

Improving Care for People with Dementia: Development and initial feasibility study for evaluation of Life Story Work in Dementia care

**Kate Gridley¹, Jenni Brooks¹, Yvonne Birks¹, Kate
Baxter¹ and Gillian Parker¹**

**Social Policy Research Unit
University of York**

NIHR 2658 - April 2015

1. Corresponding author: Social Policy Research Unit, University of York, Heslington, York YO10 5DD

Tel: 01904 321950; Email: gillian.parker@york.ac.uk

Keywords: People with Dementia, Dementia, Life Story Work, Carers, Feasibility study, Outcomes, Care staff, Systematic Review, Survey, Resource use, Costs

Competing interests: None declared

© Queen's Printer and Controller of HMSO 2016. This work was produced by Gridley *et al.* under the terms of a commissioning contract issued by the Secretary of State for Health. This 'first look' scientific summary may be freely reproduced for the purposes of private research and study and extracts may be included in professional journals provided that suitable acknowledgement is made and the reproduction is not associated with any form of advertising. Applications for commercial reproduction should be addressed to: NIHR Journals Library, National Institute for Health Research, Evaluation, Trials and Studies Coordinating Centre, Alpha House, University of Southampton Science Park, Southampton SO16 7NS, UK.

Important

A 'first look' scientific summary is created from the original author-supplied summary once the normal NIHR Journals Library peer and editorial review processes are complete. The summary has undergone full peer and editorial review as documented at NIHR Journals Library website and may undergo rewrite during the publication process. The order of authors was correct at editorial sign-off stage.

A final version (which has undergone a rigorous copy-edit and proofreading) will publish as part of a fuller account of the research in a forthcoming issue of the Health Services and Delivery Research journal.

Any queries about this 'first look' version of the scientific summary should be addressed to the NIHR Journals Library Editorial Office – nihredit@soton.ac.uk.

The research reported in this 'first look' scientific summary was funded by the HS&DR programme or one of its predecessor programmes (NIHR Service Delivery and Organisation programme, or Health Services Research programme) as project number 11/2000/11. For more information visit <http://www.nets.nihr.ac.uk/projects/hsdr/11200011>.

The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The HS&DR editors have tried to ensure the accuracy of the authors' work and would like to thank the reviewers for their constructive comments however; they do not accept liability for damages or losses arising from material published in this scientific summary.

This 'first look' scientific summary presents independent research funded by the National Institute for Health Research (NIHR). The views and opinions expressed by authors in this publication are those of the authors and do not necessarily reflect those of the NHS, the NIHR, NETSCC, the HS&DR programme or the Department of Health. If there are verbatim quotations included in this publication the views and opinions expressed by the interviewees are those of the interviewees and do not necessarily reflect those of the authors, those of the NHS, the NIHR, NETSCC, the HS&DR programme or the Department of Health.

Scientific summary

Background

Dementia is a growing health problem internationally. When cure is unlikely imminently, providing good quality and cost-effective care, over a long period of need, will remain a major challenge for health and other care providers. Improving quality of care in general hospitals, living well with dementia in care homes, reducing the use of anti-psychotic medication and improving health outcomes through improving care outcomes are priority policy objectives for dementia.

Listening to people with dementia and understanding their rich and varied histories is seen as essential to good care. 'Life story work' (LSW) is used increasingly for this and involves gathering information and artefacts about the person, their history and interests, and producing a picture book or other tangible output – the 'life story' (LS). LSW has been used in health and social care settings for nearly three decades. Since the 1990s, there has been growing interest in its potential to deliver person-centred care for people with dementia.

Despite increased use in the NHS and elsewhere, the outcomes of LSW for people with dementia, family carers, and staff, its costs, and impact on care quality remain unevaluated.

Objectives

The aim of the project was:

☐ to carry out the development and initial feasibility stages of evaluation of a complex intervention – LSW – for people with dementia.

The research questions were:

1. How might LSW improve outcomes for people with dementia, carers, staff and wider health and social care systems?
2. How cost-effective could this be?
3. Is formal evaluation of LSW feasible?

