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Using a systematic review to uncover theory and outcomes for a complex intervention in health and social care: Life Story Work for people with dementia as a worked example

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Using a systematic review to uncover theory and outcomes for a complex intervention in health and social care: Life Story Work for people with dementia as a worked example

Objectives: To use a systematic review to uncover theories of change and outcomes for Life Story Work (LSW) in dementia care to inform a feasibility study. We describe the methods used and discuss their use in identifying appropriate outcomes for evaluative research, and their potential for improving evaluation of ‘theory poor’ interventions.

Life Story Work (LSW) involves gathering information about a person, their history and interests and producing a tangible output, usually a book. It is used increasingly in dementia care; however, underlying theory about if, how and why it affects which outcomes is poorly developed, making the choice of evaluation methods and appropriate outcomes difficult.

Methods

A systematic review, carried out using Centre for Reviews and Dissemination guidelines, searched for evidence on underlying theory, good practice, and effectiveness of LSW to inform a feasibility study. For the theory element, a ‘landscaping review’ analysed the extracted text, ~~was analysed~~ using qualitative techniques and mind maps to uncover both explicit and implicit links (causal links/routes) between LSW and outcomes. We triangulated review findings with qualitative work-research (focus groups) with people with dementia, caregivers, and professionals that explored the outcomes that they would like to see from LSW.

Results

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3 Of the 56 publications reviewed, only 16 were useful for the theory analysis. Six overarching
4
5 outcomes were identified: the self-worth and empowerment of people with dementia;
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7 individual psychological outcomes; improved relationships between care staff and the
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9 individual with dementia; better care; more effective engagement of family members/carers
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11 within the care setting; and helping carers to cope. Twelve final theories linking these
12
13 outcomes to LSW via a causal pathway were elicited. There was substantial overlap in the
14
15 outcomes identified by the review and ~~the interviews with~~by carers, people with dementia
16
17 and professionals. Together, the results informed our choice of outcome measures for a pilot
18
19 evaluation.
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25 Conclusions

26 This approach may enable researchers to identify and develop the theory necessary before
27
28 evaluation of a complex intervention in other under- or un- theorised areas. It has the
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30 potential both to shorten development stages (and thereby costs) in intervention research and ;
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32 with the potential to improve the intervention itself.
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Introduction

The evidence for complex interventions in health and social care, particularly those that cross the health and social care boundary, is often weak. For example, despite systematic reviews of large literatures, the recent ~~draft~~ English guideline for people living with dementia and their carers was able to develop only one ‘do’ recommendation for interventions to promote cognition, independence and well-being.¹ Similarly, a recent meta-review of interventions to support carers of people with a range of conditions pointed to ‘the dearth of good-quality primary research about the effectiveness of most support interventions for carers’ (p.77).²

Two major issues underlie this weakness.

First, there is ~~a the simple~~ lack of evaluative research, particularly in social care where the literature largely comprises descriptions of the intervention, accounts of its use in practice settings and, occasionally, some measure of outcome after implementation but none before.

Secondly, even where evaluation exists, it is often undermined by the absence of any theoretical underpinning that links the outcomes reported with the intervention being evaluated (pp.77-8).² As a result, evaluation searches for improved outcomes without any pre-existing theory about why and how we might *expect* the particular intervention to affect the given outcome.^{2 3} Evaluation then proceeds with chosen outcomes that might have little likelihood of being affected by the intervention. This pattern is becoming less common with the adoption of MRC guidelines for ~~the evaluation~~ evaluating of complex interventions^{3,4} but systematic reviews of such interventions are likely to remain hampered by the lack of clear, theory-driven evidence for some years to come.

1
2
3 Both these issues may reflect historic underfunding of research in such areas, where both
4 policy and practice can encourage a ‘rush to evaluation’ (and, indeed, a ‘rush to
5 implementation’) of intuitively attractive interventions before the preliminary work to
6 underpin both their development and testing has been done.^{2, 5}

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12 This was the situation we found when embarking on a feasibility study for formal evaluation
13 of life story work (LSW) in dementia care.⁶

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18 LSW gathers information and artefacts about people, their history and interests, and produces
19 a picture book or other tangible output – the ‘life story’.⁷ It has been used in health and social
20 care settings for nearly three decades, with children⁸, people with learning disabilities,⁹ and
21 older people.¹⁰ Understanding the rich and varied histories of people with dementia is seen as
22 essential to good care.¹¹ Since the 1990s there has been growing interest in LSW as a way of
23 achieving this understanding to deliver person-centred care.¹² It is now used in dementia care
24 across the world.

