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Exploring good practice in life story work with people with dementia: The findings of a qualitative study looking at the multiple views of stakeholders



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Abstract

Introduction: Despite growing international interest in life story work as a tool for person-centred dementia care, there is little agreement on what constitutes good practice and little evidence from the perspectives of people with dementia or their family carers.

Design and methods: This paper reports the findings from the qualitative element of a larger study looking at the feasibility of evaluating life story work. Ten focus groups were held with 73 participants: four groups of people with dementia (25 participants); three with family carers (21 participants); and three with staff, professionals and volunteers with experience of life story work (27 participants).

Findings: It became apparent through our focus groups that, when people talk about 'life story work', different people mean different things. This related to both process and outcomes. In particular, a person with dementia may have very different views from others about what life story work is for and how their life story products should be used. There was general agreement that a good practice approach would be tailored to the individual needs and preferences of the person with dementia. However, in practice many settings used templates and the process was led by staff or completed by family carers.

Conclusion: We produced nine key features of good practice which could be used to guide the life story work process. Key elements include the recognition that not everyone will want to take part in life story work and that some people may even find it distressing; the importance of being led by the

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person with dementia themselves; the need for training and support for staff, carers and volunteers; and the potential for life story work to celebrate the person's life today and look to the future.

Keywords

life story work, dementia, good practice, person centred, qualitative, stakeholders

Introduction

Everybody has a life story. These are rich and varied and can be used to communicate who we are to the people around us. People with dementia sometimes need help to communicate their histories and identities, and it has been suggested that life story work could present a way for them to do this more easily. Life story work involves helping people to record aspects of their past and present lives either for personal use or to improve care. A rapidly developing body of international literature suggests that life story work might be an important tool for enhancing person-centred dementia care (Brooker & Latham, 2015; Cohen, 2000; Egan et al., 2007; Grøndahl, Persenius, Bååth, & Helgesen, 2017; McCarthy, 2011; McKeown, Clarke, Ingleton, Ryan, & Repper, 2010; Thompson, 2011; Yasuda, Kuwabara, Kuwahara, Abe, & Tetsutani, 2009). However, there is currently little consensus on the specific activities involved in life story work as an intervention to improve care. Some advocate personalised approaches to recording and presenting information (van den Brandt-van Heek, 2011) while others a more prescriptive pre-specified approach (Haight, Gibson, & Michel, 2006). Some argue for the centrality of the person with dementia in their creation (Rose, 2006; Savitch & Stokes, 2011), while others work primarily with family carers (Caron et al., 1999; Hepburn et al., 1997) or care staff (Burgess, 2008).

The importance of an evidence base for interventions is stressed by policymakers, commissioners and practitioners, and some evidence for the positive effects of life story work on various standardised measures has been documented (Subramaniam & Woods, 2012). However, the lack of any consistency in approach means that it is far from proven that this is an intervention that 'works' for people with dementia. Indeed, it is questionable as to whether we can currently consider this as a coherent intervention per se, as it often looks quite different in different situations, owned and controlled by different groups and used for different purposes. If we are to properly evaluate the effects of life story work we must first agree upon what life story work *is* and what constitutes good practice. Understanding this will not only make the implications of research findings about life story work much clearer, it will also help those who are looking to implement life story work in care settings to direct their efforts in ways that are most acceptable and effective.

Background

This paper reports part of a larger study which examined life story work as a complex intervention. Review work compiled available evidence published in English between 1985 and August 2012, complemented by the views of people with dementia, family carers and professionals through a series of focus groups. A national survey of family carers and care service providers was conducted to shed light on the pervasiveness and types of life story

work currently conducted in England. Finally, a more in-depth feasibility study of life story work in six care homes and four inpatient mental health assessment wards was carried out to gain a better understanding of the practice and potential costs and effects of life story work in these settings and to assess the feasibility of full-scale evaluation (Gridley, Brooks, Birks, Baxter, & Parker, 2016).

In this paper, we focus primarily on the findings from focus groups which explored the multiple views of stakeholders on life story work, which formed part of the development stage to define and understand good practice in life story work.

