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McKinney, A. (2017). The value of life story work for staff, people with dementia and family members. *Nursing Older People*, 29(5), 25-29.

Published in:
Nursing Older People

Document Version:
Peer reviewed version

Queen's University Belfast - Research Portal:
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The value of Life Story work for staff, people with dementia and family members.

Abstract

Dementia is a term used to describe a collection of symptoms that include problems with memory, self-care, reasoning and communication. Care interventions that focus on preserving people's dignity and identity are therefore essential. Using Driscoll's reflective model to guide critical thinking, this paper reflects on the use of one intervention, namely life story work, to promote person-centred care for people with dementia. It explores the value or effect of life story work for healthcare staff, the person with dementia and family members. It also highlights best practice guidelines that are useful to consider to promote its optimal success as an intervention in dementia care, for example, instigating it early in the dementia journey and embedding it in a supportive culture. It is important to highlight to nursing students the many positive aspects of incorporating life story work into practice.

Keywords: dementia, life histories, life story work, life stories, older people, person-centred care.

Introduction

Worldwide approximately 35.6 million people live with dementia and this number is expected to double by 2030 (Tranvag et al, 2016). Dementia is a progressive condition, which means that the symptoms associated with it will gradually get worse (National Institute for Health and Care Excellence (NICE), 2013). Persons with dementia will progressively lose cognitive and social skills and, overtime, it may become difficult for them to express themselves, retain and understand information and communicate (Alzheimer's Society, 2017). This progression differs from person to person which means that the degree to which the symptoms affect the person varies (NICE, 2013). People with dementia also continue to retain their own unique life story and have the right to ensure that their identity and dignity are respected and maintained (Heggestad and Slettebo, 2015). A person-centred approach to care is, therefore, fundamental if the delivery of high-quality care for people with dementia is to be realised (NICE, 2013).

Life story work is one intervention that is an important part of person-centred care and is increasingly used in the care of people with dementia. Being able to share life stories can make it easier to communicate in ways that validate the person or individual (McKeown et al, 2006, Potts, 2012, Savundrayagam, 2014). As a relative of a person with dementia who has recently been admitted to a care home, I have been involved with constructing a life story on behalf of my relative. I am also a lecturer in nursing who is involved in the education of undergraduate nursing students about dementia care. These aspects of both my personal and professional life prompted me to reflect on life story work.

As part of revalidation requirements, the Nursing and Midwifery Council (2017) stipulates that registered nurses must reflect on activities to maintain and develop professional knowledge and competence. Using Driscoll's (2000) model of reflection, this paper therefore explores what is meant by life story work and reflect on its value for patients, relatives and carers of people with dementia. It also outlines best practice guidelines that should be considered when engaging in life story work.

Reflective Approach

According to the Royal College of Nursing (2017) reflection is a conscious effort to think about an activity and consider whether it might be improved on or done differently in the future. It is, therefore, used to give careful consideration to past experiences with the aim of learning from them in order to improve understanding and, hopefully, practice (Skinner and McKinney, 2011). Saunders et al (2016) acknowledged that reflection involves the purposeful and critical analysis of experiences in order to extract deeper meaning from them. As such, reflection is a means whereby nurses can integrate their theoretical knowledge and the practice of nursing and bring them into closer alignment (Skinner and McKinney, 2011).

Several models are available to structure any process of reflection, such as those developed by Johns (1995) and Gibb's (1998). However, the following reflective account uses Driscoll's (2000) model of "what?, so what? And now what?". This three-stage model was appealing because it is clear, simple and straightforward to use.

The what?

Life story work is more commonly being used as an intervention to enhance person-centred care. By understanding the biography of the person it can enable care workers to see the individual behind the disease and also enable the person with dementia to be seen and heard (Kellett et al, 2010, McKeown et al, 2010, Russell and Timmons, 2009). When completing life story work on behalf of my relative, I therefore wanted to include sufficient detail to make it easier for the staff to get to know my relative as best they could.

During the process, I sometimes found myself struggling with what to include and wondered if I was omitting important information. I also found it to be an emotional experience. There was some degree of sadness reflecting on the things that my relative used to do or say that she was now not able to do. However, it was also an uplifting experience as it allowed me to engage with many happy memories that perhaps had been lost.

Engaging with life story work in such a personal way prompted me to ask questions. Is there a "best" way to carry out life-story work? What value does it have for care staff and patients? Could it perhaps have value for relatives? As a nurse lecturer, it also prompted me to reflect further on the use or value of life story work in relation to the literature. I hoped this would develop my professional knowledge in this area and help to advocate best practice in life story work among nursing students.

So what?