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34 LSW is distinct from reminiscence and ‘biographical work’,¹³ because it emphasises using
35 the life story in day-to-day care and is oriented to the future. ~~Life stories, as The~~ tangible
36 products, are owned and held by people with dementia and can travel with them to other
37 settings, for example into acute medical care or from home to long-term care. LSW is thus
38 also different from the simple logging of life history details in care records.

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46
47 LSW has key features ~~that justify its description as of~~ a complex intervention, as defined by
48 MRC Guidance.⁴ It can involve large numbers of and interactions between its components,
49 significant numbers and difficulty of behaviours for those who deliver and receive it, ~~targets~~
50 ~~for the need for~~ change at more than one organisational level, numerous and variable
51 outcomes, and flexible and tailored delivery.

1
2
3 Embarking on our study, LSW seemed an archetypal example of an under-theorised and
4
5 under-evaluated intervention that was nonetheless popular in care delivery. There was
6
7 enthusiasm for it, practitioners felt that they observed change when ~~they used~~using it, but it
8
9 was difficult to pin down any theory about why these changes might ~~come about~~occur. ~~For In~~
10
11 ~~evaluating evaluative work on LSW (as for many other interventions in health and social~~
12
13 ~~care), there was thus a danger that evaluation might choose the wrong outcomes – both~~
14
15 intermediate and final ~~– might be to~~assessed. Research might then fail to demonstrate
16
17 change, when ~~re~~ ~~change it~~ was ~~actually~~ taking place, or demonstrate change that had little to
18
19 do with the intervention's underlying aims.
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24
25 The first stage of our work included a systematic review of the ~~existing~~ literature. While we
26
27 did not exclude the possibility of finding ~~some~~ evidence of the effectiveness or costs of LSW,
28
29 the developmental and feasibility-testing nature of the project meant that it was more
30
31 important to identify different approaches to LSW, and to elucidate ~~its theories of change~~ ~~its~~
32
33 ~~theoretical model(s)~~. This would then help to identify ~~intermediate~~ processes that might be
34
35 important in implementation, and outcome measures that could be sensitive to the
36
37 intervention in full-scale evaluation. The complete review, covering all its objectives, is
38
39 described elsewhere;⁶ here we present a ~~reflex~~etive account of using qualitative analysis of
40
41 published texts ~~to~~ identify underlying theoretical models ~~for LSW~~.
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47 The processes and challenges of using systematic review methods for identifying and
48
49 synthesising theory in areas that are already well-theorised but ~~usually~~ contested, and for
50
51 developing a theoretical model to help with the design of a review, have already been written
52
53 about¹⁴⁻¹⁶. In areas already well served by evidence across the causal chain between
54
55 intervention and outcomes, ~~theoretical models for~~ ~~programme theories of~~ interventions,
56
57 ~~elements of care delivery~~processes and outcomes, have been developed using ~~existing~~
58
59 literature, stakeholder interviews, previous research and experience (p.9).^{17, 18, 19} By contrast,
60

1
2
3 we are writing here about ~~the processes, challenges and benefits of~~ using a systematic review
4
5
6 to uncover intervention theory when both theory *and* evidence are scarce, in order to choose
7
8 appropriate outcomes for primary research. As such, this is a ‘theory-landscaping’ review,
9
10 that identifies the outcomes of an intervention and the implied explanations of the links
11
12 between intervention and outcomes.²⁰

15 We defined theory for this part of our work more widely than ~~‘realistic’~~ or ‘realist’
16
17 approaches might recommend or that others conducting systematic reviews of theory have
18
19 done. Thus, while we hoped to find writing that described context, mechanism and outcome
20
21 ^{21, 22} or that allowed description of ‘a-causal association’ connecting LSW to an outcome
22
23 ‘through a specific pathway or mechanism’ (p.5),¹⁶ we examined *any* literature that argued
24
25 ‘any kind of outcome from LSW.’