Methods

Medical Research Council guidance points to the special challenges that evaluation of complex interventions poses for evaluators (Craig et al., 2008). The guidance suggests that, before formal evaluation of effectiveness and costs commences, an understanding of the existing evidence base and a developed theory of change must be in place, including a clear definition of the intervention in question and the outcomes predicted. In order to establish stakeholder views on definitions, good practice, predicted outcomes and routes to achieving those outcomes, focus groups were held with people with dementia, family carers, and professionals or volunteers with experience of life story work. Research ethics approval for this stage of the project was obtained from the NIHR Social Care Research Ethics Committee for England (REC reference number: 12/IEC08/0046).

Recruitment to the focus groups was supported by two community interest companies, Innovations in Dementia CIC and the Life Story Network CIC, and a national charity, Dementia UK. Focus groups with people with dementia were held in settings already known to and attended by participants, such as day centres, to maximise comfort and familiarity. Written consent was obtained from all participants. Only people with the capacity to give informed consent were included in this stage of the project.

Ten focus groups were held with 73 participants in total. Four focus groups were held with people with dementia (25 participants); three with family carers (21 participants); and three with staff, professionals and volunteers (27 participants). Participants with dementia had a range of experiences of life story work (from having recently made a life story book, to having never heard of life story work) and all had capacity to give informed consent to take part. Family carers all had experience of 'doing' life story work with the person they cared for (or formerly cared for), and included daughters, sons, wives and husbands, as well as one son-in-law, one daughter-in-law, one niece and one granddaughter. Participants in the staff focus groups included nurses, occupational therapists, support workers, service managers (day centre, care home, social work) and self-employed practitioners. All had direct experience of life story work.

A recent review of strategies to ensure the meaningful inclusion of people with dementia in qualitative research underlined the importance of tailoring the chosen approach to maximise the capacity of participants to respond (Murphy, Jordan, Hunter, Cooney, & Casey, 2015). Simply asking people with dementia to answer factual questions that rely heavily on immediate memory may be anxiety inducing for the participants and not fruitful for the research. Aguirre, Spector, Streater, Burnell and Orrell (2011) used pictures and activities in their focus groups to help stimulate discussion. Experts on our research advisory panel felt it would be helpful to use props or visual aids in our focus groups with people with dementia to ground the discussion and encourage debate. Four specimen life stories were used in the

focus groups: one based on a template; one created by a researcher using photographs and text; one digital life story on a touch screen tablet; and one in a memory box with objects, photographs and documents. Although these did not cover the full range of life story formats possible, they are the formats most often referred to in the literature. We also asked participants to bring in their own life story products or an object or photograph that they would be happy to share with the group. The focus groups began with a discussion of these specific products and artefacts before moving on to more general topics such as the outcomes of recording and sharing life stories and the best ways to do this. The researchers followed a topic guide designed with input from our network of advisers with dementia and carers. The topic guide can be viewed on the project webpage <https://www.york.ac.uk/spru/projects/life-story-feasibility/>.

The specimen life stories were also shown at the focus groups with carers and professionals but the discussion was less focussed on these examples, as the expectation was that participants would be able to talk more from their own experiences of doing life story work in their professional or caring roles. Again, the topic guides for these focus groups can be found on the project webpage.

All focus groups were audio-recorded, transcribed and analysed thematically using the Framework approach (Ritchie, Spencer, & O'Connor, 2003). To maximise the robustness of findings, the analysis focused on identifying those characteristics of good practice where there was agreement across all types of participant. Using Excel, data were first arranged into categories, by focus group, participant type and individual participant, allowing themes common to all groups to become more visible. Central charts were then constructed relating to good practice, observed and desired outcomes, problems and challenges.

A virtual advisory group of people with dementia, and another of carers, worked with us throughout the larger project. When findings from the focus groups were available we met with a subgroup of these advisers to discuss our initial interpretations and further develop the analysis.

