

# **The Experience of Student Nurses Developing and Disseminating Dementia Life Stories on Inpatient Wards**

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## **[Main text]**

Life story work can help to counter the threat to a person's sense of identity posed by dementia. It uses information about the person to promote their personhood, wellbeing and connectedness; the information gained can translate into care plans and inform person-centred care (Kaiser & Eley 2017).

In their systematic review, Grøndahl et al (2017) reported that life story work enabled the person to be heard, enabled relatives to reconnect and increased staff understanding. Staff knowledge of residents with mild to moderate dementia has been found to increase significantly once life story books have been completed (Subramaniam et al 2014)

Although much of the literature focuses on people with mild to moderate dementia, life story work could still be important for those in later stages. It has been shown, for example, that people with severe dementia can talk about their situation and related emotions, grounded in a strong sense of identity (Clare et al 2008).

Staff training is necessary for integrating psychosocial interventions into nursing. As Fossey et al (2014) discovered, effective staff interventions involved continued supervision or support following initial training. The current study aimed to understand how student mental health nurses

experienced making life stories with patients on dementia inpatient wards.

## **Method**

### *Participants*

Participants were student mental health nurses on dementia inpatient wards who received training and mentorship in life story work with people with dementia. All students were invited to volunteer for the study and 15 decided to participate.

### *Materials*

As the primary aim was to find out about participants' experiences of life story work and its impact, data was gathered using an explorative evaluation form. The evaluation consisted of seven open questions that explored participants' experience of the training and mentoring, the process of developing a life story and its effects on the care they provided.

### *Procedure*

Participants attended a two-hour training session on life story work, which included the theoretical underpinning, what it is, why it is helpful and how to approach development and dissemination. Materials intended to support completion of life stories were provided. Participants formed small groups to develop a life story collaboratively with a patient. This approach enabled less experienced student nurses (first year students) to pair with more experienced students.

Participants had five weeks to develop a life story. This involved working closely with the patient, and often their family, alongside liaison with multidisciplinary colleagues. Participants could access a weekly mentorship session to support their work and were encouraged to contact the project facilitators with any queries.

On the sixth week, participants presented their life story work to the project facilitators, students and clinical staff with access to this information in their role. Subsequently, participants completed the evaluation form, which provided the data used in the evaluation.

## Data analysis

Thematic analysis was used to qualitatively analyse the evaluation forms (Braun & Clarke 2006). All evaluation forms were read multiple times to familiarise with the data, which was then formally coded. Codes were given names and represented discrete participant extracts relevant to the project's aims.

Codes were grouped together to start to identify patterns in the data, leading to the development of themes and subthemes. Once this had been done, we re-read the evaluation forms to ensure the themes reflected the data and to identify relevant participant extracts.

## Results and discussion

### *Theme one*

Analysis led to the development of three main themes and several subthemes (table 1). The first theme involved the use of life stories to improve person-centred care and four subthemes help to demonstrate different aspects of this.

<b>Theme</b>	<b>Subtheme</b>
Life story to improve person-centred care	Seeing beyond dementia
	Engaging and communicating with patients
	Getting to know patients
	Understand patient behaviour
Facilitators and barriers to developing life story	Working with the patient
	Family involvement
	Professional support
	Time
Developing personal skills	

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Table 1: Themes and subthemes

First, life story work helped participants see beyond patients' dementia diagnosis and reinforce their personhood:

*I was aware before that each individual has history and are not the same person they are now. This, however, reinforced this belief even further due to having the evidence right in front of me... (participant P9).*

Two comments from participant six described how life story work helped to challenge their assumptions about dementia:

*It is easy to view people as 'patients' and not as people that have lived full lives. Helped me to see them as an individual*

*Was able to get more info than expected; it is easy to assume the patient won't be able to give the info themselves.*

Seeing patients as unique individuals affected participants' ability to provide person-centred care in ways demonstrated in the other subthemes. In terms of engaging and communicating with patients, participants perceived life story as a useful communication tool to use with patients:

*[The project] allowed us to be able to build therapeutic relationships and our abilities to gain information (P4).*

And they could use life story to positively engage patients:

*Showing the selected patient their life story work appeared to promote positive engagement, more so than usual (P13).*

Communication and engagement are important in dementia inpatient settings to help patients feel comfortable in unfamiliar surroundings, and ensure that their voice is heard and they are at the centre of care decisions. For example, one participant commented:

*Communication is vital in improving care. It allows people to have a say in their future care (P4).*

Completing life story work helped participants get to know patients and discover their likes and dislikes, which in turn threw light on the kinds of activities they might engage in:

*Was able to... discover what our patient liked, rather than family giving this information (P5)*

*I also got to know the person's favourite activities and this understanding is important in engaging patients with activities that are meaningful and enjoyable to them (P1)*

Participants noted how this linked to person-centred care:

*[Life story work] enabled you to give person-centred, holistic care by knowing about that person and their life in-depth (P15).*

A final subtheme emerging from the use of life stories to improve person-centred care was understanding patient behaviour. Participants commented on how their understanding of this issue grew and how life story could be helpful in this context:

*It will also help you understand some of their behaviour (P5).*

*If they do unusual behaviour or speak of unusual things, I try to review their life story as part of an explanation (P9).*

Jackman and Beatty (2015) described the Newcastle Model of challenging behaviour in dementia care, which discusses life story as a means of understanding it. For example, a person who has experienced sexual abuse might find being supported with personal care distressing.