29 Our project also included ~~qualitative work~~ focus groups with people with dementia (facilitated
30
31 by *Innovations in Dementia*), informal carers and LSW professionals. This explored both
32
33 what people thought would be ‘good practice’ in LSW²³ and what outcomes might be
34
35 expected ~~to emerge~~ from doing it well. Having both elements in the project presented an
36
37 opportunity to compare different methods for identifying relevant outcomes for evaluation.⁶
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44 **Methods**

46 We followed CRD guidance²⁴ for the conduct of systematic reviews, intending to use a
47
48 narrative synthesis²⁵ of the extracted material, and a ‘realist’-informed approach.^{21, 22}

51 All elements were carried out between August 2012 and May 2014 and a full description of
52
53 methods and findings is available.⁶ Here we give brief details of the whole review for
54
55 context, while concentrating in detail on the theory element where the main research question
56
57 was:
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59
60

- What underlying logic models or theories of change for LSW are articulated in the literature?

Search strategy

An information specialist (WW) carried out the searches, using electronic searching of a range of databases covering the fields of health, mental health, nursing and social care. Search strategies focussed on the retrieval of published studies and 'grey literature' where interventions were described explicitly as life story/life history/life review or life narrative within the title/abstract. The complete search strategies are included in the final report⁶ and an example is [at 1 in the on-line supplementary reporting material](#). The searches were carried out in August and September 2012, were not limited by date, but were limited to English language results.

The results were loaded into EndNote bibliographic software and de-duplicated using several algorithms.

The reference lists of all articles included for review were searched for relevant additional studies.

Inclusion and exclusion criteria

We developed inclusion and exclusion criteria based on the literature and in consultation with the project steering group and our project advisers, and finalised them through an iterative process during the early stages of searching (table 1).

Selection of studies for relevance

1
2
3 We selected material first using titles and abstracts (where available) to assess relevance.
4
5 Two researchers (XX and YY) worked individually and then in pairs to reach agreement
6
7 about relevant studies. We then obtained full copies of the studies selected for relevance and
8
9 read them before making a final decision about inclusion for review. Three members of the
10
11 team (XX, YY, ZZ) worked individually and then in pairs to reach agreement about relevant
12
13 studies. Where we could not reach agreement in pairs, the third member of the team
14
15 arbitrated.
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19

20 For the theory element, we were interested in any links that authors made - either explicitly or
21
22 implicitly - between doing LSW and outcomes (whether for people with dementia, family
23
24 members/carers or care staff). We originally included publications that argued *any* connection
25
26 between LSW and *any* outcome, whether or not they also described intermediate causal links.
27
28 were also described. At the final stage, we further excluded two papers that did not articulate
29
30 any type of causal link between LSW and the outcome.
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37 **Quality assessment**

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39 Given the limited evaluative literature on LSW, and the nature of our research questions, we
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41 did not include or exclude papers based on their methodological quality.
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47 **Data extraction**

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49 Data extraction focussed on outcomes reported as arising, actually or potentially, from LSW,
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51 for whom these outcomes arose, explicit or implicit assumptions about causation, and any
52
53 data on changes in outcomes. We also extracted details about the type of LSW described,
54
55 participants, the care setting, study design and any data or discussion related to good practice
56
57 in LSW.
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1
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3 For the theory element of the review, the unique data extraction headings were:
4
5

- 6 • model of LSW
- 7
- 8 • argued links between LSW and outcomes
- 9
- 10 • types of primary (final) outcomes argued or demonstrated
- 11
- 12 • types of intermediate or process outcomes (causal links) argued or demonstrated
- 13
- 14 • contextual influences and factors that might affect outcomes.
- 15
- 16
- 17

18 All data extraction for the theory part of the review was carried out by one researcher (YY)
19 and progress and initial findings shared and discussed with team members and the project
20 steering group.
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28 **Data analysis and synthesis**

29 *Identifying underlying logic models*

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31 All findings for the theory review were analysed qualitatively and, where possible, meta-
32 synthesised, which involved aggregating conclusions from the reviewed publications to
33 generate a set of statements that represented that aggregation, with the aim of producing a
34 single comprehensive set of synthesised findings.
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44 Clear accounts of underlying theory about LSW's impact on outcomes were not common.
45 However, implicit arguments within text were analysed qualitatively to expose implicit
46 theory. The worked example (table 2) shows how we did this from theoretical models deeply
47 embedded in descriptive or discursive text, rather than articulated explicitly.
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52 We used this process to identify all causal links between LSW and the outcome or outcomes
53 that the authors were arguing. In some papers, there was a single such theory; in others there
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1
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3 were several. We summarised these theories into an Excel spreadsheet using the data
4 headings outlined earlier, and then mapped them all in a mind map.²⁶
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6

