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Realising the Potential: Developing Life Story Work in Practice

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Summary

This project aimed to support the introduction of life story work for people with dementia and their families within a number of clinical areas across two Mental Health NHS Trusts. Admiral Nurses were supported by the project leader and an external facilitator worked with ward staff to enable them to develop understanding and skills in doing life story work; encourage the creation of life story books with patients, relatives and family carers and use the life story work to inform practice/care. During the period of the project, many life story books were created and feedback from all involved suggests that the life story work has had a positive impact on care. The support from the facilitators and the Admiral Nurses was identified as being key to achieving developments in practice, as was strong and supportive leadership in the clinical areas.

Background

Between 2005 and 2007 significant investment was made by Central and North West London (CNWL) Mental Health Foundation NHS Trust, in delivering training and supporting the development of health care assistants working in older adult services. This included communication skills and life story work. A life story template was developed and disseminated via direct consultation with clinical managers and qualified nurses (see Thompson, 2007). However despite these efforts, life story work was only implemented in one clinical area.

In another clinical area within the Berkshire Healthcare NHS Foundation Trust, the CNWL dementia life story template was adopted successfully. It was through discussion with the staff in this unit, that a decision was taken to submit a joint proposal for funding to develop life story work further.

Admiral Nurses employed by CNWL NHS Foundation Trust were invited to participate in the project and approval was given by the Director of Nursing.

Seven Admiral Nurses agreed to participate and six in-patient clinical areas were chosen within CNWL, based on the locations in which Admiral Nurses were already based and/or were familiar.

One Admiral Nurse was seconded to work with Berkshire Healthcare NHS Foundation Trust for half a day per week. It was considered that the learning and experience from Berkshire could be shared and that external facilitation from an Admiral Nurse may help embed the life story work further into care practice.

Aims and objectives of the project

The aim of the project was to support the introduction of life story work for people with dementia and their families within a number of clinical areas across two Mental Health NHS Trusts, Central and North West London (CNWL) Mental Health Foundation NHS Trust and Berkshire Healthcare NHS Foundation Trust. This work was facilitated by Admiral Nurses in collaboration with clinical nurse leaders within the respective clinical areas. Whilst it is recognised that life story work may benefit people with a variety of needs, for the purpose of this project the focus was those affected by dementia being cared for within in-patient settings. This decision was based on the specialist role and expertise provided by Admiral Nurses in working with people with dementia and their family and carers.

The objectives of the project were:

- To enable Admiral Nurses to facilitate the introduction of life story work using a systematic approach which includes considering the context and culture in which development is taking place
- To promote knowledge and understanding of the principles and benefits of life story work
- To evaluate the potential benefits of life story work in:
 - Improving assessment and understanding of people with dementia and their families
 - Promoting positive relationships between staff and patients
 - Improving attitudes towards older people
 - Promoting the delivery of person-centred care
- To support the development of Admiral Nurses as facilitators of practice development

Nature of clinical areas

The in-patient wards involved in the project were all based within older adult mental health services. These included:

- Three mental health assessment wards
 - One organic assessment ward (twelve beds)
 - Two mixed functional and organic assessment wards (one with sixteen beds and one with twenty four beds)
- Four continuing care wards
 - Three based within the same unit with fifteen beds each
 - One ward with twenty three beds

Facilitating development

A steering group was formed involving ten key stakeholders from the respective trusts, including: directorate manager, service managers, practice development nurse, medical lead and two family carers. Guided by agreed Terms of Reference, the steering group met four times within the period of the project to discuss and monitor progress, offer expertise and leadership and provide key links to the participating trust's governance structures.

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Following initial discussion with the FoNS practice development facilitator, an introductory day was arranged for all the Admiral Nurses to discuss the aims and objectives of the project and agree upon structures to support the process. It was agreed that the Admiral Nurses would meet every six to eight weeks for development days to provide support, learning and development in relation to their role as facilitators of practice development.

