

The best laid plans...

Implementing life story work with people with dementia in care homes

Kate Gridley, University of York, Social Policy Research Unit

kate.gridley@york.ac.uk

Acknowledgements and disclaimer

This event presents findings from research funded by the National Institute for Health Research Health Services and Delivery Research Programme.

The views and opinions expressed are those of the research team and do not necessarily reflect those of the HS&DR Programme, NIHR, NHS or the Department of Health.

Overview

- o Background
- o The life story work study
- o The plan
- o The reality
- o Links to Normalization Process Theory (NPT)



Background

- o Dementia strategy (DH, 2011) and Prime Minister's Challenge on Dementia 2020 (DH, 2015)
 - o Policy to increase research
 - o with people with dementia
 - o in care homes
- o Still a long way to go (NIHR 2017; DH 2019)

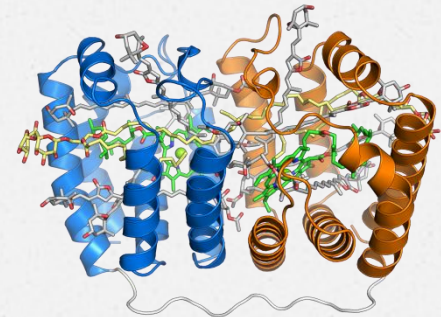
Research in care homes - a messy business

SSCR review (Luff et al. 2011) showed care homes research is complex. Progress can be influenced by:

- o Cognitive and physical frailty
- o Staffing pressures
- o The unique environments of care homes, which are both:
 - o homes
 - o workplaces

I would add:

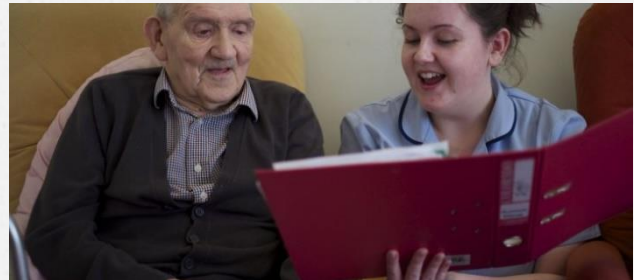
- o Management/leadership (continuity/style)
- o Divergent priorities (research vs care)



NIHR funded feasibility study into life story work

- o Life story work – a process and a product
- o Multiple study elements (Gridley et al. 2016):
 - o Qualitative exploration of experiences and good practice
 - o Literature review
 - o National survey of services and carers
 - o Feasibility study in care homes and hospital wards

Today's focus:
care homes feasibility study



Full disclosure...

‘...scientists divorce product from messy process for the sake of a clean performance’

(Mountz et al. 2003, p 31)

The plan

- Six care homes to implement life story work (all run by the same provider)

Commitment:



- The provider was partnered with the project and committed to implementing life story work across all sites
- Homes were only approached if they were keen to be early implementers
- Managers met with the research team in advance to agree plans



The plan



Life story work training:

- Informed by literature review and focus groups
- Devised and delivered (on site) by a single dementia specialist employed by the provider (reimbursed by the study)
- Offered to all staff (from cooks to managers)

Collect process and outcomes data for 6 months:

- From 10 randomly selected residents and carers
- From all consenting staff who undertook training

The reality

Lack of continuity:

- 2 sites withdrew (and were replaced) before the study started
- A further 2 had a change in management before the study started and further changes during the study
- **These new managers inherited the decision to take part...**

Implications of lack of ownership

Both care homes with new management seemed:

- o Less interested in the intervention
 - o Confusion over whose responsibility it was to implement (i.e. “I don’t know anything about it” or “I’ve done some life story work *for you*”)
- o Less engaged in the research
 - o Difficult to arrange fieldwork visits
 - o And things didn’t always go smoothly when we did visit....



Extract from field notes:

'Popped up to see business manager who didn't recognise me (and didn't seem to be expecting me), and who also said she didn't know about any life story work, but the care manager [who was currently off site] would . . . She said the staff would know if they'd done any life story work.'

(Gridley et al. 2016, p 67)

TABLE 44 Approach to LSW implementation and organisational context

Care home ID	PWD	Numbers of study participants who actually 'did' LSW	Staff undertaking LSW	Approach to LSW	Organisational context
CH1	8	8 (100%)	Activities co-ordinator (some info collected by care staff)	Tailored to the individual	Consistent management, activities co-ordinator allocated dedicated time
CH2	7	2 (29%)	Staff who undertook training were allocated to work with named residents	'Some important things' template	Two changes in management, activities co-ordinator did not receive training
CH3	8	4 (50%)	Single member of staff undertook all LSW	Tailored to the individual	Consistent management, but activities co-ordinator left early on
CH4	6	3 (50%)	Activities co-ordinator	Tailored to the individual	Consistent management
CH5	5	1 (20%)	Staff who undertook training were allocated to work with named residents	Tailored to individual, done by volunteer	Two changes in management, activities co-ordinator did not receive training, staff suffering project fatigue
CH6	5	5 (100%)	Activities co-ordinator (some information collected by care staff)	Tailored to the individual, group activities	Consistent management, activities co-ordinator and care staff allocated dedicated time. SCH

CH, care home; ID, identification.

