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Citation: McKeown, Jane, Ryan, Tony, Ingleton, Christine and Clarke, Amanda (2015) 'You have to be mindful of whose story it is': The challenges of undertaking life story work with people with dementia and their family carers. *Dementia*, 14 (2). pp. 238-256. ISSN 1471-3012

Published by: SAGE

URL: <https://doi.org/10.1177/1471301213495864>
<<https://doi.org/10.1177/1471301213495864>>

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“You have to be mindful of whose story it is”:

The challenges of undertaking life story work with people with dementia and their family carers.

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Abstract

Introduction: Life story work (LSW) is increasingly being used with people with dementia; this paper offers a critical appraisal of some challenges that may be faced in practice.

Design and Methods: An in-depth case study analysis was undertaken to understand the experiences of people with dementia, family carers and care staff in using LSW in an NHS mental health and social care Trust. Data collection included semi structured interviews, observation, conversations and field notes.

Findings: Private memories were sometimes recalled by the person with dementia that were not for inclusion in any written product; enabling the person with dementia to tell their own life story could be a challenge; quality of the life story books was variable and; at times LSW may be overused with the person with dementia.

Conclusion: Services should not be deterred from undertaking LSW with people with dementia but there is a need to adopt a planned approach to its implementation that includes facilitation, education and supervision.

Background

Life story work (LSW) has been used in a number of countries within a range of health and social care settings with a range of groups such as: older people (Heliker 1997; Adams *et al.* 1996, 1998; McKee *et al.* 2002; Clarke *et al.* 2003; Wills and Day 2008; Bakken *et al.* 2009); people with learning disabilities (Hewitt 1998, 2000; Moya 2010); and older people with dementia (Gibson 1991, 1994; Caron *et al.* 1999; Hansebo and Kihlgren 2000; Murphy 2000; Batson *et al.* 2002; Keady *et al.* 2005; Russell and Timmons 2009; Gibson and Carson 2010; Kellett *et al.* 2010; McKeown *et al.* 2010a; Thompson 2009).

LSW has been described as an approach to working with a person and / or their family to find out about their life, recording that information in some way and then using the information with the person in their care (McKeown *et al.* 2006).

When used specifically with people who have dementia positive outcomes may include: Improving care for the person with dementia (Gibson 1994, 1991; Hansebo and Kihlgren 2000; Murphy 2000; Batson *et al.* 2002; Gibson and Carson 2010; McKeown *et al.* 2010a; Thompson 2009); offering family support (Caron *et al.* 1999; Kellett *et al.* 2010); enabling a reflection on services received (Keady *et al.* 2005) and hearing the voice of the person with dementia (McKeown *et al.* 2010a).

Health and social care policy and guidance in England are increasingly recommending the use of LSW in the care of people with dementia. The National Dementia Strategy for England (DH 2009:58) for example, refers to the use of LSW as: *“an effective vehicle for care home staff to communicate and develop relationships with residents, based on their unique life experiences”*. Social Care

Institute for Excellence (SCIE) / National Institute for Health and Clinical Excellence (NICE) Guidance on Dementia (National Collaborating Centre for Mental Health 2006) recommends the need for the assessment of a person's biography and interventions that take into consideration a person's past interests and preferences, both of which LSW can elucidate. The SCIE Dignity in Care campaign makes a direct link between finding out about people's life stories and helping maintain their choice and control (SCIE 2011). More recently the use of LSW has been identified as one approach to maintaining a person's human rights (Equality and Human Rights Commission 2011; Life Story Network 2011).

Previous research on the use of LSW with people with dementia has helped to demonstrate positive outcomes for the people involved. Some studies undertaken with older people have drawn attention to the possibility of upsetting memories being evoked (Clarke *et al.* 2003; Wills and Day 2008) or the potential for LSW to locate the person in the past (Adams *et al.* 1998). To date, few challenges of undertaking LSW specifically with people who have dementia have been revealed.

This paper draws on an in-depth case study analysis exploring the use of LSW from the perspectives of four people with dementia, their family carers and health and social care professionals involved in their care in the United Kingdom.

Aims

The aims of the paper are to:

- Critically appraise some of the challenges that may emerge through the process of undertaking LSW

- Recommend how such challenged may be overcome or minimised
- Contribute to what is currently a gap in the LSW literature.

Methods

Study Design

A multiple case study design was used in the LSW research. Case study research has the capacity to be flexible and sensitive to different contexts and meanings (Stake 1995). Additionally, case study research is defined as:

“an empirical enquiry that investigates a contemporary phenomenon [LSW] within its real-life context [Health and Social Care practice], especially when the boundaries between phenomenon and context are not clearly evident” (Yin 2009:18).

The chosen design allowed LSW to be applied within everyday practice; exploring both the experiences of the people involved and the processes taken for LSW to be implemented. An earlier published review reported on LSW from the perspective of staff, rather than those of all stakeholders involved in each initiative (McKeown *et al.* 2006). This study focusses upon the perspective of all key stakeholders by taking a constructivist approach. Constructivism holds a ‘relativist’ ontology; that is it recognises the existence of multiple and intangible realities (Appleton and King 2002; Rodwell 1998). This accepts that ‘multiple knowledges’ can exist together and, consequently, a range of views may emerge (Guba and Lincoln 1994). The constructivist research study primarily aims to illuminate these different constructions (Lincoln 2001) and involves the iterative development of the research method

through stakeholder involvement at every stage. Additionally, Nolan *et al.* (2003) define the goals of constructivist research as a means of promoting action and change in order to develop knowledge and understanding.