7
8 We looked both for theories articulated in the introductory sections of each paper (initial
9 theories) and again for those articulated in the discussion and concluding sections
10 (concluding theories). In both cases, we concentrated on theories that the authors themselves
11 were arguing, not ones that they were repeating or reviewing from others' publications. (See
12 2 in the supplementary material for the map of the concluding theories. ~~This is displayed~~
13 ~~to~~ Only two levels of the map are shown level two only, given the complexity of the diagram).
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22 We synthesised the material from the mind maps, and identified a set of overarching
23 outcomes. ~~Given that most~~ Most of the papers in this part of the review included some
24 empirical work (even if only a description of the use of LSW). ~~We therefore, we took the~~
25 used concluding theories as the basis for this final stage of analysis, assuming that these
26 would be a more accurate reflection of the authors' views about LSW, its outcomes and its
27 causal pathways.
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40 Results

41 Numbers of papers identified

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43 The PRISMA diagram (figure 1) shows the process through which ~~the~~ 657 identified studies
44 were reduced to a final selection of 56 papers for the whole review and 18 for the theory
45 work. Two theory papers were subsequently removed (see p.8). ~~We also identified six~~ Two
46 existing systematic reviews or meta-analyses were included in the wider review, but none of
47 these was used for the theory work ~~neither synthesized programme theory relating to LSW~~
48 processes and outcomes. Publication details for the whole review are in the final report.⁶
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59 Table 3 shows ~~D~~ details of the 16 studies ~~that were~~ included in the theory work ~~are in table 3~~.
60

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3 As figure 1 suggests, ~~little of the identified literature~~ few studies presented any explicit or
4
5 even implicit explanation of why LSW might lead to better outcomes for people with
6
7 dementia, their carers or care staff.
8
9

10 11 12 13 **Theories for LSW**

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15
16 The mind mapping generated complex ~~and complicated~~ pictures of both initial and
17
18 concluding theory. The included papers outlined 26 initial, but 47 concluding theories.
19

20
21 Some theories were relatively simple, with only one intermediate outcome or mechanism
22
23 between LSW and a final outcome. So, for example, concluding theory 3 (~~see~~ appendix 1,
24
25 boxes 1 and 2 in the final report⁶) was that LSW leads to interactions between care staff and
26
27 family members (*causal link*), thus strengthening understanding of, and the relationship with,
28
29 family members (*outcome*).
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31

32
33 Others theories were much more complex, and sometimes argued two separate final
34
35 outcomes from the same causal chain. For example, concluding theory 24 (final outcomes in
36
37 bold) was:
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41 **24: LSW enables staff to gain a fuller and more dynamic picture of person with dementia**
42
43 which

44
45 24.1: increases their knowledge of the person (*causal link*), which

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47
48 **24.1.1: enables them to find out more about a person's needs and**
49
50 **behaviour (*outcome*);**

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52
53 **24.1.2: helps staff see the person in context of their whole life rather than**
54
55 **in terms of their medical condition/physical needs (*outcome*);**

56
57
58 24.1.3: provides a talking point between staff and the person with dementia
59
60

(*causal link*), which

24.1.3.1: helps develop a common bond between the person with dementia and staff (*outcome*)

Here we see an intermediate outcome (24.1) that led to two final (24.1.1 and 24.1.2) and one further intermediate outcome (24.1.3), which led itself to a further final outcome (24.1.3.1).

Despite the complexity, overarching or common final outcomes were evident. ~~In the~~The next stage of analysis ~~we~~-identified these and synthesised the causal links that the literature suggested led to them. Here we included only outcomes that at least four papers identified as resulting from LSW. This was an entirely pragmatic decision; with only 16 publications to draw on, setting a criterion of around a quarter that argued a similar chain between intervention and outcome offered at least some possibility of a secure security-of message from the analysis.

Then, within each outcome, we included only theories where at least two studies had argued that the same or similar causal links led to these outcomes. Again, this was a pragmatic decision.

In total, we identified six overarching outcomes and 12 theories, derived from 16 different papers.