Methods

We used a mixed methods design in two stages to explore the feasibility of formal evaluation of LSW in health and social care settings.

Stage 1a: a systematic review of the existing literature to produce a narrative synthesis of good practice and of theories of change.

Searches were designed to identify any type of study about LSW published in or after 1984.

Algorithms guided selection of publications for relevance and for review by three team members. One team member was responsible for data extraction and analysis but discussed

© Queen's Printer and Controller of HMSO 2016. This work was produced by Gridley *et al.* under the terms of a commissioning contract issued by the Secretary of State for Health. This 'first look' scientific summary may be freely reproduced for the purposes of private research and study and extracts may be included in professional journals provided that suitable acknowledgement is made and the reproduction is not associated with any form of advertising. Applications for commercial reproduction should be addressed to: NIHR Journals Library, National Institute for Health Research, Evaluation, Trials and Studies Coordinating Centre, Alpha House, University of Southampton Science Park, Southampton SO16 7NS, UK.

progress with other team members and the project advisory groups throughout. Narrative synthesis and mind-mapping were the predominant approaches to analysis.

Stage 1b: qualitative focus groups and individual interviews with people with dementia. These elucidated the outcomes people wished to see from LSW and the routes through which they felt those outcomes might be reached. Framework Approach was used to analyse the material.

Stages 2a and b: two national surveys carried out via electronic survey software. One survey was of a representative sample of health and social care settings, and the other was of family carers of people with dementia, drawn from a third sector support organisation for carers. Both surveys drew on findings from stage 1 and discussion with our advisory groups. The national survey of health and social care settings was also used to estimate the spread of LSW.

Analysis was largely descriptive and bivariate.

Stage 2c: feasibility study

We carried out two small feasibility studies to test data gathering processes and instruments. One used a stepped wedge design to introduce LSW in six care homes and the other study used a pre-test post-test design in three NHS assessment units already using LSW and one that did not. In both settings, we also aimed to examine the potential size of outcomes from and costs of using LSW to inform design of a full evaluation.

Measures mapped onto outcomes identified in stage 1 (where these were available) covering:

- quality of life (QoL) for the person with dementia (assessed by themselves, where possible, and by a family carer or other proxy);
- the quality of relationships between people with dementia and family carers (assessed by the person with dementia themselves, where possible, and the carer);
- the experiences of family carers;
- staff attitudes towards dementia care and staff burnout.

We tested different ways of identifying, collecting and measuring relevant resource inputs. We then valued these using local or national unit costs to establish the costs of LSW.

Public and patient involvement

The project was informed throughout by the involvement of people with dementia, family carers and staff working in dementia care. This was done through an advisory group, supported by virtual advisory groups of people with dementia and family carers. These groups met throughout the project and advised on the contents of the survey, the findings of the review and the qualitative work, and the choice of outcome measures for the feasibility study. They also commented on the findings.

Results

Stage 1a and b: We identified 657 studies from our reviews of which 55 were included in the review; 47 were used in the good practice review and 18 in the theories of change review. Twenty-five people with dementia, 21 family carers and 27 professionals and care staff participated in a total of ten focus groups or interviews.

Material from the review and from the qualitative work was used to produce good practice 'learning points' and to elucidate the routes through which LSW was felt to achieve given outcomes. The good practice learning points are an outcome of the project in their own right but also informed questionnaire development for the surveys in stage 2.

The qualitative work identified QoL, both for the person with dementia and family members/carers, and relationships between them, as outcomes.

The review identified outcomes that might eventually lead to improved QoL. These included an increased sense of self-worth for the person with dementia, improved psychological well-being, reduction in behaviour that challenges, and improved 'coping' for the family carer. Improvements in the care environment were also important in the review, reflecting the professional orientation of the publications included. There was sufficient commonality in the outcomes and the hypothesised routes between LSW and achievement of these to inform stage 2.

Stage 2 surveys: Response rates varied across the health and social care settings, from 32% from generic care homes to 70% in NHS specialist assessment units. Overall, we had a return of 58% (307 responses).