Stakeholders were central to the study's development and on-going progress: a reference group, comprising family carers and care staff was established prior to data collection. This group acted as a critical friend to the research team, helping for example, to suggest ways of overcoming barriers. Group members engaged in the process of data analysis through coding sections of the interview transcripts and refinements to the thematic framework in response to emerging themes. People with dementia were not asked to join the reference group and more meaningful involvement was sought through discussions about the research in forums where people with dementia already met and felt comfortable; such forums included a memory service café and an established day centre group. Opportunities were taken at various forums with a range of stakeholder to share early findings to assess their relevance. These activities aimed to strengthen the trustworthiness of the study and were consistent with a constructivist approach where stakeholder engagement is central to the research process.

Gaining ethical approval

The study received approval from the local Research Ethics Committee on two occasions; initially, when the study commenced and again in light of the enactment of the Mental Capacity Act 2005. Dewing's (2007) process consent framework was used to ensure maximum involvement of the person with dementia in the continual assessment of their agreement to participate. Carers were asked if the person with dementia was someone who enjoyed talking about their past as opposed to being a private or secretive person and also whether they were the sort of person who would

have enjoyed participating in research. Names have been changed to maintain confidentiality. The challenges in ethically seeking the active involvement of people with dementia in the research have previously been reported (see McKeown *et al.* 2010b).

LSW Intervention

LSW was undertaken with four people with dementia, their family carers and care staff across four care settings within an NHS Health and Social Care Trust in the UK. The LSW was facilitated by the researcher (JMc), who was also a senior nurse, working within the organisation. A practice development approach was taken to ensure a systematic and transparent approach to the implementation of LSW in clinical practice. The principles of practice development were fundamental to the clinical role of the researcher and were consistent with the action focussed and participatory nature of the research methodology. Manley *et al.* (2008) define eight practice development principles that include: it strives to achieve person-centred, evidence based care; observes micro-systems of care; integrates work based learning; integrates evidence into practice and evidence from practice and encourages creativity. An individualised approach was taken in each case in response to the wishes of those involved. Three cases developed a life story book which is a photograph album or scrap book that includes for example, photographs, and text to depict a persons' story; one person's story was depicted in a pen picture which was a two page written account of the person's life.

Setting and sample

Four case studies were undertaken across four different NHS care settings for people with dementia at different stages of the condition. The details of each context are shown in Table 1.

Table 1
Description of Case Study Context

Case Study 1 - George	A 24 bedded assessment ward for people with dementia living in the South of the City; although well established it was due to close within 6 months due to service reconfiguration. There had been a recent change of staff with some patients being admitted with 'challenging needs' who had previously been cared for on another ward. The ward was in the process of moving from a task orientated culture to one embracing a more person-centred approach. A support worker and occupational therapy assistant worked with George's wife to develop a life story book.
Case Study 2 - Harry	A 24 bedded assessment ward for people with dementia living in the South of the City; although well established it was due to close within 6 months due to service reconfiguration. There had been a recent change of staff with some patients being admitted with 'challenging needs' who had previously been cared for on another ward. A newly qualified staff nurse worked with Harry to develop a pen picture and an experienced staff nurse worked in a more ad-hoc way in talking with Harry about his life. Follow up took place in a general nursing care home where Harry moved to.
Case Study 3 - Rachel	A 24 bedded intermediate care ward for people with dementia from across the City who had been physically unwell and were well enough for discharge from a medical ward but were not ready to go home. The ward was staffed by an established multi-professional team of staff. A life story book was produced with Rachel by an occupational therapy assistant with contributions from Rachel's daughter; a support worker also participated. Follow up took place in a specialist nursing home for people with dementia.
Case Study 4 - Eileen	A day centre offering care for people with dementia in the South East of the city. Staffed by joint health and social care experienced staff and supported by volunteers. The centre had a reputation for strong leadership and an emphasis on person-centred care for people with dementia and their family carers. A student

	nurse and the nurse manager worked with Eileen and her daughter in developing a life story book. Follow up took place in a social care resource centre where Eileen attended for day care and respite.
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The people with dementia were selected by care staff based on set criteria to ensure that the ‘cases’ helped to answer the research questions and to address ethical considerations. Criteria included: people with dementia with complex behavioural needs; those not nearing discharge; and only carers who were willing to participate (i.e. avoiding cases where a carer was unwell, or especially distressed). To ensure, as far as is possible, that participation was guided by the wishes and/or best interests of the person with dementia care staff and relatives/carers were asked to consider a number of questions which were particularly relevant to LSW (see Figure 1).

Figure 1
Questions used to assess the suitability of the person with dementia to participate in life story work

<p>Has the person been someone happy to talk about their life to others?</p> <p>Have there been any past indications of distressing or unpleasant memories the person may prefer not to relive?</p> <p>Do you think the person would have liked care staff to know more about their life to assist in their care?</p> <p>Is the person someone who was happy to share their views and opinions with others if given the opportunity?</p>
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Multi-professional staff, working with the selected person, were asked if they would participate. Participants included a range of staff including registered nurses, occupational therapy assistants, support workers, a student nurse and care home assistants. Male and female staff and those from black and minority ethnic groups contributed to the diverse participant sample. See Table 2 for participant

characteristics in each case study. The research design allowed for the person to be followed up in other care environments; for example, when they moved to a nursing home or if they received day care in another setting.

