Manuscript title: Biographical films as a person-centred approach to reduce neuropsychiatric symptoms of dementia in residential care: a feasibility study

Short title: Biographical films for dementia

Emma R Francis1, Jared G Smith1, 2 Mustabshira Qayyum1, Jessica Lee1, Philip Woodgate1, Robert M Lawrence1, 2

1Clinical Research Unit of the Psychiatry of Old Age and Neuropsychiatry, South West London and St. George’s Mental Health NHS Trust, London, UK

2Population Health Research Institute, St George’s, University of London, London, UK

**Key words.** Neuropsychiatric symptoms, dementia, reminiscence, person-centred care, biographical films

**Corresponding author:** Miss Emma R Francis, Department of Psychological Medicine, Institute of Psychiatry, Psychology and Neuroscience, De Crespigny Park, London, SE5 8AF, UK; Email: Emma.Francis@kcl.ac.uk

**Abstract**

Objective

Neuropsychiatric symptoms are a major component of dementia irrespective of severity or subtype. We aimed to determine the feasibility of biographical films to reduce neuropsychiatric symptoms in people with moderate to severe dementia over a 32-week period.

Method

Eleven people with dementia situated in a residential care home took part in this mixed-method feasibility study. Carers reported neuropsychiatric symptoms of residents at three time-points, and their experience of the study was obtained at a feedback session.

Results

There was a significant reduction in neuropsychiatric symptoms in residents with neuropsychiatric impairment from baseline to end of study (p=0.042, d=0.98). Thematic analysis identified three major themes: Triggered memories, knowledge gained to support care and perceived changes in the resident.

Conclusion

The findings suggest that it is feasible to use biographical films long-term to reduce neuropsychiatric symptoms of dementia, alongside routine care.

**Introduction**

Neuropsychiatric symptoms, also known as Behavioural and Psychological Symptoms in Dementia (BPSD), include agitation, depression and various other observed behavioural dysfunctions (Finkel et al, 1997). It is recommended that first-line treatment for neuropsychiatric symptoms are non-pharmacological therapies, and person-centred care should be employed by considering how life experiences and personality play a role in the individuals’ response to dementia (National Institute for Health and Care Excellence, 2018). One psychosocial intervention is person-centred reminiscence therapy involving the discussion of past events and experiences one-on-one with another person (Woods et al., 2018).

An extensive review into different types of technological interventions to facilitate reminiscence therapy reported that a multimedia approach can encourage the person with dementia to participate in social interaction and may reduce the burden of therapeutic delivery (Lazar, Thompson, & Demiris, 2014). Previous research has investigated the use of multimedia biographies (Damianakis et al, 2009), digital life storybooks (Subramaniam & Woods, 2016), touchscreen technology (Astell et al, 2010) and ‘YouTube’ videos (O'Rourke et al, 2011) to support and foster relationships with carers and relatives, and to create enjoyment for the person with dementia. However, while there are promising psychosocial benefits, it is yet to be determined if the use of multimedia technology can reduce neuropsychiatric symptoms over the longer term. As such, we introduce a method of person-centred reminiscence therapy in the form of biographical films for people with dementia situated in residential care.

We sought to assess the feasibility of using biographical films as a form of person-centred reminiscence therapy for people diagnosed with dementia situated in a residential care home, and determine whether this intervention has the potential to reduce symptoms in residents with neuropsychiatric impairment over a 32-week period.

**Methods**

This was a single-site mixed-method feasibility study carried out from April 2016 to July 2017. Ethical approval was provided by the (UK) National Research Ethics Committee (London - Camberwell St Giles Research Ethics Committee; REC number 15/LO/2032), and local R&D/HRA approval was also obtained. The study was carried out in accordance with the Code of Ethics of the World Medical Association (Declaration of Helsinki).

*Participants*

Participants were recruited from a community residential care home specialising in dementia care (all types/severities) in London, UK. Participants comprised of the ‘resident’ (i.e. the person with dementia residing in the care home), and their carer (i.e. ‘care assistants’ employed at the care home). All residents were under the care of South West London and St George's Mental Health National Health Service (NHS) Trust.

To be included, residents were required to be 65 years old or older with a diagnosis of dementia (based on National Institute of Neurological and Communicative Disorders and Stroke and the Alzheimer's Disease and Related Disorders Association [NINCDS-ADRDA] criteria; Jack Jr et al, 2011), resident of the care home for at least 8 weeks, able to provide written informed consent, or if unable, had a personal/nominated consultee who advised on their behalf, and with sufficient fluency in English. Participants were excluded if they had an uncontrolled illness that inhibited completion of the study, or if they had a complete visual and/or hearing impairment that would hinder their ability to see images and/or hear sounds presented in the film. Formal carers were required to be solely or jointly responsible for the care of the resident for at least 2 hours per day on at least 3 days per week and involved in assisting the resident in activities of daily living (e.g. hygiene, grooming, dressing, eating, and toileting). Due to limited care staff availability, carers were permitted to consent for more than one resident if they met the inclusion criteria.