Life story work

Before analysing the value that life story work has for care staff, patients and relatives, it is useful to describe what is meant by life story work and its origins. Life story work may be defined as an intervention carried out in health and social care, and encompasses a range of term such as biography, life history and life story. It involves working with a person and/or their family to record an account of a person's past and present life with the aim of using it to affect the care they presently receive (McKeown et al, 2006, Kellett et al, 2010). It usually results in a "product", for example, a story-book or a life history/biography, which might also include pictures, photographs or

memorabilia. This product is compiled to capture memories and stories about a person's life (Alzheimer's Society, 2017).

The principles and philosophy that have shaped life story work were influenced by the work of Tom Kitwood who instigated debates about the importance of maintaining personhood in dementia care (Kaiser and Eley 2017). Kitwood (1997) defined "personhood" as "a standing or status that is bestowed on one human being, by others" and "implies recognition, respect and trust". From this, the concept of providing "person-centred care", a term also coined by Kitwood, has been further explored. The literature has identified a range of characteristics central to the concept of person-centred care, including valuing the person, understanding the biography of the person and developing relationships (Kitwood 1997, McKeown et al 2010).

Knowing the person therefore appears to be at the heart of person-centred care and life story work may be one way to put some of these principles into action (Kaiser and Eley 2017). Heggstad and Slettebo (2015) proposed that "stories tell who we are" and therefore life stories can be valuable tools that can help people with dementia to reclaim their identity. The Alzheimer's Society (2017) maintained that there is no one standard format for a life story book, however, it should be sufficiently inviting to encourage people to look inside, remember, share and engage.

Value of life story work for healthcare staff

Life story work has the capacity to humanise patients as it allows staff to see beyond the diagnosis. It helps staff to understand the person being cared for in the context of their past and it may also help staff to understand behaviours that they observe in the present (McKeown et al, 2006). The literature also refers to the subsequent effect that life story work can have on a person's care. It can help staff to promote more personalized care (McKeown et al, 2010), reinforce an individual's identity (Heggstad and Slettebo, 2015) and help to facilitate interaction (Keady and Swarbrick, 2013). Kellett et al (2010) illustrated the positive effect of life story interventions in the form of a "family biography workshop" on staff and people with dementia and their families. The staff in this study highlighted that the workshop facilitated greater possibilities of "seeing" residents and opened up purposeful opportunities to connect with residents. It also helped staff to understand difficult situations and use these to calm the person. Furthermore, staff identified that the workshop provided increased opportunities to see the person with dementia in the family context and therefore helped to improve the quality of interactions between staff and family members (Kellett et al, 2010).

However, challenges can exist in integrating life story work in practice. Time constraints can limit the degree to which staff can fully incorporate life story work into their care practices (Keown et al, 2006). This highlights the need for organisational and management support if life story work is to succeed. Kellett et al (2010) also identified that finding the best time to focus on the activity may be problematic. They found that a number of staff participants stated that some families were not ready to engage with biographies, particularly if the patient has been recently moved into a care home. However, possible strategies to mitigate this challenge include beginning the process at home and linking new families with a key staff member who has responsibility for facilitating the incremental collection of information (Kellett et al, 2010).

McKeown et al (2010) also argued that life story work should be implemented in a model of practice development whereby facilitation, education and supervision of staff are seen as integral to its

success. Otherwise, there is a risk that life story work may become a task without necessarily meeting its intended person-centred care outcomes (McKeown et al, 2010).

As Gridley (2017) identified, unless care staff take or are granted the time and opportunity to absorb life story information and use it in practice, there is a risk that lovingly crafted life story documents may not fulfil their intended potential. Savundranayagam's (2014) study, for example, found that there were missed opportunities for staff to engage in person-centred communication during routine care tasks.

Value of life story work for patients

As cognitive function declines for people with dementia, they may experience difficulties in talking about and remembering the present, but for many their past stories may remain easier to access. Edvardsson and Nordvall (2008) maintained that telling stories from the past may provide feelings of belonging and safety. For people with dementia, telling their life story can be a way of trying to bring attention back to who the person is and maintaining identity (McKeown et al 2010, Heggstad and Slettebo 2015). However, as noted by McKeown et al (2006) research that focuses on patient perceptions of life story work are less frequently reported in the literature.

McKeown et al (2010) sought to investigate the experiences of older people with dementia in using life story work as well as family carers and care staff. The findings indicated that life story work provided opportunities for people's voices to be heard. Some patients were able to decide what went into the life stories. For others, however, their experience of dementia meant it was difficult for them to contribute to its' development. Nevertheless, the study highlighted the evident pride that individuals experienced in their life story. Heggstad and Slettebo (2015) echoed this finding and emphasised that the residents appeared to have a need to tell their life story. The study also highlighted that some residents became calmer when they started to tell stories and it appeared to have some therapeutic benefits. This perhaps demonstrates how life story telling can help to give a feeling of coping and safety (Heggstad and Slettebo 2015).