Case studies 1 and 2 were chosen from similar care environments with the aim of replicating the findings. Progress in implementing LSW was slow in these cases due to complex circumstances; these included a service re-configuration; high activity on the ward and staff sickness. Eisendhart (1989) describes the utility of sampling decisions in case study research. Far from seeking to achieve a representative sample, cases are selected to explore specific issues or hunches, or to test a conceptual framework. In view of the slow progress and perceived difficulties in LSW being implemented, case studies 3 and 4 were chosen as ‘theoretical replications’ (Yin 2009) to predict contrasting results (i.e. a speedier implementation of LSW) and to understand the conditions that may enhance the uptake of LSW. In case study 3, for example, the occupational therapy assistant was given dedicated time to devote to undertaking LSW; in case study 4 LSW was undertaken by all student nurses on their placement at the day centre and LSW was well established. Case studies 3 and 4 did demonstrate a swifter approach to the implementation of LSW.

Table 2
Participant characteristics across 4 case studies

Case Study	Person	Age	Diagnosis	Length of Diagnosis	Life Story ‘Product’	Care Environment	Other Participants	Duration of Case Study
1	Male George	87	Vascular Dementia	4 Years	Life story book	Assessment Ward	Registered Mental Nurse; Carer – Wife; Support Worker; OT Assistant	23 months
2	Male Harry	80	Dementia with Lewy Bodies	1 Year	Pen picture	Assessment Ward	2 Registered Mental Nurses; Registered General Nurse – Nursing Home	21 months
3	Female	88	Alzheimer’s	4 months	Life story book	Intermediate	OT Assistant;	13

	Rachel		Disease			Care Ward	Carer – Daughter; Support Worker; Care Assistant – Nursing Home	months
4	Female Eileen	83	Alzheimer's Disease	5 Years	Life story book	Day Centre / Group	Registered Mental Nurse; Carer – Daughter; Student Nurse; Outreach Worker in social care facility.	10 months

Data Collection

The process of using LSW was observed, key stakeholders were interviewed once or twice using a loosely structured topic guide to facilitate a two-way discussion centred on respondents' priorities, experiences and concerns (see Figure 2 for an example of the topic guide). Conversations and observations that took place with the person with dementia or with participants separate to the interviews were recorded immediately after the interaction and a research diary was maintained. Other documentary analysis of care plans and meeting notes was maintained throughout the study. Methods were consistent with commonly used methods in case study research (Yin 2009). Twenty one interviews were conducted with registered nurse, support worker, family carer, occupational therapy assistant and care worker participants and seventy hours were spent by the researcher in the field.

Figure 2

An example of topic guide questions

Can you describe your experience of being involved with this life story approach?

What have been the main benefits of taking this approach from your point of view?

Have there been any particular concerns or difficulties in taking this approach ?

Data Analysis

A Framework Analysis (Richie and Spencer 1994) approach was used, characterised by the following distinct and interconnected stages: Familiarisation; Identifying a thematic framework; Indexing; Charting and Mapping and Interpretation. This approach utilised the thematic framework that had been developed prior to data collection and is consistent with case study research which: *'benefits from the prior development of theoretical propositions to guide data collection and analysis'* (Yin 2009: p18). The thematic framework was developed following a systematic literature review and was refined throughout the study. Framework analysis allows for *a priori* as well as emergent codes to be used in the analysis (Lacey and Luff 2001). The transcribed interview data and research diary entries from observations and conversations were coded and applied to the framework by the lead researcher (JMc). Documentary data and reference group meeting notes were not applied directly to the framework but were used as demographic / contextual data to inform the discussion. New emergent themes were used to update the framework. Consensus was reached through discussions with academic supervisors (CI, TR and AC) and with the research reference group.

Findings

The LSW research identified a range of findings relating both to the process and outcomes of using LSW. Outcomes relevant to person-centred care were demonstrated and these have been reported in a previous paper (McKeown *et al.* 2010a). A critical analysis of the data on the process of undertaking LSW revealed the challenges that emerged through our study; these are:

- Personal disclosures;
- Whose story is it?
- Quality of life story books;
- Under and overuse of life story books.

Personal disclosures

The LSW research highlighted that personal disclosures and sensitive information might be divulged through LSW. The staff nurse working with Harry was privy to some private and intimate memories of his life:

“Harry told me some quite personal information that others might not be aware of, including wife and ... I was very aware of what he was telling me was very, very personal information.” Cs2: Staff Nurse 1.

In order to maintain the dignity of Harry a difficult decision was made to edit his story and was vindicated when we met Harry in the nursing home to show him his pen picture, as the staff nurse described:

“He almost – not looked embarrassed but suddenly the thought of putting things in that he didn’t want people to know was quite alarming to him so I think leaving out them bits was a good thing cos I think it would have been quite stressing for him if we’d put in all about what he told me.” Cs2 Staff Nurse 1.

The nurse manager spoke of personal disclosures taking place within the context of a trusting relationship when using LSW:

“You do access family secrets people do tell you things that you would never be privy to because you are using photographs and ... working on a one to one and spending a lot of time doing it people do tell you ... private things.” Cs4 Nurse manager.