*Study intervention and procedure*

Following baseline assessments, the ‘My Life Films’ team began the process of creating the biographical film. ‘My Life Films’ is a non-profit, UK-based charity (registration number: 1157198) that uses participatory strategies to produce biographical films for individuals with dementia. Film making occurred over 3-4 two-hour meetings (total range 6-8 hours according to the amount of material the family of the resident made available). At the first meeting, family members completed a questionnaire discussing the memorable parts of the resident’s life. The resident/ family decided on content for the ten chapters about the resident’s life, to be included in the film with each chapter being 3 minutes (childhood, youth, school, job, sport, travel, marriage, children, grandchildren and hobbies). The second meeting involved the film makers, the resident and their family whereby material for the chapters were scanned and chronologically ordered, and music tracks were chosen to accompany visual information. At the third/fourth meeting, video interviews were recorded with the family members for inclusion. Subsequently, the film team edited the material and produced a 30-minute biographical film which took approximately seven weeks.

At study week 8, the film premiere for each resident took place. Following this, the carer watched the 30-minute film with the resident at least twice per week until the post-intervention assessment at week 32. The frequency of film viewings during the study period was documented in the resident’s care plan. The mid-intervention and post-intervention assessments were completed in the care home at week 20 and week 32, respectively. Participant carers’ feedback was obtained post-intervention.

*Data collection and outcome measures*

At pre-intervention, sociodemographic characteristics, date of entry into the residential care home, date and type of dementia diagnosis and (total) Clinical Dementia Rating (CDR; Hughes et al., 1982) score were obtained. A standardized evaluation, employing carer-based measures, was completed at each of the three-study time-points. The carers were asked to answer questions based on behavioural observations in the previous 2 weeks. We aimed to ensure that the same carer participant was administered the questionnaires for the same resident throughout the study-time period, and that the same research team member administered the questionnaires.

The primary outcome was (change in) neuropsychiatric symptoms. Secondary outcomes included quality of life, agitation and challenging behaviour. Information was also collected from care plans regarding the frequency of and reason for film viewing. Responses from carer participants were obtained by a clinical team member with experience in administering neuropsychiatric measures. They also trained and supervised a research assistant when administering these measures.

We administered the Neuropsychiatric Inventory-Nursing Home (NPI-NH) scale, a semi-structured interview adapted from the original NPI for use in residential care homes (Wood et al., 2000). The scale assesses the frequency (scale of 0–4), severity (0–3) and level of occupational disruptiveness to staff (0–5) of behavioural and psychological symptoms of dementia across 12 domains: delusions, hallucinations, agitation, depression, anxiety, euphoria, apathy, disinhibition, irritability, aberrant motor behaviour, night‐time behaviour and appetite disturbance; a domain score of 4 or more or NPI-NH total score of 4 or more is commonly taken to be indicative of clinically relevant symptoms (Schneider et al., 2001) and a change of 11 points on the NPI-NH total score is considered indicative of true behavioural change (Zuidema et al., 2011). Quality of life (QoL) was measured with the proxy-rated Quality of Life in Alzheimer's Disease scale (QoL–AD; Logsdon et al, 1999); a dementia-specific QoL tool which can be completed by caregivers. The frequency and severity of behaviour difficult to manage in residents was assessed using the Challenging Behaviour Scale, a 25-item checklist measuring agitation, aggression, eating and sleep problems (CBS; Moniz-Cook et al., 2001). The Cohen-Mansfield Agitation Inventory (CMAI; Cohen-Mansfield et al., 1989) was used to assess the frequency of agitated and disruptive behaviours; this 29-item scale has good construct validity and reliability in people with dementia residing in care homes (Cohen-Mansfield et al., 1989; Zuidema et al., 2011*)*.

Research team members also met with the participating formal carers as a group at study end. Open-ended questions (based on a pre-designed topic guide) were asked concerning carers’ experience of using the biographical film and how they incorporated the film into routine care. The group session was approximately two hours long.