In total nine development days were held between November 2007 and May 2009. These were supported by the project leader and the FoNS practice development facilitator and used a variety of approaches to enable reflection, action planning, the development of facilitation skills and evaluation. These development days were written up and shared as a record of the process and the developments made.

At the outset of the project, discussions were held with the ward managers resulting in three or four members of staff from each clinical area being identified to work on the project with the supporting Admiral Nurse. The role of the Admiral Nurse was clearly identified as that of a facilitator to support staff to develop understanding and skills in doing life story work and in encouraging ownership of this work by the staff.

A life story training day was offered to two representatives from each of the ward teams plus the associated Admiral Nurse from each of the clinical areas to provide an opportunity for participants to learn more about life story work and to support skill development. An exercise was also used to identify both driving forces and hindering forces to doing life story work in the respective clinical areas.

The Admiral Nurses aimed to visit the clinical areas approximately once every two weeks to work with at least two of the identified staff. This was achieved in most cases although there was some variance. Sometimes this was not possible due to the workload of the Admiral Nurses themselves and in some areas difficulties were experienced in arranging visits with staff due to rota changes, night duty and problems arranging for identified staff to meet together. The latter was particularly an issue in areas where leadership was not consistent.

When working with staff, the Admiral Nurses used a variety of approaches to enable staff to develop a greater understanding of the values and beliefs they held about caring for patients with dementia and the culture and context of the clinical area as well as facilitating the use of life story work itself. This included:

- A values clarification tool (see full report), the Context Assessment Index (McCormack et al, 2009) and observations and discussions with staff
- Working with staff in groups where possible to promote discussion and sharing of information
- Role modelling working with family carers/patients to gather life story information
- Encouraging use of a communication book between visits
- Organising tea parties/social events with patients, staff and family carers to launch and promote life story work
- Using action planning with staff
- Offering individual guidance and support with using the computer to compile life story books
- Modelling development of person-centred care plans to incorporate life story information

The initial project plan estimated that the Admiral Nurses might work with the clinical areas for 6 months, however it became clear that this was not a sufficient amount of time. Instead all the Admiral Nurses agreed to offer support for approximately one year. In three areas where the Admiral Nurses have an ongoing relationship, continued support is being offered but on a less frequent basis.

Evaluating the impact

The impact of the life story work was evaluated in a number of ways. These included:

- A record of the number of life story books developed
- Analysis of staff responses using the values clarification tool before and after involvement in life story work
- A staff questionnaire
- Admiral Nurses' reflections
- Feedback from relatives and family carers

The findings of each of these are outlined below.

Number of life story books developed

In the three continuing care areas held within one unit, ten life story books were developed (three, four and three respectively). In the other continuing care unit, life story books had already been developed for most of the twenty two residents but were not being used well to inform care. The focus was therefore on facilitating staff in transferring this information into care plans. This was completed in partnership with a relative for one resident and at the time of reporting another one was underway.

In the mixed functional and organic assessment wards, the number of life story books developed was eight and six respectively. The focus here was on disseminating/sharing this work amongst the rest of the staff. Twenty four life stories were completed in total by the unit.

Feedback about the impact and experience of doing life story work was gathered using a number of methods. These included analysis of the values/beliefs clarification tool before and after involvement in life story work and a staff questionnaire to gather feedback about the impact of life story work in each clinical area. Admiral Nurses also reflected on their experience of facilitating life story work including considering both driving and hindering factors to its development. This took into account the context and culture of the respective clinical areas and influence of this on realising outcomes.

Analysis of values clarification

A values clarification exercise (Warfield and Manley, 1990) was used with each of the staff participants prior to their involvement in the project. This was followed by presentation and explanation of the evidence and anticipated benefits of life story work. This process helped to encourage participants to reflect on and consider their present understanding and views of their role in working with people with dementia. It also helped to promote discussion on the potential implications of life story work and how this might be used to support care.

Some of the findings from the initial values clarification exercise revealed a task orientated approach and medical model understanding to working with the client group. Comparison of the values and beliefs held by staff pre and post life story work was carried out on two of the clinical areas. Overall this showed that staff were developing a more person-centred understanding of people with dementia. This is illustrated in the following responses:

The things I value about working with people with dementia include:

Pre life story work – Support and assist them with their personal needs.