Her concerns that Eileen might share her secrets more widely in the group were unfounded:

“I was a bit concerned about her talking about that at the group and not getting the right level of support..., but that seems to have been unfounded ...she seems to only talk about that when it’s on a one to one in a more private setting.” Cs4 Nurse manager.

Personal memories can also relate to photographs, this was evidenced when Georges’ wife spoke of choosing not to include some photographs in George’s life story book. I asked her to enlarge on her decision and she explained:

“It was about half a dozen that I decided I didn’t want to go in...cos they was quite personal to me as well.” Cs1 Wife.

These findings demonstrate that private and intimate disclosures may emerge uninvited as a consequence of spending time talking with an older person about their life story.

Whose story is it?

The LSW research uncovered a range of different ways that the person with dementia and their family carers worked together with staff to share life story information. Rachel and Eileen were both enabled by their daughters and by the staff working with them to tell their story. Each chose how their life stories were reflected by the choice of the photographs and the accompanying words.

The nurse manager described how Eileen was able to take much more of a lead in the process than she had expected:

“She was very definite about what she wanted in and what she didn’t want in where [her daughter] had picked photographs that she had thought Eileen would want and quite a few of them, weren’t what Eileen wanted at all.... so she very much collaborated, participated in and took the lead.” Cs4 Nurse manager.

Similarly, the OT assistant described how she worked in collaboration with Rachel in putting the book together:

“She chose the photos and she cut them out so really I worked closely with her ...she’s had a choice throughout her likes it could be the photos.” Cs3 OT assistant.

In privileging Rachel's story it is possible the daughter may have felt excluded from contributing to her mother's book:

"[The OT assistant] only engaging with daughter through me, very Rachel centred, good – collaborating with her, I feel uneasy daughter left out?" Research Diary.

George's wife provided the information about his life story and a genuine collaboration emerged between her and the staff in developing George's life story book. Care staff, although pleased with George's life story book, described their disappointment that his story was largely from the perspective of his second wife whom he had been married to for sixteen years. The deputy manager reflected:

"He's not participated in any of the evidence gathering ...I think there are other difficulties like not being able to get George's point of view as well cos I think that's really important and while we've got quite a good insight we've not got George's insight really I mean we haven't even got any extended family there's really just [his wife]." Cs1 Deputy manager.

The OT assistant felt a similar way:

"I think it would have been nice to have had some more about his life before [his wife] ... I would have liked to have got a little bit more of that first bit." Cs1 OT assistant.

It appeared important for care staff to involve the person as much as possible, but when not possible in conventional ways, as with George, the staff appeared to feel disappointed, even suggesting that George had not been the best choice of person to undertake LSW with; this is reflected by the deputy manager and the OT assistant:

“But I think and even with a different person I think we probably could have got so much more out of it – for the staff team and for the person involved really.” Cs1 Deputy manager.

“With other people it might work a lot better I mean George’s a case on his own isn’t he?” Cs1 OT assistant.

The findings reflect the complexity in finding a way to involve the person with dementia and their family carers in LSW.

Quality of the life story books

Different views were expressed about the content and quality of the life story books. George’s wife was pleased with the overall balance of George’s life story book and she describes a collaborative approach to its development between herself, the OT assistant and support worker.

“So I think it worked pretty well, I think we all complimented each other ...I think we got the balance right in the book.” Cs1 Wife.

By being involved and collaborating closely with staff, George’s wife described how she was able to influence the quality of the book by arranging for the photos to be scanned onto photographic paper:

“Small things like I wanted each photograph labelling up not just writing on the back but I didn’t want it just scribbled on a piece of paper, so I just wanted to do it so that was nice...Even they [staff] passed comment that they was better.” Cs1 Wife.

I noted in my research diary:

“Was really lovely, mixture of pictures and captions ...it was lovely.”

Research diary.

Although George was unable to verbalise his opinion on the book, the observational records of him using it indicated that he appreciated it.

“When he looks at it his face changes, his eyes light up, it’s almost as if someone turns a light on, he’s like the ‘Ready Brek Man’, all lit up. His posture alters, he sits up tall. The other day he was walking down the corridor with it, like Eamon Andrews, he was tall and upright.” Cs1 Wife.

Rachel and Eileen’s life story books both contained typing errors. I observed Eileen’s reaction when she shared her book with me:

“Throughout the book there were some spelling mistakes on family names ...on one occasion Eileen had corrected it in pen, on each occasion she pointed it out with mild irritation or disappointment however she did not voice her displeasure even when asked if she would change anything about the book.” Research diary.

I was not alone in observing this; Eileen’s daughter commented that her niece had noticed the mistakes when looking through Eileen’s book; similarly the care worker in the nursing home commented on Rachel’s reaction to the spelling errors in her life story book:

“I noticed Rachel spotted spelling mistakes so it shows she is reading it and taking notice.” Cs3 Nursing home care worker.

I sum up some of these contradictions in my research diary after a meeting with Rachel and her daughter:

“Re the content of the book I feel mixed, typos, stuck in pictures, not polished – or how long it will last? But the great thing is it was done in collaboration with Rachel ... spelling mistakes, bad grammar does it matter?” Research Diary.