*Data analysis*

Quantitative data was used to examine pre-intervention characteristics of residents, frequency of film viewing, and, for those individuals with clinically relevant neuropsychiatric impairment, changes in study measures over time. For carer-based (standardised) outcome measures, baseline values were compared with those at mid-intervention (week 20) and post-intervention (week 32) using paired-sample *t*-test and effect sizes (Cohen’s *d*) obtained. Where one or more of the data distributions was clearly non-normal (i.e., skewness < -1 or > 1, kurtosis < -1.5 or > 1.5; Hair, Anderson, Tatham, & Black, 1998) bootstrapping was employed to calculate 95% confidence intervals of mean difference and associated *p* values, and effect sizes were calculated with values transformed using Box-Cox methods (Sakia, 1992). The level of significance was set at *p* < 0·05. All statistical analyses were completed with SPSS statistical software (Version 24.0). The carers’ feedback session was transcribed verbatim from a digital recording with all personal identifiers removed to preserve anonymity and replaced with codes (such as C1, C2). An inductive thematic analysis was employed as a method of identifying themes within the data (Braun & Clark, 2006) using the qualitative research software programme NVivo (Version 11). Reliability of analyses was ensured between researchers (EF and RL).

**Results**

*Demographics and clinical profile*

Eleven residents participated in the study. All but one were female, with an average age of 89.3 years (range 72-97). Five residents were diagnosed with Alzheimer’s disease (AD), 3 with vascular dementia, 1 with mixed AD and vascular dementia, 1 with Parkinson’s type dementia and another with unspecified dementia. Residents had been in the care home for, on average, 31.8 months (SD = 28.1, range = 2-96). The average time from dementia diagnosis was 37.5 months (SD = 27.3) although this varied widely across residents (range = 2-92). CDR was only available for eight residents; 7 were in the moderate range and 1 severe. Across residents, a wide variety of medication (with evidence of polypharmacy) was being administered, which remained constant during the study period; 8 residents receiving antidepressant medication, 3 receiving cholinesterase inhibitors, 2 taking memantine, 2 taking antipsychotics, and 1 receiving anxiolytic medication (Lorazepam).

*Frequency and timing of viewing of biographical reminiscence film*

Films were viewed by participating residents on a frequent basis, ranging from twice weekly (2), to 3-4 times per week (5), everyday initially then 2-3 times per week (3) and every day (1). Typically, residents were shown films when exhibiting signs of distress (4) or anxiety (4), and for some residents, at meal times when they were refusing to eat (3). A small number of residents viewed films as an activity (4).

*Carer-based assessments of resident function at pre-, mid- and post-intervention*

Eight residents evidenced clinically relevant neuropsychiatric symptoms at pre-intervention. The mean scores of these residents on (outcome) measures prior to viewing of their biographical film (pre-intervention), at week 20 (mid-intervention), and at the week 32 (post-intervention) are displayed in Table 1. Measures were not completed for one resident at mid-intervention and one (different) resident at post-intervention. At mid-intervention, there were numerical improvements in neuropsychiatric function, QoL and challenging behaviour, although overall differences were non-significant and effect sizes tended to be small-to-medium in magnitude. Scores at the 32-week assessment indicated marked changes from pre-film scores for neuropsychiatric function and QoL, with large effect sizes for both measures and a significant improvement for neuropsychiatric function. Notably, all 5 participants with pre-film NPI-NH scores ≥ 11 showed improvement at post-intervention indicative of true behavioural change (i.e., decrease of 11 or more points). Pre- versus post-intervention differences were most obvious (although non-significant) for residents in NPI-NH domains of Agitation/Aggression (*M* = 4.29, SD = 5.38 vs. *M* = 2.14, SD = 1.68), Depression/Dysphoria (*M* = 3.00, SD = 4.51 vs. *M* = 1.00, SD = 1.53) and Irritability/Lability (*M* = 3.71, SD = 4.07 vs. *M* = 1.86, SD = 1.86)**.**

**Insert Table 1 about here**

*Carers’ views of the biographical film intervention for residents*

Four carers (1 male, 3 females) took part in the feedback session. Three themes emerged, “Triggers memories”, “Increased knowledge that supported care” and “Perception of change that took place”. “Triggers memories” was predicated on the reduced cognitive abilities of the resident. The personal identity of the resident was discussed amongst the carers, with the intervention being used to enable the resident to elicit a re-connection with oneself and trigger memories about their life. These memories involved their careers, family members and/or close relationships, and were positive memories they wanted to share.

The second theme was “Increased knowledge that supported care”. Carers discussed how being involved in the study helped to develop knowledge of the resident and effectively use this when caring for them. Carers also referred to the intervention as the “right tool for us to have to enable understanding of the individual” and ensure “changes were led by new learning”. They began using the intervention as a therapeutic tool when the resident displayed behaviour that was difficult to manage or when the resident was distressed.