How people with dementia present their life story has also been explored. Karlsson et al (2014) illuminated different aspects of their life that persons with dementia focused on. Many commented on their childhood and families, therefore highlighting that connectedness seemed to be a special dimension.

Participants also wanted to highlight their ability to be self-reliant and talked about areas of their life they were proud of such as school, careers or travel (Karlsson et al 2014). These findings are reinforced by Tranvag et al (2016) who also explored the personal dimensions of life that people with dementia perceived as important. Appreciating meaningful work and activities that enriched life in their past still seemed crucial even after the onset of dementia. The data also highlighted how living according to their own moral codes continued to have importance, such as having good manners. These findings highlight some of the key areas that healthcare professionals could encourage people with dementia to talk about when developing life story work. However, as noted by McKeown et al (2017), life story work is not for everyone. For some it may evoke painful memories, therefore a degree of sensitivity should be adopted.

It may also be useful to try adapting their life story around current interests or re-engaging with it at a different time. As McKeown et al (2017) identified, "just because life story work is not right at a particular time, it does not mean that it is never right".

Value of life story work for relatives

Caring does not stop once a person is admitted to a care home and/or hospital setting. Relatives have a need to preserve the identity of the person with dementia and also their own role/identity as a carer (Keady and Swarbrick 2013). Involving family members in life story work is one possible intervention that could help to provide a defined role (McKeown et al 2006). Kellett et al (2010) also indicated that involving family members in biography work has other additional benefits.

One significant finding in their study was that it enabled the family to turn their thoughts to their relative as a person who had lived, enjoyed accomplishments and had meaningful events in their lives. It allowed the relative to “step out” of their everyday experience and see beyond the dementia.

However McKeown et al (2010) also illuminated that life story work has the potential to emphasise what has been lost. Being involved in life story work can be emotional for some relatives and may trigger the grieving process. From a personal perspective, all of these findings were similar to mine. I experienced a variety of emotions during the process, and laughed and cried as I recalled many memories.

My experience was similar to one of the relative's in Kellett et al's (2010) study: “It is an emotional thing....remembering things. But I am learning to look at photos that can make me feel sad and realise the joy of having had that time and those memories rather than never having had them”. I also felt a degree of empowerment through the process as I was doing something positive to enable staff to get to know my relative better and, hopefully, provide more person-centred care. Kellett et al (2010) concurred with this view and noted that family felt that staff purposefully used the knowledge of their relatives' lives to shape their care and interactions. However, while family involvement in life story work may well be valuable, ideally the person with dementia should be supported to take control of their own stories (Jennings 2014, Kaiser and Eley 2017). After all, as one person living with dementia highlighted, “the best perspective for understanding behaviour is from the internal reference of the individual themselves” (Dunne 2017).

Unfortunately, in my relatives' case, due to the extent to which the dementia had progressed, she was no longer able to actively contribute to the life story document. This reinforces the importance of facilitating the process early on in the illness (Kaiser and Eley 2017).

Now what?

Using Driscoll's (2000) model to reflect on life story work has promoted an enhanced appreciation of the value of life story work for people with dementia, care staff and their relatives. It has also highlighted that challenges exist to ensure it can be implemented successfully and illuminated some best practice guidelines that should be considered. In particular, it has emphasised key areas to focus on during the gathering of life story work, including childhood memories, significant relationships, work, hobbies and other activities that the person enjoyed or was proud of and the moral issues of importance to them (Karlsson et al 2014, Tranvag et al 2016).

Where possible it is beneficial to collaborate on the process with the person who has dementia, the family and care staff in a sensitive and supportive way, appreciating that it may evoke emotional experiences and respecting that it may not be for everyone. Emphasising that life story work is not a one off task is also important. A person's life story is never finished and should be viewed as an ongoing process that can always be added to (Thompson 2011). Finally, for life story work to be successfully integrated into practice it should be implemented in a culture where education and support for the process are facilitated (McKeown et al 2010, Thompson 2011).

Conclusion

The aim of this article was to reflect on life story work from the perspective of staff, people with dementia, and family members and to identify best practice guidelines to promote its successful use. Life story work can promote person-centred care for individuals with dementia and is of value for staff and relatives. It is more likely to be successful if it is instigated early in the dementia journey and is embedded in a supportive culture. It is important to highlight to nursing students the many positive aspects of incorporating life story work into practice.

By reflecting on the value of life story work, this article has also demonstrated how the integration of reflection, evidence base and nursing practice can develop personal and professional knowledge. It is hoped that this process will help to encourage other healthcare professionals to re-examine their care practices and, where necessary, to adjust them.