Permission to engage?

Engagement was highest where managers demonstrated to staff that spending time on the study was a legitimate part of their work:

‘Did staff baseline [questionnaires] in the morning starting with the manager, who sat with us in the communal area so other staff could see it was part of the working day and not something that had to be done in their own time’

Field notes from Care Home 3 (Brooks et al. 2019)

Shared responsibility





Sites that did well combined:

- A shared responsibility among staff to collect information
- A designated worker who had dedicated time to compile and present information

'Spoke to manager on [date] who said that staff are feeling a bit overwhelmed and as a result are struggling to get going with life story work (they have lots of good ideas but are struggling/or don't have the confidence to put these into action). Has decided to backfill the activities coordinator for two full days to support the other staff to get going with life story work. The activities coordinator is experienced in this sort of work.'

Extract from field notes (Gridley et al. 2016, p 67)

TABLE 44 Approach to LSW implementation and organisational context

Care home ID	PWD	Numbers of study participants who actually 'did' LSW	Staff undertaking LSW	Approach to LSW	Organisational context
CH1	8	8 (100%) 	 Activities co-ordinator (some info collected by care staff)	Tailored to the individual	Consistent management, activities co-ordinator allocated dedicated time
CH2	7	2 (29%)	Staff who undertook training were allocated to work with named residents	'Some important things' template	Two changes in management, activities co-ordinator did not receive training
CH3	8	4 (50%)	Single member of staff undertook all LSW	Tailored to the individual	Consistent management, but activities co-ordinator left early on
CH4	6	3 (50%)	Activities co-ordinator	Tailored to the individual	Consistent management
CH5	5	1 (20%)	Staff who undertook training were allocated to work with named residents	Tailored to individual, done by volunteer	Two changes in management, activities co-ordinator did not receive training, staff suffering project fatigue
CH6	5	5 (100%) 	 Activities co-ordinator (some information collected by care staff)	Tailored to the individual, group activities	Consistent management, activities co-ordinator and care staff allocated dedicated time. SCH

CH, care home; ID, identification.

Properly resourced?

'It's great [care home provider] get involved in these kind of studies but I do think that they need to offer support to the staff. If we're going to be doing this study as we'd wanted to do it, and as we should, there should have been staffing arrangements made to free up time for people to do it properly'

Member of care staff, Care Home 1 (Brooks et al. 2019)

Links to NPT

Coherence

- **Internalization:** Managers who inherited the study did not value/see the benefit of the intervention or the activities required to evaluate its effectiveness
- **Differentiation:** Some staff and managers felt they were 'already doing' life story work because they included biographical info in resident files

Links to NPT

Cognitive participation

- **Legitimation:** Where managers led by example staff felt they had permission to follow
- **Activation:** After the initial training, staff faltered. Where things went best, key individuals took a lead and supported others to understand and implement their roles

Links to NPT

Collective Action

- o **Skill set workability:** In theory it was everyone's job to integrate LSW into their working lives, but in practice this requires people to understand their unique contribution and how these can combine
- o **Contextual integration:** Even in sites with high buy in from staff and managers the lack of dedicated resources (time, money) impeded implementation

In summary

- o Real world implementation
- o Management/leadership context influenced:
 - o Coherence
 - o Cognitive participation
- o Everyone's responsibility is no-one's responsibility
- o Adequate resources
- o Thanks NPT!

References

- o Brooks, J., Gridley, K., & Parker, G. (2019). **Doing research in care homes: the experiences of researchers and participants**. *Social research practice*, 8(Autumn), 19-27.
- o Department of Health (2011) **Living Well With Dementia: A national dementia strategy**
- o Department of Health and Social Care (2015) Prime Minister's challenge on dementia 2020.
- o Department of Health and Social Care. (2019) **Dementia 2020 Challenge: 2018 Review Phase 1**.
- o Gridley K, Brooks J, Birks Y, Baxter K, Parker G. (2016) **Improving care for people with dementia: development and initial feasibility study for evaluation of life story work in dementia care**. *Health Services Delivery Research* 4(23)
- o Luff, R., Ferreira, Z., & Meyer, J. (2011). **NIHR SSCR Methods Review 8: Care Homes**. <http://eprints.lse.ac.uk/41191/>
- o Mountz, A., Miyares, I. M., Wright, R., & Bailey, A. J. (2003). **Methodologically becoming: power, knowledge and team research**. *Gender, Place and Culture: A Journal of Feminist Geography*, 10(1), 29-46.
- o Murray, E., Treweek, S., Pope, C. et al. **Normalisation process theory: a framework for developing, evaluating and implementing complex interventions**. *BMC Med* 8, 63 (2010).
- o National Institute for Health Research. (2017). **Advancing care: Research with care homes**. NIHR Dissemination Centre Themed Review
- o NPT Toolkit <http://www.normalizationprocess.org/what-is-npt/>

Questions?

For more information contact:

Kate Gridley, SPRU, University of York

kate.gridley@york.ac.uk