The overarching final outcomes (in bold) for the person with dementia were:

1. **LSW supports the self-worth and empowerment of people with dementia**, for example by increasing a sense of control, pride in their lives and opportunity for reciprocity.²⁷⁻²⁹
2. **LSW affects a range of psychological individual outcomes positively, for example reducing anxiety, depression, agitation, mood and behaviour.** ^{13 30 27 31 32 33, 34 35 28, 36}

Final outcomes in relation to the care setting were:

1. **LSW improves relationships between care staff and the individual person with dementia.**^{10, 30, 35, 37}

2. **LSW leads to better care**, for example encouraging more person-centred, individualised, less ‘pathological’ care on a one-to-one basis.^{13 29 30 38 27 34, 35, 37, 39}

For family members and carers, the final outcomes were:

1. **LSW allows more effective engagement of family members/carers within the care setting**, for example leading to enhanced communication with staff and more meaningful involvement in care planning and delivery.^{10, 13 38 28, 37}

2. **LSW helps carers to cope better.**^{38, 40 28 31, 33}

The models and their links to the overarching outcomes are summarised in figures 2 to 7.

Synthesising the logic model review and material from the qualitative work

We shared the results of both the review and the **focus groups** ~~qualitative work~~ with our steering and advisory groups, the partner organisations hosting the feasibility study, and with specialist advisor Professor Esme Moniz-Cook, lead author of the INTERDEM European consensus document on outcome measures for psychosocial intervention research in dementia care⁴¹. There was general agreement in discussion that the primary overall outcome of interest for people with dementia was quality of life (QoL), albeit that this might be influenced by intermediate outcomes such as the maintenance of skills or feeling understood. Interpersonal outcomes might also influence quality of life; impact on relationships, in particular, was felt to be worth exploring as an outcome in its own right, along with impact on identity.

1
2
3 QoL was also agreed to be a primary outcome for carers, with impact on relationships and
4
5 satisfaction with care ~~also~~-important.
6
7

8 Staff approaches to care, ~~both in terms of person-centred care and perceptions~~in terms of both
9
10 person-centred care and perceptions of service users with dementia, might also have an
11
12 impact on QoL, whether through individual outcomes or changes to care routines. We also
13
14 hypothesised that improvements to care might influence staff burnout.
15
16
17

18 Table 4 presents the outcomes we agreed to include in the feasibility study. As this suggests,
19
20 this choice took some of the final outcomes from the review to a further stage of abstraction.
21

22 For example, for people with dementia, increased self-worth and reduced ‘negative’
23
24 psychological and behavioural outcomes were translated into ‘quality of life’. Similarly,
25
26 enhanced coping for carers was subsumed into a general assessment of quality of life.
27
28

29 In other cases, intermediate outcomes in the theories from the review – for example,
30
31 perceptions of clients with dementia, and person-centred approaches to care that might lead to
32
33 ‘better care’ for the person with dementia – were adopted as final *staff* outcomes for the
34
35 feasibility work.
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39 One outcome from the review that did not feature in the chosen outcomes was engagement
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41 with family members/carers in the care setting. Conversely, an outcome from the qualitative
42
43 research work that did not feature in its own right in the theory review was an enhanced sense
44
45 of identity for the person with dementia.
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52 Discussion

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55 A possible problem of searching for theoretical papers within the results of an existing
56
57 systematic review is, as Campbell et al have argued, that the inclusion and exclusion criteria
58
59 may exclude publications that ‘provide detailed theoretical discussions without presenting
60

1
2
3 empirical data' p.6.¹⁶ Our wide approach to searching, by including anything that might
4
5 throw light onto the theoretical underpinnings of LSW, avoided this issue. Despite this, only
6
7
8 168 publications were finally relevant to the theory element.
9

10 A further limitation, given the small literature, is the lower likelihood of finding contrasting
11
12 theoretical accounts. The LSW in dementia field has a relatively small number of actors, with
13
14 much joint authorship, and the publications showed a high degree of cross-referencing. While
15
16 we confined our analysis to authors' own argued or implicit theories, not those they were
17
18 repeating from others' work, shared theoretical commonality across authors is still possible.
19

20
21 The type of review described here, derived from an under-developed literature will,
22
23 inevitably, depend on reviewers' own formulation and characterisation of 'theory' from what
24
25 others have written. Given the lack of explicit theory in the papers, the dangers of over-
26
27 interpreting the text are obvious. However, we have provided a worked example of our
28
29 analysis, and our data extraction tables are freely available, as are the mind maps that drove
30
31 the final synthesis, thus allowing others to judge whether our conclusions are warranted.
32
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35