Clearly to Rachel and her daughter it did matter, as an e-mail sent by Rachel’s daughter indicated:

“Mother and I look at it quite often and every time she comments that things are not spelt correctly etc; she and I have always been very fussy about the correct use of English ...Of course it does not matter very much but it is just an observation!” Cs3 Daughter.

Eileen’s and Rachel’s daughters felt the life story book was not exactly how they would have wished them:

“I think it’s good, I would probably like to have seen a bit more writing, but that’s just me, I think it’s fine.” Cs4 Daughter

“I just wish it was more comprehensive and more photographs had been used that I had put though and I suppose I could have put more into it” Cs3 Daughter.

Both daughters made these comments to me with almost an apology – *“It doesn’t matter very much it is just an observation”*; *“But that’s just me I think it’s fine”* *“I suppose I could have put more into it”*. Rachel and Eileen’s daughters were less involved in producing the life story books than George’s wife who, interestingly, described being able to influence the quality of the book throughout.

Under and over use of the life story books

An unexpected finding from this research is that, at least initially, there is the potential for the life story book to be overused with the person with dementia. The nurse manager reflected this in her experience of working with a range of volunteers with Eileen:

“I think you also have to be aware that she tires very easily and I think what we’ve had to watch out for is that she’s not actively engaged for the full day... so I think it’s our job to look for signs that she’s wanting a bit of a rest.” Cs4 Nurse manager.

Similarly, George’s wife felt the same thing happened when the OT assistant, support worker and herself all shared George’s life story book with him for the first time:

“There was a time in the early days when he got agitated but there were a lot in the room with him and I think there was ‘overkill’ as it was new” Cs1 Wife.

George’s wife, however, was confident that George would demonstrate he had ‘had enough’ by closing the book.

I report in my research diary that I felt we had spent too long with Rachel and her book when it was first completed:

“[The OT assistant] joined us and to be honest I think we spent a little too long. Rachel became more distracted and [her daughter] looked tired.” Research diary.

Conversely, Rachel's daughter described how when she reached the end of the book, Rachel picked it up again and asked what it was and looked through the book afresh as if she had not seen it before.

Harry's pen picture was transferred with him to the nursing home he moved to. Although he expressed the wish that it be displayed in his room, future visits to the home suggested that did not happen and Harry's life story information remained hidden in his care records.

Discussion

This paper has identified a number of challenges that can present when using LSW with people with dementia.

Personal disclosures

Private and personal stories were sometimes divulged during the LSW process. It was evident that some of the disclosures were not for public knowledge and were not included in the person's life story product. Clarke *et al.* (2003) highlighted that older people (without dementia) were sometimes pleased to share information verbally but expressed that they did not always wish it to be recorded. This may be more of a challenge to negotiate when a person has dementia. This was clearly evident with Harry. Gibson (2005) urges staff working with people with dementia to exclude sensitive information from records but not from discussions. This is precisely how the nurse dealt with Harry's disclosures; she listened to Harry's story, but through discussions in clinical supervision decided the information would not form part of his written story.

Brooker (2010) proposes the analogy of a chest of drawers to illustrate different information that might be shared, with the top drawer being information that might freely be shared, the middle drawer being information that might be shared in the context of a trusting relationship and the bottom drawer being personal information and family secrets which should not form part of life story work (see Table 3). Harry most definitely shared ‘bottom drawer’ information with the staff nurse and, as such, it was appropriate to keep that private and not public since the information may have been upsetting or harmful to other family members.

Table 3
Analogy of how personal information may be categorised (Adapted from Brooker 2010)

Drawer	Type of Personal Information
Top Drawer	Information freely available about a person often kept on case notes and that may be collected on admission. May include: demographics, what the person did for a living, family members, basic preferences.
Middle Drawer	Information a person may choose to disclose in the context of a friendship or caring relationship and that might be disclosed when using LSW. May include: Thoughts, feelings, beliefs, significant relationships, more personal memories.
Bottom Drawer	Information that may be private to a person or perhaps a few close others and not for the public domain. May include: Family secrets, private or traumatic memories.

The LSW undertaken within this study was closely observed by the researcher who was able to take on a supervisory role with the staff nurse working with Harry. This enabled a considered response and the intimate parts of Harry’s story remained private. The danger of not having support processes in place is reflected by Day and Wills (2008) who describe the burden placed on a worker who felt compelled to keep

a secret divulged by a patient during LSW to themselves. This does highlight the need for skilled facilitation and access to supervision for workers using LSW if the dignity of the person with dementia and their family members are to be maintained.

Whose story is it?

There are potential challenges for some people with dementia to contribute to their own life story in conventional ways and this was the experience of care staff working with George. Baldwin (2008a) describes how some people with dementia are denied the opportunities to talk and share their stories because the traditional 'rules' of narrative are not always relevant when a person has a cognitive impairment. It is interesting that staff had felt in some way disappointed that George had not been able to contribute to his own story. In wanting to know more about his life before his second wife, staff may have been placing importance on his life story being told in a chronological way. Such an approach has the potential to exclude his wife and place less value on his more recent and shared life story.

A challenge exists to develop a broader perspective on involving a person with dementia in telling their story. Baldwin (2006) describes some alternative approaches that may '*re-possess*' the narratives of people with dementia by interpreting the rules of narrative more flexibly. These include the piecing together of smaller stories and joint authorship, which was something perhaps the care staff working with George were not able to recognise the value of.