LSW has spread relatively widely, particularly in hospital assessment settings although to a lesser extent in care homes.

Services varied widely in the type of LSW they did, its overall objectives (including involvement of the person with dementia), whether it was past or forward looking, and how it was used. These differences probably reflect the different places on the dementia care pathway that services were located.

The day-to-day use of the LS product was not as high as might be hoped for. Doing LSW is one thing; using it to inform and improve care is clearly another.

The service survey emphasised the role of carers in LSW, and the carers' survey confirmed this. Carers reported heavy involvement and, in some cases, had led the LSW. However, while they played an important part in services' LSW, carers were unlikely to be offered training to do it. Again, the reported actual use of the LS by care staff, and even by the person with dementia and carers, was lower than might be expected.

Stage 2: feasibility study process

© Queen's Printer and Controller of HMSO 2016. This work was produced by Gridley *et al.* under the terms of a commissioning contract issued by the Secretary of State for Health. This 'first look' scientific summary may be freely reproduced for the purposes of private research and study and extracts may be included in professional journals provided that suitable acknowledgement is made and the reproduction is not associated with any form of advertising. Applications for commercial reproduction should be addressed to: NIHR Journals Library, National Institute for Health Research, Evaluation, Trials and Studies Coordinating Centre, Alpha House, University of Southampton Science Park, Southampton SO16 7NS, UK.

Recruitment and retention was challenging, being most difficult for people with dementia in the NHS assessment settings, and most difficult for staff in care homes. Recruitment and retention of family carers was somewhat more successful. Staff turnover, differing priorities and continuity of management in the care settings all influenced the success of recruitment of people with dementia, over and above any issues of their capacity to consent. Fifty-one staff, 39 people with dementia, and 31 carers were recruited in care homes. Twelve people with dementia, 10 carers and varying numbers of staff participated in the NHS settings.

Stage 2: feasibility study outcomes

Even after successful recruitment, gathering data was difficult. Completion rates for outcome measures were best overall for family carers in care homes (up to 61% at final follow-up) and worst for people with dementia in hospital wards (none at final follow-up). Completion of measures by staff in care homes was disappointing, given the commitment of the care home provider to the study.

However, there was useful learning for future research. We observed fatigue effects in completion of outcome measures over time, the competing demands of the routines in care settings, and the inability of conventional outcome measures to capture 'in the moment' benefits for people with dementia. The measures also missed how LSW was used, in particular for de-escalation of behaviour that challenges in hospital settings.

We observed some change in our outcome measures from baseline to follow-up and these were significant for staff attitudes towards dementia in care homes, for self-reported quality of life (DEMQOL) between baseline and final follow-up for twelve people with dementia in care homes who were able to complete the measure, and for the experiences of carers.

The first change may be an effect of LSW, as we saw evidence of it in both measures of staff attitudes. Whether the change was due to the training associated with implementing LSW or to LSW itself is not clear.

The people with dementia able to complete DEMQOL may have been less cognitively impaired than others in the study, meaning that we cannot extrapolate this finding to everyone.

Carers' experience scores in the care homes worsened but improved in the hospital setting. We are not sure that LSW caused either effect. People with dementia in the care homes were often approaching the end of their lives, while for carers of people in hospital the person with dementia had often been admitted in a crisis but during their stay was stabilised, assessed and had their future care planned (in some cases meaning admission to long-term-care).

Stage 2: collecting resource use data

Collection of resource use data in all settings was time-consuming and complicated. In all cases, data collection was better when assisted by the presence of a researcher.

© Queen's Printer and Controller of HMSO 2016. This work was produced by Gridley *et al.* under the terms of a commissioning contract issued by the Secretary of State for Health. This 'first look' scientific summary may be freely reproduced for the purposes of private research and study and extracts may be included in professional journals provided that suitable acknowledgement is made and the reproduction is not associated with any form of advertising. Applications for commercial reproduction should be addressed to: NIHR Journals Library, National Institute for Health Research, Evaluation, Trials and Studies Coordinating Centre, Alpha House, University of Southampton Science Park, Southampton SO16 7NS, UK.