## *Theme two*

Our second main theme describes aspects that facilitated the completion of life story and barriers that made the work more difficult. It demonstrates that the context and culture in which participants worked impacted on the development of life stories.

The first subtheme here is working with the patient and challenges in relating to their presentation or cognitive difficulties. Several participants commented on the patient's faltering memory and consequent difficulties with obtaining a full history:

*Given their diagnosis – they had difficulties remembering some of their past and current stories, which made it difficult to approach them when they were at their best (P2).*

Commenting that life story work should be completed at an early stage, another said:

*...need to advocate that people complete their life story when they still have the cognitive ability (P1).*

Participants pointed out that not all patients wanted to engage in life story work, or that some started but withdrew their consent to continue. It could be hard...

*...getting the patient to stick with it! Some patients, regardless of what the benefits are, will not want to get involved or feel unimportant to get involved (P10).*

One-to-one life story work may not be suitable for all individuals. Before starting it patients should be able to give their views on it, which enhances rather than undermines their care.

Family involvement, our second subtheme, contributed to life story work too:

*The service user and their family were all very much involved. The family provided in-depth information and clarification (P3).*

The family role was especially relevant when people in the later stages of dementia were less able to give a full account of their life, experiences and preferences. Participants also commented on how it helped families:

*I feel working with the family members helps them feel more involved in their relative's care (P13).*

On inpatient wards contributing to life story work enables families to have a meaningful role in their relatives' care and to be included in care decisions. It might also reassure them that staff have an appropriate understanding of their relatives.

Three participants commented that there was no family to provide additional information. One suggested that, due to the lack of

collaboration, the history gathered could be “biased”. A further five students said that it was generally challenging to get information from family members, one adding that this was because of “family conflicts”.

Some of the challenges are illustrated in the following example:

*At first the wife was difficult to approach and did not want to interact. Didn't 100% cooperate as didn't bring any photos when requested. Finding the time to speak to her [was challenging], whilst bearing in mind her mood and the fact she came to visit him, not me (P9).*

In terms of the professional support subtheme, participants found the facilitators of this project helpful in completing life story work as they provided resources, guidance and regular contact:

*Training facilitator was very supportive. She provided clear instruction and guidance throughout the process (P3).*

Support from fellow students was also valued:

*Working with students from different years was good in terms of the different ideas and knowledge each bring to the table (P1).*

But other participants commented that working with wider teams could act as a barrier:

*Because my patient had no family we sought help from his previous care-co and social worker. However, despite agreeing to help us, they never did and ignored our multiple attempts of contact... (P14).*

In general, though, professional support had a vital role for students undergoing training in their core profession; they may have limited experience of working in health care or with people with dementia. Training, mentorship and support were essential to enable the participants to develop life stories with patients.

The final subtheme in this section is “time” and the need for allocated time to engage in all aspects of life story work:

*...given time by the ward staff to complete the LSW (P1).*

*It has allowed me to give more time to listen to other people's stories (P3).*

Conversely, finding time was a challenge for other participants:

*It was difficult to find the time to complete the life story work on the ward as I feel this piece of work needs a lot of time in order to build a rapport with the patient and their family and gain a good understanding (P11).*

*There was insufficient time to prepare for this as there was other more pressing nursing duties to be carried out. Therefore, I had to make time by myself to talk to patients (P2).*

For the implementation of life story work to be successful, it needs to take place in an organisational culture that recognises and values its importance (Kaiser & Eley 2017).

### *Theme three*

The third main theme was developing personal skills, which focuses on participants' perception of the impact this work had on shaping and developing their skills. Participants felt that the project improved their engagement skills:

*I found building a life story beneficial for my own rapport-building skills... (P14).*

*[Learnt] how to speak to family member that are reluctant to engage at first (P9).*

Other participants commented on how the work had increased their affective skills, including empathy, understanding and patience towards people with dementia:

*My empathy increased for these individuals as it gives me a better idea of their emotions and behaviour and therefore greater understanding (P9).*

*It gave me a lot more patience with patients (P12).*

The project helped develop core knowledge and skill proficiencies required of newly registered nurses as set out by the Nursing and Midwifery Council (2018). These proficiencies include communication and relationship building skills, and there is specific mention of



reminiscence therapies under evidence-based communication approaches.

Since this project did not gather the experiences or views of patients themselves, future studies might consider including the patient perspective, although this would require careful planning given the issues of capacity and consent. For example, how do life story sessions on an inpatient ward affect patients and their care from their point of view.

## **Conclusion**

Training and mentoring students in developing life story work on dementia inpatient wards appeared to have a positive impact on patient care and benefit participants in terms of their clinical work and professional development.

While life story work can enhance the provision of person-centred care, it needs to be embedded in the organisational culture and participants need to be supported with the challenges inherent in this work.

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