36
37 Triangulation of findings from the review and the qualitative research showed a high degree
38
39 of commonality in the outcomes identified that the review and the qualitative work identified,
40
41 albeit with some variation in whether they were defined as identified as final or intermediate
42
43 outcomes. The review identified one outcome absent from the qualitative work, related to
44
45 involving family members or carers in care settings. This probably reflects the number of
46
47 publications in the theory review that were about LSW in long-term care settings. Similarly,
48
49 the qualitative work identified one outcome – enhancing personal identity for the person with
50
51 dementia - that did not feature in its own right in the review. However, the intermediate
52
53 outcomes of self-affirmation and pride and of an increased sense of control or power for the
54
55 person with dementia that the review *did* identify might imply an enhanced sense of identity.
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1
2
3 ~~In areas of~~When health and social care ~~that~~ interventions are both under-theorised and under-
4
5 researched, but already widely used, our approach may offer a more rapid way of identifying
6
7 appropriate outcomes for evaluation. A theory review may not be able completely to replace
8
9 the need for qualitative work with stakeholders. However, if our ~~theory~~ review had happened
10
11 before, rather than alongside, the qualitative research work perhaps we could ~~, perhaps,~~ have
12
13 had more focussed discussions with participants about the outcomes they thought might arise
14
15 from LSW and the related causal pathways. Achieving saturation of the qualitative material
16
17 might then have been more rapid, allowing both smaller numbers of participants and faster
18
19 collection and analysis ~~in the qualitative work~~. Future methodological research could
20
21 compare these two approaches formally.
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26
27 A theory review of this type might also create opportunities for improving interventions,
28
29 allowing practice refinements towards achieving the outcomes that theory suggests are
30
31 important.
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37 **Conclusions**

38
39 We have described here a way of using a systematic review to elucidate theory in a currently
40
41 under-theorised area of dementia care. Doing this alongside in-depth qualitative work and
42
43 validation with stakeholders allowed us to choose outcomes and outcome measures for a
44
45 feasibility study that mapped clearly onto the derived theories. This approach in other under-
46
47 theorised areas, of which there are many in health and social care, may enable ~~, post-hoc,~~ ~~the~~
48
49 ~~identification and development of~~ identification and development of theory that MRC
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51 Guidance on the evaluation of complex interventions mandates,⁴ and perhaps also
52
53 ~~improvement of~~ improvement of the interventions themselves.
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Under Review

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Table 1. Inclusion and exclusion criteria

Inclusion criteria		Exclusion criteria
<i>Types of participants</i>	Studies that included, and papers that were about, people with dementia or Alzheimer's disease (including 'confusion' or 'memory problems')	Literature on LSW outside the dementia/Alzheimer's disease context.
<i>Phenomena of interest</i>	Studies that evaluated or that threw light on the theoretical underpinnings of LSW with people with dementia.	
<i>Types of outcomes</i>	Any outcomes reported for the person with dementia, their informal carers, or paid care staff.	
<i>Study designs</i>	Any study design, qualitative or quantitative.	Opinion pieces and letters.
<i>Date</i>	Studies published after 1984.	
<i>Language</i>		Studies not in English.

Table 2. Worked example of how analysis uncovered underlying theory from text

Text	Analysis	Underlying theory
<p>The group that participated in a dyadic life review (caregiver and care receiver) seemed to gain most from the intervention, particularly in their assessment of the care receiver's problem behaviours. Possibly ... because they were enjoying the process simultaneously and were sharing an event again.²⁴ (p.171).</p>	<p>The carers' assessment of the care receivers' 'problem behaviours' improved (<i>final outcome for family carers</i>) because the dyadic life story process was shared (<i>implicit causal link</i>) and was enjoyed (<i>implicit causal link</i>).</p>	<p>LSW --- that was a shared process --- that was enjoyed --- changed the carers' assessment of 'problem behaviours'.</p>

Table 3. Study details: final selection of studies for logic models element of the review

Study	Country	Type of publication or study	Setting	N involved	Methods used, if research	Who delivered LSW?
Batson et al., 2002 ²⁷	UK	Evaluation of LSW	Home/care home	9	Semi-structured interviews	Health care professionals
Buron, 2010 ³⁷	USA	Evaluation of LSW	Nursing home	5 pwd, 36 staff	Pre-test, post-test staff individualised care measure	Nursing care staff
Caron et al., 1999 ³⁸	USA	Description of LSW project	Nursing home	At least 12 'biography groups' of family carers	-	Not entirely clear but probably care staff and a facilitator.
Chapman et al., 2004 ³⁶	USA	Evaluation of LSW when in combination	Own home	54 with mild to moderate AD	RCT (creation of LS book plus drug vs. drug + placebo)	Speech and language therapists/students.