Stage 2: resource use outcomes

The cost of delivering the LSW training in care homes ranged from £950 to £1581 and the average cost of creating and using LSW products for a resident in the care homes was £37.42 spread over 16 weeks. If all costs were additional, resource implications would be relatively small at an individual resident level but could be substantial if extrapolated to all residents.

LSW was a part of routine care in the hospital intervention wards, so there were no initial training costs. The average cost of creating and using LSW products was £68.21 per patient over three weeks. The more intensive activity may be due to staff attempting to complete LS products before patients are discharged, or to staff having dedicated time for this activity.

The most frequently used services in care homes were visits to the care home by the GP and the district nurse. Care home staff accompanied residents to these consultations on at least 25 per cent of occasions, which potentially adds to overall costs. Visits by the GP showed some reduction at follow-up compared to baseline, but visits by the district nurse did not.

The resources with the highest monetary values per use were an inpatient stay on a general medical ward; an A&E attendance by ambulance; an outpatient appointment; and a GP visit to a care home. Because of their relatively high cost, these events are more likely to affect total costs than other types of input. Over a larger number of residents in a full evaluation, differences in the costs of this type of activity might be substantial.

Care home use of prescribed medication for anxiety and depression by participants was low. Only two homes provided home-wide data on anti-psychotic prescribing. In one, prescribing was low; in the other (the specialist dementia care home) 12 residents were prescribed antipsychotics, all but one on a continuous basis. Overall, however, for study participants in care homes, the use of anti-psychotic or other drugs was not a big driver of costs. The small numbers of participants in the hospital settings make it impossible to judge from individual patient data how extensively antipsychotic drugs were used. Ward level data suggest antipsychotic prescribing cost up to £1,350 per ward over six months.

Although never intended to be robust enough to demonstrate change, this feasibility work does suggest a possible reduction in service use and adverse events and indicated the main drivers of costs.

Stage 2: participants' experiences of LSW as part of the research project

Carers in particular were unsure of the benefits of LSW, particularly where the dementia had progressed, which sometimes led to reluctance to get involved, feeling LSW would have no effect. People with dementia in the study enjoyed looking at their LS books, and staff were more certain of a positive effect, particularly in facilitating interactions and encouraging staff to get to know the person.

Staff were positive about collecting LS information but with some scepticism about the need for a physical LS product, particularly as these were considered time consuming to make. LSW was easier when one person or small team took responsibility for it; where this had been implemented in sites, all staff members were encouraged to collect information, but did not have responsibility for making a product.

While some aspects of LSW can be beneficial for people with dementia, it is unclear whether this is attributable to the presence of a physical LS product, or the act of spending time with someone, learning about their life. This may occur without LSW, but LSW can be a mechanism for this learning, and a physical LS product may facilitate interactions and enhance relationships with family members and staff.

Conclusions

Implications for health care

Stage 1 of our work was based on in-depth qualitative research and a systematic review of the literature. This found consistent messages about good practice in doing LSW. The survey of health and social care services showed that not all services follow these practices. We have drawn together good practice learning points and will disseminate these widely to health and social care audiences.

Stage 2 was intentionally exploratory. While we did observe effects in this stage of the work, particularly in relation to staff attitudes in care homes, it is clearly not right at this stage to draw out implications for health and social care providers.

Recommendations for research

Our work means that we now have a clear idea of the challenges and benefits of attempting to establish evaluation of this complex intervention in care settings that are themselves complex and often complicated. In order of priority, there is a need for:

1. Formal evaluation of LSW as a method of changing staff attitudes about dementia, and particularly in care homes. This should compare LSW against more general training input about dementia.
2. Qualitative research that explores the motivation and 'emotional intelligence' of care staff, recognising that delivering person-centred care for people with dementia requires particular qualities of both.
3. Methodological development in assessing quality of life (QoL) for people with dementia 'in the moment'.

Word count 2480