Post life story work – To understand more about them as a person, their life history and their likes/dislikes.

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Analysis of staff questionnaires

Semi-structured questionnaires were distributed to staff who were identified to have been involved with the life story project; either directly or indirectly. Completed questionnaires were returned to the Admiral Nurse working in the respective clinical area, in a provided envelope to allow for anonymity. Of the thirty-five that were given out, twenty-two questionnaires were completed and returned. Three key themes arose from the responses.

1. Use of life story work

All respondents felt that the information that had been gathered using life story work has been used to improve understanding of the person and many also considered it has been used to inform care plans. Only a few respondents within two clinical areas identified its use in handovers and only two respondents within one clinical area indicated information was being used in ward rounds. Some respondents indicated that they believed that the use of life story work should be extended:

All older adult wards should be using this.

Would like more staff to become involved in this work and to have regular training/support days.

2. Impact on staff understanding and relationship with patients/residents

All the respondents, except for one who replied 'not sure', felt that life story work had improved staff understanding of patients life/needs either 'a lot' (fifteen out of twenty two respondents) or 'a little'. Relationships with patients/residents were accordingly felt to have improved either 'significantly' or 'a little' (fourteen out of twenty two responding with 'a lot'). Comments from the questionnaires support these views:

It gave me an opportunity to see the patient – they had a life before they came here.

The life story project helped in getting to know (Patient's name) lifestyle previously, presenting behaviour happening now and marrying the two together. Significantly helped understand night pattern.

Staff are able to approach and talk to relatives more confidently.

Life story work has a positive impact on the standard of care being given... clients respond and participate better.

It enabled us to build up a rapport with family carers as we had something to approach them about.

Some relatives now seem more able to speak to staff when they have concerns.

3. Role of the Admiral Nurse

Responses indicated that the support provided by the Admiral Nurse in all the areas was clearly seen as instrumental to the development of life story work and in supporting staff. This is illustrated in the following responses:

She was a godsend because she had a clear understanding of what life story is and how it should be used in relation to patient care.

Teacher, mentor supporter and motivator in encouraging staff involved.

Reflections from Admiral Nurses

Admiral Nurses were asked to reflect on their experience of facilitating life story work in their respective clinical areas. Throughout the project the use of reflection had been encouraged using structured questions based on Borton's developmental framework (1970) and adapted by Rolfe et al (2001). This involved Admiral Nurses using three types of questions; 'What?', 'So What?' and 'Now What?', in preparation for each development day. This framework was also used within a facilitated discussion as part of the final development day and the feedback summarised. Feedback was also based on a consideration of the culture and context as well as identification of hindering and driving forces, which may have influenced the work.

Common hindering forces to the development of life story work were identified as:

- Limited access to and limited skills with using computers and scanners
- Shortages of staff particularly qualified nurses; this was a particular issue with the continuing care settings
- Lack of or limited protected time to compile life story work
- Absence of or inconsistent leadership within the clinical area; on comparing results between clinical areas this seemed to be the singularly most important influence on the ability of staff to implement life story work

In contrast significant driving forces for the development of life story work were identified as:

- Visible support and encouragement from managers/leaders
- Support, guidance and encouragement in carrying out life story work
- Direct involvement and experiencing 'first hand' the benefits including using life story information in reducing distress and improving care
- Improved relationships with family carers
- Making life story 'fun' – the use of social events/tea parties was particularly successful in increasing involvement in life story work
- Using life story work as a component of NVQ assessments

In relation to the desired outcome for the development of Admiral Nurses' knowledge and skills in facilitation of practice development projects, Admiral Nurses described significant learning in relation to using facilitation skills, action planning and role modelling. There was clear enthusiasm for the project and although it was reported to be time consuming and often clashed with other responsibilities, ongoing support via development days and seeing positive outcomes from life story work in the clinical areas, acted as motivating factors. The ongoing support from the project leader and the FoNS practice development facilitator were identified as helping to maintain motivation and purpose and enabling and sustaining a systematic approach and achieving real development in practice.