Study	Country	Type of publication or study	Setting	N involved	Methods used, if research	Who delivered LSW?
		with Donepezil			condition)	
Chaudhury, 2002 ³⁹	USA	Evaluation of LSW	Nursing home	12 pwd and their family carers, plus 12 professional and care staff	'Short survey' n.o.s.	Not clear but probably the author.
Clarke et al., 2003 ¹⁰	UK	Evaluation of LSW project	Transitional care unit in NHS trust and nursing home		Qualitative before and after design, with focus groups with staff in both settings and semi-structured interviews with pwd and family members	Support workers in care settings

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Study	Country	Type of publication or study	Setting	N involved	Methods used, if research	Who delivered LSW?
Damianakis et al., 2010 ²⁸	Canada	Evaluation of LSW	10 in own home, 2 in long-term care setting	12 family members of pwd (6 with diagnosed AD and 6 with diagnosed MCI)	Observation and in-depth interviews.	Family members supported by 'multi-media biographers and social workers'
Egan et al., 2007 ³²	Canada	Evaluation of LSW	Long-term care settings	4 pwd and all staff who worked with them.	Single subject, repeated measures design logging aggressive behaviours, plus interviews with staff.	Research assistants
Gibson et al.,	UK	Evaluation of	Residential	30 pwd, 14 care	Pilot study using pre-	Not entirely clear. One

Under Review

Study	Country	Type of publication or study	Setting	N involved	Methods used, if research	Who delivered LSW?
2006 ³⁴		LSW	care setting	staff	test, post-test design and control group. Range of standardised measures.	part of chapter mentions family members (p. 128), but rest of chapter is about care staff.
Hagens et al., 2003 ³⁰	Canada	Evaluation of LSW project	Nursing home	5 people with confirmed cognitive impairment	Participant observation and interviews with two residents.	Authors
Haight et al., 2003 ³³	USA	Evaluation of LSW when done with and without family carer	Not clear but appears to be in own home of pwd	22 pairs of pwd and family carers	Pre-test, post-test comparing LSW with and without involvement of family carer, and a control	Not entirely clear but seems that authors worked with pwd and carers.

Under Review

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Study	Country	Type of publication or study	Setting	N involved	Methods used, if research	Who delivered LSW?
					condition.	
Morrow- Howell et al., 1997 ⁴⁰	USA	Description and 'field testing' of LSW	Nursing homes	-	-	Professional facilitator and family members
Kellett, Moyle, McAllister, King, & Gallagher, 2010 ¹³	Australia	Evaluation of LSW	Residential care	7 family members, 7 care staff	Qualitative pilot study using focus groups with participants	Family members and care staff facilitated by researcher
McKeown et al., 2010 ²⁹	UK	Evaluation of LSW	NHS in- patient and day care	4 pwd, their family carers and care staff.	Multiple case study design. Semi- structured interviews,	Author facilitated.

Study	Country	Type of publication or study	Setting	N involved	Methods used, if research	Who delivered LSW?
			settings		observation and conversation.	
Murphy, 2000 ³⁵	UK	Description of LSW and guide to practice	-	-	-	-
Yasuda et al., 2009 ³¹	Japan	Evaluation of LSW	Memory clinic	15 memory clinic out-patients with probable diagnosis of AD	Experimental ABCA design, with TV programmes as control conditions.	Authors

AD – Alzheimer’s disease

MCI – mild cognitive impairment

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LS/LSW – Life story/life story work

NHS – National Health Service (UK)

PWD – person living with dementia

Under Review

Table 4: Outcomes identified for feasibility study

Outcome chosen	Outcome for
Wellbeing/ QoL	People with dementia
	Carers
Relationships (person with dementia/carer)	People with dementia
	Carers
Identity	People with dementia
Overall satisfaction with care	Carers
Perception of clients with dementia	Staff
Person-centred approach to care	Staff
Staff satisfaction and strain/burnout	Staff

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Figure 1. Flow diagram for selection for relevance and review (PRISMA 2009)