The piecing together of smaller stories enables a person with dementia to contribute to their own narrative. This process has been described as '*narrative quilting*' (Moore and Davis 2002), where staff collaborate with the person with dementia over time in order to re-introduce details and topics from earlier conversations to help the

person expand on it. Crisp (1995) demonstrates that fragments of memory and metaphor can be brought together to construct the identity of the person with dementia. It is possible George may have been helped to contribute more to his story by taking this approach.

Joint authorship is another way of supporting a person's ability to contribute to their own story. Phinney (2002) argues that when a person has dementia, the telling of their own story alone becomes impossible and, as stories are jointly lived, so they should be jointly told. Keady *et al.* (2007) explore a collaborative approach to storytelling through co-constructed inquiry which involves the person with dementia, their family carer and researcher negotiating a life script. Some of the differences between care staff and George's wife in his life story book may have resulted from care staff and his wife privileging different aspects of George's 'life script'.

Baldwin (2008b) warns that when another person takes over the narrative of a person with dementia, care needs to be taken to ensure that person is not distanced from society. These findings reflect the complexity for care staff working with people with dementia in successfully being able to incorporate and integrate the views and opinions of family members whilst also keeping the story of the person with dementia central. This discussion raises the fundamental question of the purpose of life story work. LSW in health and social care settings meet different needs for different stakeholders (see Table 4). It seems important at the outset of implementing LSW with an individual to agree the primary purpose of the work, although in reality LSW, often has value for the person with dementia, family members and care staff.

Table 4

The range of uses of life story work with people with dementia

Purpose of Life Story Work
For the person with dementia to tell their story – as a way to be heard or for therapeutic benefits
As a tool to use with person with dementia as part of care
Therapeutic for family members – participating and reviewing life
Helping staff to understand and care for the person
As a way of expressing experience of condition / and or services
As a legacy
Assistance in transition between care environment

Quality of the life story books

The LSW research revealed a finding that has previously been unreported in the literature relating to the content and quality of the LSW product. The quality of Eileen and Rachel's life story books was tarnished by the spelling mistakes and poor grammar, something that both women and their daughters commented upon. These errors may have occurred due to a lack of accuracy checking on the part of the staff completing the books. This finding may have implications if staff completing the books do not speak English as their first language or if they have poor literacy skills. Life story books provided the people with dementia a sense of pride about themselves and their lives and for family carers LSW enabled them to 'show off' and 'celebrate' the life of their relative who had dementia (McKeown *et al.* 2010a). Therefore to have a life story book that is rushed, contains errors or is of poor quality somehow detracts from the person and their life. There is a need for a final quality checking process that includes the person with dementia and family members before life story books are completed. Rachel's book was a completed scrap book with text and pictures which were fixed making it more difficult to edit. Eileen's book, however, had been completed electronically with scanned pictures and word processed text, making it easier to edit and indeed add to in the future.

Under and overuse of life story books

In his study into the use of LSW Murphy (2000) reports that in some cases, staff were unaware of the existence of life story books and consequently, they were not used with residents. Batson *et al.* (2002) report that staff can sometimes find it emotionally draining listening to people with dementia tell the same story over again and staff need to recognise that the experience may be novel each time the person with dementia views it.

The life story books that were produced as part of the LSW research were all used with the people with dementia during the life span of the research project. Contrary to current literature the LSW research revealed the potential 'over-use' of the life story books with George, Rachel and Eileen. Finding the 'correct' balance in using the LSW product can be challenging to care staff and family carers to ensure that the person with dementia is not overwhelmed or over-tired. Harry's 'pen picture' that accompanied him to the care home was not used. It may have been that as a written pen picture it was less attractive and noticeable than, for example, a life story book with photographs. Additionally, the staff who received Harry's pen picture at the Nursing Home where he had moved were not involved in the process of LSW and so perhaps had less understanding of its value in terms of Harry's s well-being and care.

Limitations to the Study

The study was undertaken within an NHS mental health and social care Trust and it is not possible to say to what extent the findings have relevance for other care settings.

The sample of older persons with dementia was white British and reflected the population currently receiving care within the organisation where the research was undertaken. Similarly all but two of the care staff participants were white British. The findings, therefore, do not reflect the experiences of people with dementia or staff from black and minority ethnic groups or culturally diverse communities and this identifies a need for future research.

Setting exclusion criteria, necessary in taking an ethical approach to the research, has implications for the findings as judgements were made as to who is 'suitable' for LSW. We do not know, for example, whether the challenges of using LSW are different for people with carers who are especially distressed, as these people were excluded from the research sample. Similarly, the screening questions made the assumption that a person who was private and did not talk much about their life in the past would not wish to do so in the present. This reflects that sometimes the mechanisms put in place to protect people in the research process may impact on the research findings.

Conclusion and Implications for Research and Practice

This paper has reported the possible challenges that may emerge when undertaking LSW with people with dementia. Previous research has concluded that LSW is not for everyone (Clarke *et al.* 2003; Day and Wills 2008). Notwithstanding this many people with dementia do enjoy talking about their lives and should be offered the opportunity to talk about and record their life story if they wish. However as we have highlighted in this paper unexpected issues can still arise and being aware of

potential challenges may help care staff to identify and minimise any compromises to the dignity and wellbeing of the person with dementia.