References

- Alzheimer's Society (2017) Remembering together. Making a life history book. www.alzheimers.org.uk/download/downloads/id/1434/rememberingtogethermakingalife-historybook.pdf (Last accessed: 2 May 2017).
- Driscoll J (2000) *Practising Clinical Supervision: A Reflective Approach*. Bailliere Tindall: London.
- Dunne T, Dunne J (2017) Foreword. In Kaiser P, Eley R (Eds) *Life story work with people with dementia. Ordinary lives, extraordinary people*. Jessica Kingsley, London, 7.
- Edvardsson D, Nordvall K (2008) Lost in the present but confident of the past: experiences of being in a psychogeriatric unit as narrated by persons with dementia. *Journal of Clinical Nursing*. 17, 491-498.
- Gibbs G (1988) *Learning by doing: A guide to teaching and learning methods*. Further Education Unit Oxford Polytechnic, Oxford.
- Gridley K (2017) Understanding the outcomes of life story work. In Kaiser P, Eley R (Eds) *Life story work with people with dementia. Ordinary lives, extraordinary people*. Jessica Kingsley: London, 69-82.
- Heggestad A K T, Slettebo A (2015) How individuals with dementia in nursing homes maintain their dignity through life storytelling – a case study. *Journal of Clinical Nursing*. 24, 15-16, 2323-2330.
- Jennings, L (2014) Introduction. In Jennings L (Ed) *Welcome to our world. A collection of life writing by people living with dementia*. Forget-Me-Nots: Canterbury, 15-19.
- Johns C (1995) Framing learning through reflection within Carper's fundamental ways of knowing in nursing. *Journal of Advanced Nursing*. 22, 2, 226-234.
- Kaiser P, Eley R (2017) Conclusions and looking ahead. In Kaiser P, Eley R (Eds) *Life story work with people with dementia. Ordinary lives, extraordinary people*. Jessica Kingsley: London, 237-245.
- Karlsson, E, Savenstedt S, Axelsson K, Zingmark K (2014) Stories about life narrated by people with Alzheimer's disease. *Journal of Advanced Nursing*. 70, 12, 2791-2799.

Keady J, Swarbrick C (2013) Dementia care: family and significant others. *Nursing and Residential Care*. 13, 11, 546-548.

Kellett U, Moyle W, McAllister M, King C, Gallagher F (2010) Life stories and biography: a means of connecting family and staff to people with dementia. *Journal of Clinical Nursing*. 19, 11-12, 1707-1715.

Kitwood T (1997) *Dementia Reconsidered: The Person Comes First*. Open University Press: Buckingham.

McKeown J, Clarke A, Repper J (2006) Life story work in health and social care: systemic literature review. *Journal of Advanced Nursing*. 55, 2, 237-247.

McKeown J, Clarke A, Ingleton C, Ryan T, Repper J (2010) The use of life story work with people with dementia to enhance person-centred care. *International Journal of Older People Nursing*. 5,2, 148-158.

McKeown J, Gridley K, Savitch N (2017) Identifying and overcoming challenges in life story work. In Kaiser P, Eley R (Eds) *Life story work with people with dementia. Ordinary lives, extraordinary people*. Jessica Kingsley, London, 200-211.

National Institute for Health and Care Excellence (2013) Dementia: independence and wellbeing. Quality Standard 30. www.nice.org.uk/guidance/qs30 (Last accessed: 2 May 2017).

Nursing and Midwifery Council (2017) Revalidation. revalidation.nmc.org.uk. (Last accessed: 2 May 2017).

Potts D (2012) The art of preserving personhood. *Reflections: Neurology and the humanities*. 78, 11, 836-837.

Royal College of Nursing (2017) Revalidation requirements: Reflection and reflective discussion. www.rcn.org.uk/professional-development/revalidation/reflection-and-reflective-discussion. (Last accessed: 2 May 2017).

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

Saunders R, Singer R, Dugmore H, Seaman K, Lake F (2016) Nursing students' reflections on an interprofessional placement in ambulatory care. *Reflective Practice*. 17, 4, 393-402.

Savundranayagam M (2014) Missed opportunities for person-centered communication: implications for staff-resident interactions in long-term care. *International Psychogeriatrics*. 26, 4, 645-655.

Skinner J, McKinney A (2011) Acute cardiogenic pulmonary oedema: reflecting on the management of an intensive care unit patient. *Nursing in Critical Care*. 16, 4, 193-200.

Thompson R (2011) Using life story work to enhance care. *Nursing Older People*. 23, 8, 16-21.

Tranvag O, Petersen K, Naden D (2016) Crucial dimensions constituting dignity experience in persons living with dementia. *Dementia*. 15, 4, 578-595.