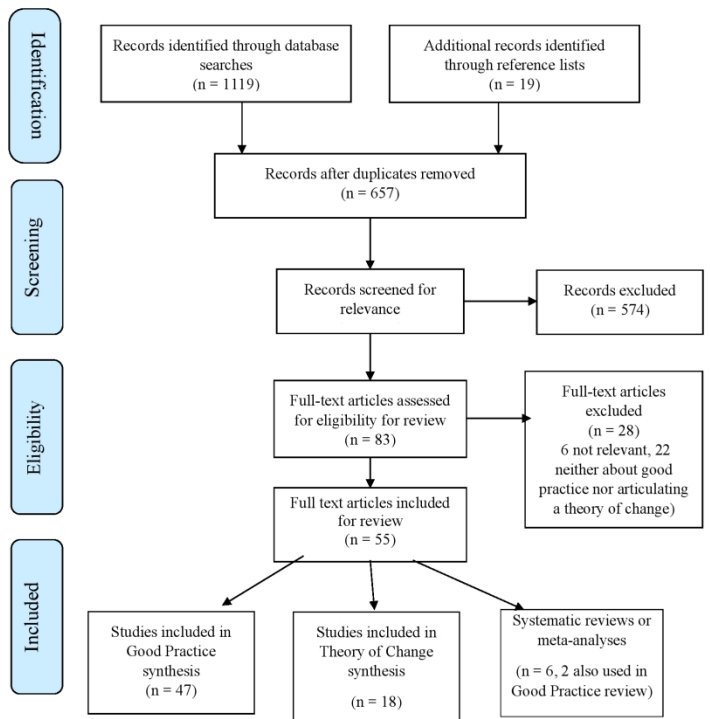


Figure 1. PRISMA diagram

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Figure 2. Theories of change for increased self-worth of person with dementia

Study	First link	Second link	Third link	Final outcome
Batson ²⁷ Hagens ²⁸	Being listened to/ opportunity to share self with staff	Increased sense of control/power	-	Increased self- worth
Damianakis ²⁶ McKeown ²⁵	Being valued and recognised	Self-affirmation and pride	-	

Figure 2

210x296mm (250 x 250 DPI)

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Figure 3. Theories of change for improved individual outcomes for person with dementia

Study	First link	Second link	Final outcome
Egan ³⁰ Kellett ⁴⁰ Hagens ²⁸	Increased staff knowledge of, and interaction with, person with dementia	Facilitates more person-centred or individualised care	Reduced 'negative' psychological and behavioural outcomes
Chapman ³³ Haight ²³ Gibson ³² Yasuda ²⁰	Person with dementia is engaged in/enjoys the LSW process	-	



Figure 3

210x296mm (250 x 250 DPI)

Figure 4. Theories of change for improving relationships between staff and the person with dementia

Study ID	First link	Second link	Final outcome
Murphy ³¹	Get to know the person with dementia	Improve interaction and communication	Improve relationships between staff member and person with dementia
Clarke ¹⁰		Understand current actions and behaviour	
Hagens ²⁸			
Chaudhury ³⁶			
Clarke ¹⁰			




Figure 4

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Figure 5. Theories of change for improving care

Study ID	First link	Second link	Third link	Final outcome
Chaudhury ³⁶ Gibson ³² Kellett ⁴⁰ McKeown ²⁵ Murphy ³¹	Increases staff understanding of the person with dementia	Enables staff to 'see' the person with dementia/ makes the person with dementia 'knowable'	Facilitates more person-centred or individualised care	Better care
Batson ²⁷ Buron ³⁴ Chaudhury ³⁶ Murphy ³¹ Hagens ²⁸	Increases staff knowledge about the person with dementia	Improves 'fit' between care provided and person with dementia's needs/interests	Improves overall care environment	
Buron ³⁴ Chaudhury ³⁶	Increases staff knowledge about the person with dementia	Changes aspects of the 'job' and staff behaviour		

Figure 5

210x296mm (250 x 250 DPI)

Figure 6. Theories of change for more effective engagement of family/members in care setting

Study ID	First link	Second link	Final outcome
Caron ¹⁵ Damianakis ¹⁶ Kellett ⁴⁰	[Care-led or focussed LSW] improves recognition and empowerment of family member/carer in care setting	More inclusive relationship between family member/carer and care setting with care planning and delivery	More effective engagement with family members/carers in care setting
Chaudhury ¹⁶ Chapman ³³	[Staff-led LSW] leads to more interaction and involvement with family members/carers	Care staff have more knowledge and understanding of family members/carers of people with dementia	More effective engagement with family members/carers in care setting

Figure 6

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Figure 7. Theory of change for helping family members/carers to cope better


Study ID	First link	Second link	Final outcome
Caron ¹⁵ Damianakis ¹⁶ Monow-Howell ¹⁷	Enables carer to remember past life of person with dementia	Changes family members/carers' appraisal of person with dementia and their current condition	Enhances coping of various types
			

Figure 7

152x215mm (300 x 300 DPI)