The Admiral Nurses identified several recommendations for sustaining life story work:

- Using collages to minimise issues with access to/skills with computers
- Addressing staff shortages and providing consistent leadership
- Identifying leaders in the clinical areas to motivate and disseminate life story work to the wider staff team and recognising/rewarding achievements
- Providing further life story training and support for new staff

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Feedback from relatives/family carers

Feedback was gathered from a total of twelve relatives and family carers using a questionnaire or by inviting written/verbal feedback. This was carried out by the Admiral Nurses in the project who directly approached relatives who had been involved to request feedback in their preferred format.

Due to limitations on resources and time this was only possible with a small number of relatives. In addition, a number of patients whose life stories had been developed had either moved to a different care setting or had passed away. The feedback gathered however indicated that involvement in life story work had been a positive experience for family carers and for their relative. Benefits were felt to include better relationships with staff, feeling more involved and included in care and feeling reassured that staff knew more about and cared for their relative. In addition, feedback indicated that the process of doing a life story had been both beneficial and therapeutic. The following comments from relatives illustrate these points.

I feel that staff see my mother as a person now, not just a patient.

I am so glad that (member of staff) asked me to do this and encouraged me with doing it. I was worried it would be upsetting for us both but I have found a new lease of life in doing this and it has made me appreciate what we had. I can see positive things now, where as before I could only see negative things because of this illness and it gives me something to talk to (Resident) about. I even think I see a spark occasionally.

Doing life story work with my husband has made a difference to our relationship. I thought we had nothing in common these days but doing the life story made me realise we had a lifetime of experience and joy. My husband loves looking at the photos of us all.

Conclusion

The outcomes of this project indicate that where life story work was successfully implemented within in-patient settings, this resulted in improved understanding of patients, relatives and family carers by staff. The experience of doing life story work was overwhelmingly positive and there was some evidence that the delivery of care had become more person-centred as result.

Whilst successful implementation of life story work was achieved within all the in-patient settings, outcomes were better in areas which had the following characteristics:

- Strong/consistent leadership
- A higher ratio of qualified staff to unqualified staff and
- A context/culture that supports change and encourages communication

The staff involved were mostly health care assistants, although efforts were made to ensure involvement from staff nurses and deputy/ward managers.

The direct involvement of staff nurses in the project proved to be difficult in most clinical areas due to a shortage of qualified staff and/or other roles/responsibilities being identified as a barrier to getting involved. This was felt in some areas to have hindered the incorporation of life story work into practice.

The assessment wards despite having a quicker turn-over of patients were able to produce more life story books. This was considered to be influenced by a number of factors including; evidence of clearer leadership, patients/carers who were more able to participate and facilitators who were familiar with the clinical areas/staff group. However in all wards, there was a commitment to following through this work and ensuring that further life story books were completed.

The format of the life story template was considered by all to be helpful, especially as it could be amended and shaped individually. The use of images and photographs rather than lots of text was particularly welcomed and the use of collages based on images was felt more appropriate within the continuing care settings.

The facilitation of this work was considered a key factor to the success of this project in supporting a systematic and informed approach to the development of practice. Support provided by the Foundation of Nursing Studies and for dementia has resulted in significant learning for those involved. The project has been acknowledged as an example of innovative practice on the Department of Health Care Networks website: http://www.dhcarenetworks.org.uk/_library/Resources/Dementia/Admiral_Nurse_Life_Story_Work_Case_Example.doc and has also been accepted for two conference presentations.

The steering group has supported the outcomes of the project and is making recommendations to the local trust to support the further development of life story work by identifying local leaders, supporting staff with care planning based on life story work, incorporating life story work into assessment and involving activity coordinators in developing person-centred activities informed by life story work.

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Further reading

A copy of the final report can be downloaded from the FoNS website: <http://www.fons.org>

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