Total TF
ANNE	BCC	B	C	C	A	B	C	C	C	N	N	N	K														+3
	ME	+1	-1	-1	+3	+1	-1	-1	-1	-	-	-	+3														9
TERRY	BCC	L	L	L	L	L	B	A	E	E	B	A	A														+22
	ME	+3	+3	+1	+1	+1	+3	+3	+1	+1	+1	+1	+3														12
SID	BCC	W	U	C	U	U	X	Q	Q	P	F	F	B														-12
	ME	-3	-3	-1	-3	-5	-1	-	-	+1	+1	+1	+1														10
MARY	BCC	O	O	O	O	O	T	T	O	T	Y	Y	T														+24
	ME	+3	+3	+1	+3	+3	+1	+1	+1	+1	+3	+3	+1														12
RALPH	BCC	V	V	V	V	K	G	G	G	I	R	L	L														+42
	ME	+3	+5	+5	+5	+3	+3	+5	+3	+3	+1	+3	+3														12
ROSE	BCC	B	J	J	J	J	D	D	D	D	S	Q	Q														+22
	ME	+1	+3	+3	+5	+3	+1	+1	+1	+1	+3	-	-														10

APPENDIX B: CHALLENGES

Time was a significant concern for the quantitative evaluation of the RADIQL study, particularly at the start-up of the study. The following section documents some of the contributing factors.

NHS ETHICS

Gaining NHS ethical approval for RADIQL took a considerable amount of time to obtain. In addition to completing the lengthy online form through the Integrated Research Application System [IRAS], additional multiple research documents (e.g. participant information sheets and consent forms) were submitted in accordance with NRES guidance.

RESEARCH GOVERNANCE

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).

ENGAGING CARE HOMES IN THE SET-UP OF RADIQL

Changes in the structure of care homes: Restructuring of management, and care staff having to reapplying for their existing jobs, brought instability to some work places.

IDENTIFICATION OF RESIDENTS FOR THE STUDY

Whilst working with care staff to gain consent from residents, it became apparent that the researcher was in fact identifying potential participants for the RA groups. Consequently, the referral process of residents to Age Exchange did not appear to work adequately, as care staff were bypassing this route and using the researcher as the referrer. Some residents had not been approached by care staff about the study in advance of speaking with the researcher. This resulted in multiple visits to the care home to speak with the residents about the RA groups before embarking on gaining their consent to participate in the evaluating research.



DIAGNOSIS OF DEMENTIA

Some care staff did not know whether the resident they had suggested to join RADIQL had a diagnosis of dementia to be included in the study. Two residents were inappropriately referred to RADIQL; one in the hold arm and one in the intervention arm. The participant in the intervention arm had already participated in a few RA groups and appeared to be gaining a lot from the experience. This caused an ethical dilemma for the researcher and RAPs. For this resident it was decided that they should continue to join the study, and his data for the study was excluded; the participant was informed and content with this decision. However, to help clarify the appropriateness of including further residents to the study who did not have a formal diagnosis of dementia, a short assessment was used (i.e. ICD-10).

CONSENT ISSUES FOR RESIDENTS IN CARE HOMES

In line with guidance by the Mental Capacity Act (MCA), it was assumed that residents had the capacity to make an informed decision about whether they wanted to take part in RADIQL, unless it was demonstrated that they did not have mental capacity to do so.

Many people with dementia did not have mental capacity to make a decision about whether they would like to take part in the study. Consequently, their next of kin were asked to act as their consultee to sign a declaration form. Although time consuming, the consent process took a person-centred approach, and aimed to be as inclusive as possible within the limits of MCA.

Some residents did have the mental capacity but required time and support to decide whether to take part in the research or not. Others wanted time to think about the information that had been provided, and to discuss it with a relative or friend before making a decision. We found that devoting additional time to gaining consent yielded positive results. For example, with one resident it took over an hour to explain the study, ascertain their mental capacity, answer their questions and gain their consent. At the end of this process, the participant said how she had appreciated the researcher spending time with her to explain the study and answer her questions so that she was able to decide what to do.

INVOLVEMENT OF STAFF IN RADIQL

Engaging staff in RADIQL overall was problematic at times. The aim was to invite keyworkers of the residents involved in the group to take part in the study. However many of the keyworkers were unavailable (e.g. worked nights) or declined to participate. Consequently, any care staff who worked with the participants in the group were approached and invited to take part in the study. Although many care staff returned their signed consent form, some did not complete the four questionnaires.