The final theme was the “Perception of change that took place” with three sub-themes: ‘Psychosocial function’, ‘Physical health’ and ‘General wellbeing and compliance’. Carers discussed how the intervention facilitated communication with the resident and consequently strengthened relationships with their families and other residents. Specifically, the film appeared to aid the formation - and in one case the re-formation - of relationships. Carers discussed how, in some cases, residents’ physical health benefited after viewing the film with increased motivation to be involved in previously undertaken activities.

**Discussion**

To our knowledge, this is the first study to have investigated the feasibility of biographical films as a form of person-centered reminiscence therapy to reduce neuropsychiatric symptoms in people with dementia residing in a care home. We found that biographical films are acceptable to residents with dementia and their carers, have the potential to decrease neuropsychiatric symptom levels and improve quality of life. The films increased the carers’ knowledge of the resident, which enhanced relationships and facilitated better care. This finding is in line with previous research reporting that reminiscence therapy can increase knowledge of the person with dementia and encourage support and maintain relationships (Lazar et al, 2014; Subramaniam & Woods, 2016).

Our results support long-term exposure of the intervention as evidenced by the larger effects on resident’s neuropsychiatric symptoms post-intervention (week 32) compared with the mid-intervention assessment (week 20). Interestingly, Morgan and Woods (2012) observed improved mood and autobiographical memory at a 6-week follow-up for people with dementia participating in a life story book reminiscence intervention, and argued that tangible outcomes of reminiscence work, such as a (life story) book, allow benefits obtained from reminiscence work to be maintained over an extended period. From this perspective, multiple presentation of a life story via a video medium may serve to reinforce biographical information and provide ongoing therapeutic value (Subramaniam & Woods, 2016). Future research should consider the timescale of improvements.

Our findings may offer an insight into scenarios that lead to the carers’ application of this person-centered technological intervention to reduce the occurrence of neuropsychiatric symptoms. Carers applied the intervention for example, prior to meal times to reduce agitation and facilitate healthy eating behaviour, and also in the evening to reduce distress and facilitate healthy sleep behaviour. Of their own accord, the carers used the films as a therapeutic tool supporting the use of this person-centered, holistic approach to aid the delivery of routine care and support general wellbeing of residents with dementia which may explain the reduction of symptoms.

A portable technological intervention ensures the residents’ needs are at the forefront of the care given regardless of time, place or reliance on a therapist’s availability. In contrast, group reminiscence therapy is a structured intervention that requires a trained therapist to deliver, which may result in high withdrawal rates (Woods et al, 2016). Ultimately, the use of mobile multimedia technology and applications holds promise for the future of how person-centered reminiscence therapy can be delivered. Future research should investigate whether there is a ‘dose-response’ relationship and also the cost-effectiveness of this intervention.

*Methodological considerations*

The sample size is small and results should be interpreted with caution. Due to the nature of the intervention, participatory carers were aware of the residents taking part in the study, which may have led to bias in the reporting of outcomes. Further, we did not assess carer burden, frequency of contact with resident nor carer psychiatric symptoms which we acknowledge may have impacted on the reporting of resident outcomes. Whilst we aimed for the same carer to complete assessments for the same resident throughout, due to limited staff availability this was not always possible which may have resulted in low inter-rater reliability in these instances (Zuidema et al., 2011). Finally, the lack of a (randomised) control group precludes assumptions that observed effects are a result of the intervention. It could be argued the large magnitude of (follow-up) change in the primary outcome - neuropsychiatric symptomatology - is unlikely in the absence of some type of treatment effect, however we acknowledge a control group i.e. historical video (alongside the ‘treatment’ group) should be investigated to determine if the effect observed in our study withstands versus conventional psychosocial approaches targeting neuropsychiatric symptoms.

**Conclusion**

This study concludes that biographical films are feasible as a person-centered approach to reduce neuropsychiatric symptoms in people with dementia situated in a residential care home.

**Conflict of interests**

No authors have conflict of interest to declare.

**Acknowledgements**

We thank all the research participants that took part, and My Life films for creating the biographical films. We also want to thank the residents’ families and friends who supported them, and the care home that facilitated the study.

**Funding**

This paper represents independent research completed with funding support from Friends of Barnes Hospital (Registered charity number: 290489). The views expressed are those of the author(s) and not necessarily those of the National Health Service (NHS) or St George’s University of London.

**References**

Astell, A. J., Ellis, M. P., Bernardi, L., Alm, N., Dye, R., Gowans, G., & Campbell, J. (2010). Using a touch screen computer to support relationships between people with dementia and caregivers. *Interacting with Computers*, *22*(4), 267-275.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77-101.