Recommendations for practice

- An assessment of care staff educational needs, prior to using LSW, is essential and offering an educational programme before LSW is implemented into a care setting would be recommended. Such a programme would include time for care staff to consider some of the potential challenges that may arise.
- Care staff undertaking LSW with people with dementia require access regular supervision and to expert advice in order to identify, discuss and overcome any challenges that emerge. McKeown *et al.* (2010a) and Thompson (2009) identify facilitation within a practice development approach as a key factor to the implementation of LSW.
- It can be helpful at the outset to clarify the aims and purpose of LSW for each individual

Recommendations for research

- There is currently no formal evaluation in the literature of precisely what is needed in an educational package and how it is best delivered.
- Further research is required to undertake a rigorous evaluation on the most effective approach to enable successful implementation of life story work, whilst reducing and managing the challenges that may arise.
- There is scope for further exploration and publication of the challenges of undertaking LSW to further develop the evidence base.

Recommendations for policy

- Policy makers need to highlight the challenges as well as the positive benefits of LSW.
- Policy makers could recommend that LSW is undertaken with the necessary educational and support safeguards.

With these considerations in mind then LSW can continue to be a valued and effective intervention with older people with dementia in health and social care settings.

References

Adams, J., Bornat, J. and Prickett, M. (1996) 'You wouldn't be interested in my life, I've done nothing.' Care planning and life history work with frail older women. In J. Phillips and B. Penhale (eds) *Reviewing Care Management for Older People*, 102-116. Jessica Kingsley Publishers. London.

Adams, J., Bornatt, J. and Prickett, M. (1998) Discovering the present in stories about the past. In A. Brechin, J. Walmsley, J. Katz and S. Peace (eds) *Care Matters*, 27-41. Sage. London.

Appleton, J. and King, L. (2002) Journeying from the philosophical contemplation of constructivism to the methodological pragmatics of health services research. *Journal of Advanced Nursing*, 40, 641-648.

Bakken, L., Lerdal, A. and Harding, T. (2009) Norwegian healthcare workers' experience with implementing life story work in a nursing home. *Klinisk Sygepleje*, 23, (3), 12 – 18.

Baldwin, C. (2006) The narrative dispossession of people living with dementia: thinking about the theory and the method of narrative. In K. Milnes, C. Horrocks, N. Kelly, B. Roberts and D. Robinson (eds) *Narrative Memory and Knowledge: Representations, Aesthetics and Contexts*, 101 – 109. University of Huddersfield, Huddersfield.

Baldwin, C. (2008a) Narrative (,) citizenship and dementia: the personal and the political. *Journal of Aging Studies*, 22, 222 – 228.

Baldwin, C. (2008b) Towards a person-centred ethic in dementia care: doing right or being good? In M. Downs and B. Bowers (eds) *Excellence in Dementia Care: Research into Practice*, 103 - 118. McGraw Hill Education. Maidenhead.

Batson, P., Thorne, K., and Peak, J. (2002) Life story work sees the person beyond the dementia. *Journal of Dementia Care*, 10, (3), 15-17.

Brooker, D. (2010) *The VIPS model and the Importance of Life Story Work*. Presentation to The First National Life Story Work Conference, 12th February, Leeds.

Caron, W., Hepburn, K., Luptak, M., Grant, L., Ostwald, S., and Keenan, J. (1999) Expanding the discourse of care: Family constructed biographies of nursing home residents. *Families, Systems and Health*, 17, (3), 323-335.

Clarke, A., Hanson, E. and Ross, H. (2003) Seeing the person behind the patient: enhancing the care of older people using a biographical approach. *Journal of Clinical Nursing*, 12, (5), 697-706.

Crisp, J. (1995) Making sense of the stories that people with Alzheimer's tell: a journey with my mother. *Nursing Inquiry*, 2, 133 – 140.

Day, M. and Wills, T. (2008) A Biographical Approach. *Nursing Older People*, 20, 6, 22 – 24.

Department of Health (2009) Living Well with Dementia: A national dementia strategy. DH. London.

Dewing, J. (2007) Participatory research: a method for process consent with persons who have dementia. *Dementia: The International Journal of Social Research and Practice*, 6, (1), 11 – 25.

Eisenhardt, K. (1989) Building theories from case study research. *Academy of Management Review*, 14, (4), 532-550.

Equality and Human Rights Commission (2011) *Close to Home – an inquiry into older people and human rights in home care*. EHRC, London.

Gibson, F. (1991) *The lost ones: recovering the past to help their present*. Dementia Services Development Centre. Stirling.

Gibson, F. (1994) What can reminiscence contribute to people with dementia? In J. Bornat (ed) *Reminiscence Reviewed*, 46 – 60. Open University Press. Buckingham.

Gibson, F. (2005) Fit for Life: The contribution of life story work. In M. Marsall (ed) *Perspectives on Rehabilitation and Dementia*, 175 – 179. Jessica Kingsley Publishers. London.

Gibson, F. and Carson, Y. (2010) Life story work in practice: aiming for enduring change. *Journal of Dementia Care*, 18, 20 – 22.

Guba, E. and Lincoln, Y. (1994) Competing paradigms in qualitative research. In N. Denzin and Y. Lincoln (eds) *Handbook of Qualitative Research*, 105-117. Sage. London.

Hansebo, G. and Kihlgren, M. (2000) Patient life stories and current situation as told by carers in nursing home wards. *Clinical Nursing Research*, 9, (3), 260-279.