Findings

It became apparent through our focus groups that, when people talk about 'life story work', different people mean different things. This related to both process and outcomes, so not only were activities and actors varied but descriptions of what participants were hoping to achieve and how they planned to use what was made were also heterogeneous. Our analysis focused on determining the core elements of good practice that could be agreed upon by all, with the help of our virtual advisors and advisory group.

What is life story work?

The range of activities and formats that could be grouped under the heading 'life story work' was striking: from one page summaries of key events and preferences, to animated films and lengthy books. There was general agreement that a good practice approach would be tailored to the individual needs and preferences of the person with dementia. However, in practice many settings used templates and the process was led by staff or completed by family carers. To understand these choices, it is necessary to consider the 'why', 'how' and 'who' of life story work in some detail.

Why do people do life story work?

Analysis of the outcomes that professionals, carers and people with dementia hoped for indicated that people with dementia often have very different motives for embarking on life story work from the carers and professionals who work with them. People with dementia said they would undertake life story work primarily for personal reasons: to preserve memories, to share and enjoy with friends and family, to celebrate achievements or simply to have a project to work on. While some carers and professionals shared these motives, they were also concerned about recognising personhood and tailoring care to meet the needs of individuals. Some also saw great potential for life story work to ‘problem solve’, for example to help understand and deal with behaviour they found challenging, something that the people with dementia we spoke to rarely mentioned. The distinction was perhaps best articulated by one of the participants with dementia:

... as far as I can see, we're getting a, kind of, diversion between writing the story as a matter of personal interest and writing a story ... in terms of things that would help other people to know us when we couldn't properly represent ourselves. (DF3R1)

Recognition of this distinction is crucial to our understanding of good practice. A personal document might be very different from a tool for care: both in terms of its content, its use and its format.

In terms of content, people may choose to put very different information in a document for their own personal use than they would put in something that is to be viewed and used by professionals. Brooker uses a ‘three drawer’ model to differentiate between the information we are happy to share with anyone (top drawer), that which we would only share with close friends and family (middle drawer) and that which we may not want to share with anyone (Brooker, 2010, cited in McKeown, Ryan, Ingleton and Clarke (2015)). Unfortunately, the sorts of information that might help professionals to understand a person's behaviour may be exactly the sort of ‘bottom drawer’ information that they would not choose to share with a stranger (like a history of abuse) or chose to be reminded of in a personal life story document (such as a traumatic experience). Even information that a person might happily share in a conversation with a stranger might not be aspects of their life they want to be reminded of every day or want people close to them to know. In one of our focus groups, a participant with dementia told us about many of the ups and downs in her life but said that none of these had featured in her life story book, which was reserved for pictures and memories with pleasant or happy associations.

Most of the people with dementia we spoke to felt that some support from professionals to help make the life story product would be helpful, especially for people who did not have a family carer. However, they seemed unaware of the possible motives professionals might have for encouraging them to engage in life story work or how the finished product might be used. Some people felt strongly that a life story should be ‘a private thing’, or at least that they should be present when other people looked at it. Yet most of the professionals assumed (and the family carers hoped) that the life story product would be viewed by care staff in order to get to know the person better, with some advocating its use in care planning or handover meetings, without the person with dementia present.

The choice of format, whether to make a short summary or a more comprehensive life story, was similarly influenced by the motives people had. A life story designed to ensure

care staff know something about the person might, for example, take a very different form from a document intended to be shared with friends and family. Some participants suggested making different versions for different uses or audiences: such as flash cards, a collage or a one-page summary of key information that would be easily accessible to staff, as well as a more comprehensive book or digital product that the person with dementia might enjoy looking through, sharing and adding to. The former might also be useful for transitions, for example if a person is admitted to hospital, and there are several short templates available which have been designed specifically for this purpose. However, few of the participants with dementia we spoke to felt that a short written summary could take the place of something more comprehensive that they had created themselves.

How is life story work used?

Confidentiality and data protection were common topics in our focus groups. Some staff felt so strongly about confidentiality that life story books were locked away in staff offices: ‘... it boils down to confidentiality. We can’t have them lying around in the lounge in case another patient picks them up or a relative sees them’ (PF2R2: Staff member from mental health assessment unit).