It became apparent that many of the care staff found the questionnaires difficult to understand, lengthy (and therefore time consuming), and intrusive. Care staff asked what some of the questions meant and had problems with allocating their answer (using the Likert scale provided) to the question. It was evident that some care staff were avoiding completing

the questionnaires. Activities coordinators reported that this maybe because some staff did not have English as a first language and others were not confident in their academic abilities. Consequently, the WES (90 statement questionnaire) was not used at follow-up, and some care staff completed the measures with other colleagues or with the assistance of the researcher (and Belinda).

Another issue that was reported were concerns regarding confidentiality. Some of the questions or statements in the staff measures were quite personal and asked recipients to give their views on their work place, environment and supervisors. Unsurprisingly, care staff were concerned about where this information would go, and whether they would be identified. This issue was overcome for those voicing this concern by providing staff with large, stamped addressed envelopes so that they were able to send their questionnaires directly to the researcher, who ensured complete anonymity and confidentiality.

MULTI-LAYERS OF AUTHORITY IN CARE HOMES

The multi-layers of authority within each care home had a great significance for the study. Some managers were very involved in the research and knew a great deal about the study. However, some managers (perhaps due to work pressures) did not wish to be engaged and left their activities coordinators to work exclusively with the researcher and RAPs. However, this meant at times that not everyone in the care home were involved or aware of RADIQL. Some care staff did not know anything about the research and failed to have residents ready (i.e. out of bed and dressed) in time for the groups to start. Some managers did not allocate enough staff to cover a shift, which meant that staff allocated to the RA groups were no longer able to join the group.

It was noted that some care staff had come into the care home on their day off or worked overtime to attend the RA group. Some care staff voiced their frustrations when they saw the value in the groups and the research but felt unsupported by their managers to effectively facilitate the RAPs.

In addition, even though permission had been gained from the manager of the care home and consent obtained from residents or their consultee, some nursing staff (head of the unit or section that the resident was living in) queried the research and the appropriateness of the resident attending such a group and being involved in research.

A lack of understanding of the research was particularly prominent for care staff in the hold arm of the study. They seemed to have difficulty with understanding why residents needed to give consent for the research when the RA groups did not start until six months time. Managing the expectations of care staff played a major part in maintaining their cooperation and assistance with the study.

APPENDIX C: RECOMMENDATIONS FOR FUTURE RESEARCH PROJECTS

In light of the previously discussed challenges, the following section provides a number of recommendations for future research.

ETHICS AND R&D – ALLOCATED TIME IN FUTURE BIDS.

The NHS Ethics committee are obliged to give their response to a study's application within 60 days of submission. Once NHS Ethical approval has been gained, an application to NHS R&D can then be made: this process may only take 10 days to process, but the gaining of the appropriate pre-approvals (e.g. from CAG) and completion of additional procedures and paper work may take up to three months post gaining NHS ethical approval. Consequently, it is suggested that the time allocated to apply and gain the relevant NHS Ethics and R&D approvals should be six months. If non-NHS care homes are involved in the study then four months should be adequate.

ENGAGING CARE HOME MANAGERS, CARE STAFF, RESIDENTS, FAMILY MEMBERS OVER TIME.

Initial and regular, formal, on site (at the care home) presentations of RADIQL introducing the study and those involved (RAPS, researchers) may be beneficial in sustaining the profile of RADIQL and maintaining the interest of management and care staff (as well as residents and family,

friends) in the study over time. This would also provide a forum for reciprocal exchanges of knowledge and information.

DIAGNOSIS OF DEMENTIA

To be sure that residents participating in the study have dementia, the ICD-10 assessment could be completed by a qualified nurse for all participants without a formal diagnosis.

COMPLETING STAFF QUESTIONNAIRES

Completion of staff questionnaires in a workshop forum appeared to be an effective strategy to engage staff in the research, but also provided an opportunity to reciprocally share knowledge about wider aspects of research and dementia care.

RESEARCHER (NON-EVALUATING) SUPPORTING THE RADIQL STUDY

There were many times when the evaluating researcher felt that an additional generic researcher would have been beneficial to support the running of the RADIQL study. This additional researcher could have ensured that the correct participants were in the group each week; supported staff with completing their consent forms and questionnaires; and acted as a liaison person between Age Exchange, the evaluating teams, and the care home staff and residents.

APPENDIX D: GLOSSARY OF STATISTICAL TERMS

Odds ratio: a measure of effect when the outcome is binary (positive or negative behaviour codes). An odds ratio greater than one indicates an increased chance of positive behaviour.

Random intercept: a way of accounting statistically for the fact that some residents have more severe limitations than others, without allowing this to skew the results. For example, if severely affected residents tend to leave sessions early, it could look like the group improves over time, but by including the random intercept, our statistical model will not draw this false conclusion.

Log-odds: the logarithm of the odds of a positive outcome; this is a computational trick used along the way to calculating a more meaningful odds ratio.





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