Heliker, D. (1997) A narrative approach to quality care in long term care facilities. *Journal of Holistic Nursing*, 15, (1), 68-81.

Hewitt, H. (1998) Life-story-books for people with learning disabilities. *Nursing Times*, 94, (33), 61-63.

Hewitt, H. (2000) A life story approach for people with profound learning disabilities. *British Journal of Nursing*, 9, (2), 90-95.

Keady, J., Williams, S. and Hughes-Roberts, J. (2005) Emancipatory practice development through life story work. Changing care in a memory clinic in North Wales. *Practice Development in Health Care*, 4, 203 – 212.

Keady, J., Williams, S. and Hughes-Roberts, J. (2007) Making mistakes: using co-constructed inquiry to illuminate meaning and relationships in the early adjustment to Alzheimer's disease – a single case study approach. *Dementia: The International Journal of Social Research and Practice: Special Issue*, 6, (3), 343- 364.

Kellett, U., Moyle, W., McAllister, M., King, C. and Gallagher, F. (2010) Life stories and biography: a means of connecting family and staff to people with dementia. *Journal of Clinical Nursing*, 19, 1707 – 1715.

Lacey, A. and Luff, D. (2001) *Qualitative data analysis*. Trent Focus. Sheffield.

Life Story Network (2011) <http://www.lifestorynetwork.org.uk/knowledge-research/>
Accessed 09/01/2013.

Lincoln, Y. (2001) Engaging sympathies: Relationships between action research and social constructivism. In P. Reason and H. Bradbury (eds) *Handbook of Action Research: Participative Inquiry and Practice*, 124-132. Sage. London.

Manley, K., McCormack, B. and Wilson, V. (2008) Introduction. In K. Manley, B. McCormack and V. Wilson (eds) *International Practice Development in Nursing and Healthcare*, 1 – 16. Blackwell Publishing. Chichester.

McKee, K., Wilson, F., Elford, H., Goudie, F., Chung, M. and Bolton, G. (2002) *Evaluating the Impact of Reminiscence on the Quality of Life of Older People*. Sheffield Institute for Studies on Ageing. Sheffield.

McKeown, J., Clarke, A. and Repper, J. (2006) Life story work in health and social care: systematic literature review. *Journal of Advanced Nursing*, 55, 237 – 247.

McKeown, J., Clarke, A., Ingleton, C. Ryan, T. and Repper, J. (2010a) The use of life story work with people with dementia to enhance person-centred care. *International Journal of Nursing Older People*, 5, 148 – 158.

McKeown, J., Clarke, A., Ingleton, C. and Repper, J. (2010b) Actively involving people with dementia in qualitative research. *Journal of Clinical Nursing*, 19, 1935 – 1943.

Moore, L. and Davis, B. (2002) Quilting narrative. Using repetitive techniques to help elderly communications. *Geriatric Nursing*, 23, (5), 262 – 266.

Moya, H. (2010) Identities on paper. Constructing lives for people with intellectual disabilities in life story books. *Narrative Inquiry*, 19, (1), 135 – 153.

Murphy, C. (2000) *Crackin' Lives: An Evaluation of a Life Story-Book Project to Assist Patients from a Long Stay Psychiatric Hospital in their Move to Community Care Situations*. (Unpublished work)

National Collaborating Centre for Mental Health (2006) *A NICE-SCIE Guideline on Supporting People with Dementia and their Carers in Health and Social Care. National Clinical Practice Guideline Number 42*. British Psychological Society and Gaskell. London.

Nolan, M., Hanson, E., Magnusson, L. and Andersson, B. (2003) Gauging quality in constructivist research: The Aldre Vast Sjuharad model revisited. *Quality in Ageing - Policy, Practice and Research*, 4, 22-27.

Phinney, A. (2002). Fluctuating awareness and the breakdown of the illness narrative in dementia. *Dementia: an International Journal of Social Research and Practice*, 1, 329-344.

Ritchie, J. and Spencer, L. (1994) Qualitative data analysis for applied policy research. In A. Bryman and R. Burgess (eds) *Analyzing Qualitative Data*, 173 – 194. Routledge. London.

Rodwell, M. (1998) *Social Work Constructivist Research*. Garland. New York.

Russell, C. and Timmons, S. (2009) Life story work and nursing home residents with dementia. *Nursing Older People*, 21, (4), 28 – 32.

Social Care Institute for Excellence (2010) Dignity in Care SCIE Guide 15. At: <http://www.scie.org.uk/publications/guides/guide15/index.asp>

Accessed on 09/01/2013.

Stake, R. (1995) *The Art of Case Study Research*. Sage. Thousand Oaks.

Thompson, R. (2009) Realising the potential: developing life story work in practice. In K. Sanders and T. Shaw (eds) *Foundation of Nursing Studies Dissemination Series*, 5, 5, 1 - 4. London.

<http://www.fons.org/resources/documents/Dissemination%20Series/DissSeriesVol5No5.pdf> Accessed on: 09/01/2013.

Wills, T. and Day, M. (2008) Valuing the person's story: use of life story books in a continuing care setting. *Clinical Interventions in Ageing*, 3, (3), 547 – 552.

Yin, R. (2009) *Case study research: Design and methods* (4th edn.) Sage. Thousand Oaks.

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