However, others argued this raised issues about the ownership of the life story and access rights. Instead, they suggested that consent be obtained (ideally from the individual, but if they lacked capacity then from a family member or other consultee) for information to be shared and that this should specify how widely and in what ways it could be shared.

Family carers felt that the outcomes of life story work depended largely on whether care staff took on-board and used life story information when planning and delivering care. Unfortunately, many carers were doubtful that this happened and several gave examples of lovingly crafted life story documents that were ignored in care settings:

Well, I don’t know if, as a carer, I, sort of, invested too much in the life story thing, thinking that the people who were helping me care for [husband] ... would pick these things out of this, which they haven’t done, because they haven’t had time ... (CF2R6: Wife of person with dementia)

This latter carer refers to the life story document not being used by care staff because ‘they haven’t had time’ ... This was a common theme, brought up by both family carers and care staff themselves. The professionals in our focus groups tended to state enthusiasm for the principle of life story work as a tool for improving and personalising care, but felt this was in conflict with a system they perceived to be prioritising short-term targets over such longer term gains: ‘We’ve got incredibly strong targets at the moment, which is having a heavy impact on our therapeutic work with the patients...’ (PF1R1: Occupational therapist on hospital ward).

Professionals generally felt that collecting information and learning about the person behind the diagnosis was the most meaningful part of life story work. Some argued that this could be undertaken concurrently with routine care (e.g. chatting to someone about their life while helping them dress) which might also help in a time-pressured environment where an additional component to routine care is not always viewed positively. However, focussing solely on this process could mean information is acquired by one person but never recorded or shared more widely. The wider potential for life story work to be used for care planning and problem solving could well be lost in such instances.

An alternative solution to the problem of limited time suggested by some professionals was to encourage *family carers* to put life story documents together, which could then be used by care staff, wider family and people with dementia themselves. However, in this case staff would not be actively engaged in the collection of information from people with dementia, meaning they would miss those key interactions with people with dementia which were seen by many to be the most meaningful part of the life story work process.

Another element highlighted by participants was the delayed temporal emphasis of the process and possibly static nature of resultant product. There was general agreement that it would be good practice to update life story products regularly and that the life story should not be given precedence over the current expressed preferences of an individual. However, in practice there were mixed views on the practicalities of this. The responsibility for updating life story products, for example, as well as the limitation of some formats to updates (e.g. filmed materials) present significant practical challenges. One suggestion was to combine life story work with daily reporting, as this manager of a community day service had done:

...[the life story includes] the important information that we need to report [such as medication use], but it also includes photographs of where we've taken the person. And we work with the person to compile this reporting, so they're involved and they don't feel like... "What's she saying about me?" ... we encourage [families] to include information in the book, as well ... we use a lot of scrapbooking techniques ... (PF2R8: Independent dementia care/activity provider)

Who should do life story work?

Not everyone thinks life story work is for them. Some people with dementia simply did not see the point: 'I tend to just, sort of, say, "Right, this is done" and it's done, and then move onto the next thing, rather than talking about it a lot' (DF3R4: Person with dementia).

Others actively rejected the notion that reminiscence was a desirable thing and some carers confirmed that the people they cared for had not wanted to participate in life story work, with responses ranging from indifference to considerable distress:

...a couple of times, people have tried to do life story work with him...but it wasn't very successful...he didn't want to go back. And very, very early on, he really didn't like looking at photographs, and particularly photographs of people who were dead. ...a few months on, we had another helper from the mental health team who wanted to have another crack at this, but it was just as bad. (CF2R6: Wife of person with dementia)

It is of note in this latter example that, despite the person with dementia previously indicating that he did not want to 'go back' or look at photographs, another worker nevertheless thought it wise to attempt life story work again. This implies a general belief amongst practitioners in the potential for life story work to improve outcomes that may override the evidence of experience or even the expressed preferences of the person the life story is about.