Damianakis, T., Crete-Nishihata, M., Smith, K. L., Baecker, R. M., & Marziali, E. (2009). The psychosocial impacts of multimedia biographies on persons with cognitive impairments. *The Gerontologist*, *50*(1), 23-35.

Finkel, S. I., e Silva, J. C., Cohen, G., Miller, S., & Sartorius, N. (1997). Behavioural and psychological signs and symptoms of dementia: a consensus statement on current knowledge and implications for research and treatment. *International Psychogeriatrics*, *8*(S3), 497-500.

Hair, J. F., Anderson, R. E., Tatham, R. L., & Black, W. C. (1998). *Multivariate data analysis*. Upper Saddle River.

Hughes, C. P., Berg, L., Danziger, W., Coben, L. A., & Martin, R. L. (1982). A new clinical scale for the staging of dementia. *The British Journal of Psychiatry*, *140*(6), 566-572.

Jack Jr, C. R., Albert, M. S., Knopman, D. S., McKhann, G. M., Sperling, R. A., Carrillo, M. C., & Phelps, C. H. (2011). Introduction to the recommendations from the National Institute on Aging-Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease. *Alzheimer's & Dementia*, *7*(3), 257-262.

Lazar, A., Thompson, H., & Demiris, G. (2014). A systematic review of the use of technology for reminiscence therapy. *Health Education & Behavior*, *41*(1\_suppl), 51S-61S.

Logsdon, R. G., Gibbons, L. E., McCurry, S. M., & Teri, L. (1999). Quality of life in Alzheimer's disease: patient and caregiver reports. *Journal of Mental health and Aging*, *5*, 21-32.

Moniz‐Cook, E., Woods, R., Gardiner, E., Silver, M., & Agar, S. (2001). The Challenging Behaviour Scale (CBS): Development of a scale for staff caring for older people in residential and nursing homes. *British Journal of Clinical Psychology*, *40*(3), 309-322.

Morgan, S., & Woods, R. T. (2010). Life review with people with dementia in care homes: A preliminary randomized controlled trial. *Non-pharmacological Therapies in Dementia*, *1*(1), 43-60.

National Institute for Health and Care Excellence (2018). Dementia: assessment, management and support for people living with dementia and their carers. (NICE guideline NG97). Retrieved from: <https://www.nice.org.uk/guidance/ng97>

O'Rourke, J., Tobin, F., O'callaghan, S., Sowman, R., & Collins, D. R. (2011). ‘YouTube’: a useful tool for reminiscence therapy in dementia? *Age and ageing*, *40*(6), 742-744.

Sakia, R. M. (1992). The Box-Cox transformation technique: a review. *The Statistician*, 169-178.

Schneider, L. S., Tariot, P. N., Lyketsos, C. G., Dagerman, K. S., Davis, K. L., Davis, S., & Pollock, B. G. (2001). National Institute of Mental Health clinical antipsychotic trials of intervention effectiveness (CATIE): Alzheimer disease trial methodology. *The American Journal of Geriatric Psychiatry*, *9*(4), 346-360.

Subramaniam, P., & Woods, B. (2016). Digital life storybooks for people with dementia living in care homes: an evaluation. *Clinical Interventions in Aging*, *11*, 1263-1276.

Wood, S., Cummings, J. L., Hsu, M. A., Barclay, T., Wheatley, M. V., Yarema, K. T., & Schnelle, J. F. (2000). The use of the neuropsychiatric inventory in nursing home residents: characterization and measurement. *The American Journal of Geriatric Psychiatry*, *8*(1), 75-83.

Woods, B., O'Philbin, L., Farrell, E. M., Spector, A. E., & Orrell, M. (2018). Reminiscence therapy for dementia. *Cochrane Database of Systematic Reviews* (3).

Woods, R. T., Orrell, M., Bruce, E., Edwards, R. T., Hoare, Z., Hounsome, B., & Russell, I. (2016). REMCARE: pragmatic multi-centre randomised trial of reminiscence groups for people with dementia and their family carers: effectiveness and economic analysis. *PloS One*, *11*(4), e0152843.

Zuidema, S. U., Buursema, A. L., Gerritsen, M. G., Oosterwal, K. C., Smits, M. M., Koopmans, R. T., & de Jonghe, J. F. (2011). Assessing neuropsychiatric symptoms in nursing home patients with dementia: reliability and Reliable Change Index of the Neuropsychiatric Inventory and the Cohen‐Mansfield Agitation Inventory. *International Journal of Geriatric Psychiatry*, *26*(2), 127-134