Exploring people's personal histories can be emotional and there is always the possibility of stumbling upon sensitive topics. Suggestions were made for avoiding such topics, but some argued that discussing emotional subjects is not always a bad thing and may provide a much-needed opportunity to be listened to and have feelings validated. There were mixed

views in the focus groups with people with dementia about whether they would choose to include upsetting memories in their life stories, but our advisers with dementia reiterated that those wanting to discuss difficult issues should be supported to do so. Training for people facilitating the life story work process was viewed as essential, but support should also be on hand to help handle sensitive information (including potential safeguarding disclosures) and to judge when an onward referral is required:

...closing the can of worms...for a Level 2 care staff [member], that could be an incredibly difficult feat to achieve...it's about leadership.... and training...to make sure that staff feel that they're empowered and they've got the skills to be able to do it. (PF3R6: Care home manager)

One suggestion to help care staff understand how it might feel for life story information to be shared with others was to encourage staff to make their own life story products. Some participants felt that this had the potential to create greater equality between staff and service users and build relationships. Rather than information flowing in only one direction, people with dementia and their families could learn about the staff working with them. This would clearly be important to some people with dementia, as was illustrated when this focus group participant said: 'I would like to know who you are referring to the staff and researchers in the room (DF2R4: Person with dementia).

The severity of the person's dementia is a particularly important factor in considering what type of life story work should be done and what outcomes can be achieved. The people with dementia involved in our focus groups were all in the early- to mid-stages of dementia (as they needed the capacity to contribute to a group discussion). This meant that they also had the capacity to lead or at least influence the life story work process and specify how the final product was to be used. Unsurprisingly, those with capacity wanted to use that capacity to lead the process and make something primarily for their own use.

There was concern from the carers and professionals in our focus groups, however, that people with more severe dementia may not be able to participate so actively. The experiences of family carers, many of whom had cared for a person until their symptoms had become very severe, confirmed that a person's ability to take an active role in life story work could reduce over time. As a result, the reasons for doing life story work might change, along with the approaches that are most likely to give benefit. One carer, for instance, initiated life story work with his mother in order to help her maintain her writing skills, but as her dementia progressed the mother's ability to participate in making the life story deteriorated. Over time, this dyad's life story work became less focussed on recording aspects of the mother's life and more about reminding her of the things already recorded. Nevertheless, she did still seem to benefit from this: '...this angel from Crossroads charity...she took the book, took it out and read everything to my mother and my mother does respond...I think what she remembers is a nice feeling' (CF2R1: Son of person with dementia).

The outcomes of life story work in the later stages of dementia may be different from those achievable in earlier stages. Professionals agreed that life story work was best started early, when people are still able to express their views and take a lead in the process. However, they also felt that there could be numerous benefits (not only for problem solving, but also by raising opportunities to invoke a 'nice feeling') throughout the dementia journey and that it was thus never too late to get started. Nevertheless, it should not be assumed that the feelings evoked through life story work will always be positive, even if they have been in

the past. Dementia is not a static state, and as a person's dementia progresses life story documents could evoke different responses from those they previously evoked.

Two of the key functions of life story work identified by professionals working with people in the later stages of dementia were to help manage behaviour that was felt to be challenging and to help tailor end of life care more faithfully to the needs and preferences of the person with dementia. Good practice with regard to these functions could not be commented on (from personal experience) by the people with dementia in our focus groups as none had yet reached this stage of dementia. However, we were able to consider which approaches appeared to be the most acceptable and have the most positive impact from the observations of professionals and family carers and the expectations of the people with dementia.

Discussion

We found no single approach to, or definition of what constitutes, 'life story work'. In particular, there appears to be a divergence between approaches to life story work that are led by the person with dementia and those that are led by care staff. This finding tallies with that of a recent review of life story resources which identified mixed messages about whether life story work is a formal intervention for staff to run or an informal activity that people with dementia and their families engage in (Kindell, Burrow, Wilkinson, & David Keady, 2014).

The variety of approaches to life story work reflects to some extent the wide variety of people and settings involved. The additional complication of a progressive disease process which gradually affects people's capacity to lead or influence the process and consequently what outcomes might be achieved, for them and for their care, is also an important factor. In her study of the impact of dementia on the illness narrative, Phinney (2002) observed that over time the telling of a person's story inevitably becomes a shared activity.

The motives of the people with dementia we spoke to about life story work appeared to be quite different from those of family carers and professionals doing life story work with them. This is a significant finding, as much of the literature to date has failed to report the views of people with dementia themselves (Kaiser & Eley 2017, McKeown, Clarke, & Repper, 2006). Motivations can of course be multiple and overlapping. Professionals may wish to help people with dementia (re)affirm their identity, whilst also hoping to get to know the person better *and* potentially learn something that could help explain behaviours they find challenging. This has been acknowledged by other work which refers to a 'spectrum' of definitions of life story work ranging from those concerned primarily with the construction and preservation of identity to those focussing squarely on health and social care practice (Kaiser & Eley, 2017).

There were some marked differences between the process of life story work described and recommended by participants in our focus groups, and that which is most often tested in published evaluations of life story work. To date, most of these evaluations have tested the outcomes of a very structured approach to life story work, delivered by a therapist or research student, over a limited time period (say 12 weeks) with protected time to dedicate to this (Moos & Björn, 2006; Subramaniam & Woods, 2012; Subramaniam, Woods, & Whitaker, 2014). This approach does not resemble the experience of practice reported by the participants of our focus groups and is far from the flexible, user-led approach considered by our participants to be good practice. Moreover, given the time and resource

constraints reported by the professionals and family carers we spoke to, it is hard to imagine this type of approach being sustainable in most dementia care settings.

Rather than a pre-packaged intervention, delivered by external professionals, participants felt life story work should be embedded in the culture and everyday workings of their organisations. Indeed, it is unlikely that the stated objectives of improving staff attitudes and care planning would be achievable if external professionals were brought in to deliver the life story work. Moreover, our data suggest that for a life story product to reflect the changing needs and preferences of people with dementia over time, life story work itself must be a dynamic process. A key concern of people with dementia was that, as their dementia progressed, the life story product, its words and pictures ‘set in stone’, might be given more credence than the words and deeds of the person still living and feeling. It is vital that life stories are kept alive through ongoing reassessment of their relevance and usefulness to the person with dementia by people who know and can support the person well.

Manualisation is a common feature of studies looking to ascertain the effectiveness of psychosocial interventions. The aim is to ensure that the intervention is implemented in a standardised fashion across study sites and can be replicated in the future. However, a key feature of good practice in life story work is that the approach taken is tailored towards the needs and preferences of the person with dementia. To this end, it does not seem wise to specify one preferred or standardised way of doing life story work. Rather, good practice requires flexibility, sensitivity to the wishes of the person with dementia and an awareness of certain pitfalls. In this respect, our findings tally with those of McKeown et al. (2015) who outline a number of potential challenges of life story work but conclude that, with the right training and support for staff, organisations need not be deterred.

Conclusion

The clear message from our findings is that simply advocating ‘life story work’ as a way of improving outcomes for people with dementia is too simplistic. We need to specify which approach to life story work we mean, in what setting and for what purpose. This is important for future research, which must be designed with clear definitions and articulation of who the life story work is intended to benefit, and by which route.

Asserting that there is no single ‘right’ way to do life story work presents a challenge when considering good practice, as no definitive guide or manual can be produced. Our research instead produced nine *key features* of good practice which could be used to guide the life story work process as it unfolds, in its many guises, in real world settings. These key features are grounded in the focus group data and were refined in discussion with our advisors with dementia and their carers. The full list of good practice learning points feature in a summary of the research which can be downloaded from <https://www.york.ac.uk/spru/projects/life-story-feasibility/> along with a short film which is freely available. Key elements include: the recognition that not everyone will want to take part in life story work and that some people may even find it distressing; the importance of being led by the person with dementia themselves; the need for training and support for staff, carers and volunteers; and the potential for life story work to celebrate the person’s life today and look to the future.

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