

ESSAY REVIEW

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Introduction

Besides neurological impairments, numerous factors can affect the experience of a person with a dementia, such as their physical health, their own biography and personality and the social environment they are in. It is here that the power of narrative approaches and life story has the potential to reduce disability. The aim of this book is to share what is currently known about life story work and to provide an overview from different perspectives from people with dementia themselves, carers, staff and across different settings such as inpatient wards, acute hospitals, memory services and care homes. It will help the reader to access policy and legislation in arguing for service development. It takes a practical approach in order to encourage people to commence life story work, providing important understanding of some of the tools and techniques available as well, pointing out the complexities and pitfalls to be aware of. Life story work is not always right for everyone. As life story work has grown and developed, so too have some myths and potentially rigid ideas about what it is and is not. The book is clear about what practitioners and carers can and should do and sets out some ideas and advice about when it actually might not be helpful. The purpose of life story work may also differ. For some people, the purpose might be to focus on a person's sense of identity, improving their self-esteem and wellbeing. For others it might be to inform a person-centered care plan in order to decrease so called 'challenging behaviour'. Researchers and practitioners whose work has been cited here share the one perspective that is fundamental and that is the power of story work to improve the quality of life for people with a diagnosis of dementia.

Following discussions with practitioners, family carers and people with dementia themselves, it is clear that there is enthusiasm and commitment for embarking on life story work, but it can be difficult to know where to start or the best approach to take. The chapters of this volume include

many examples of how life story work has helped people living with dementia to reconnect with their families, friends and communities and enabled staff to support them better by understanding who they have been, who they are and who they want to be. The authors are clear in their aim of inspiring people to at least experiment with life story work as a means of discovering the rich, extraordinary lives of people who are often overlooked and only seen in terms of their diagnosis and the problems that this appears to present to others around them.

Definitions

Definitions of life story work are considered in the Introduction. Since 1994 there has been a growth in the use of life story work that has outpaced its definition, research and evaluation as an intervention. As a consequence, there is no consistent definition of life story work, so that if six individual people, are asked to provide an associated definition, it is likely that six different answers will be given, depending on the purpose and context of the work. Indeed, the term 'life story work' is used to describe a wide range of activities. At one end of the continuum this can be putting one's life into perspective through therapeutic life review as part of a very structured or even unstructured life review process. This is done on a one-to-one basis with the person. The other end of the spectrum might be the development of a one-page profile. This might be put together by a family carer or staff working with the family and not necessarily by the person themselves. Life story work is usually personal, individual and more than simple reminiscence; it is about capturing memories, as well as reminiscences and also about hopes. Hopes may be modest - the opportunity to go outside into the fresh air - or more substantial, such as meeting a friend again or visiting a special place. Hopes may range from wanting to enjoy a long marriage, to simply having another beer or to starting Ming again. Whatever the aspirations gathered in a life

story, these are not necessarily set in stone and it should not be assumed that they will remain the same forever.

Part 1 of this important volume describes where the book's ideas have come from and the policy context. Part 2 looks at the current evidence base for life story work so far. Part 3 considers and defines the importance of life story work. For the first time, the views and perspectives of people with dementia are included in the debate. The benefits for carers are discussed from the perspective of a former carer and some of the work authors have done together at the Life Story Network. This is followed by explaining why it is important to staff and how it can help them. Part 4 is the most practical section which describes the variety of settings in which life story work is taking place, its core applications - from community, memory services, hospital wards, care homes and end of life - and the use of person-centered approaches further afield in Europe. The challenges of life story work are explored, with illustrations of some of the creative approaches that can be taken. Part 5 offers a broader European perspective that opens up new opportunities. There is then an overview of the work and current practice exploring what the future might hold.

Organisation of the book

Currently, there is also a drive to move life story work away from just health and social care settings to communities, as described in Chapter 10. Much of the approach here seeks to speak to busy practitioners who tend to glean people's stories each day in the course of their work. Conversations to elicit stories may be between family members and the person with a diagnosis. It may be, as the authors explain, between a person with a diagnosis and a therapist (occupational therapist, speech language therapist or psychologist) or, as illustrated in Chapters 9, 11, 12 and 13, with nurses or care staff. Or it may be between a person with dementia and a volunteer (see the case study in Chapter 11). Chapter 9 demonstrates through the use of case examples, the importance and value of using life story approach in the assessment, planning, implementation and evaluation of care. It has highlighted how using life story work can keep the person at the heart of care delivery, a core ambition of person-centered healthcare. Both eponymous and anonymous staff feedback illustrates this: knowing the life story of a person really helps with caregiving. For example, staff say, "I see the patient as a person, not just an illness" or "I understand now how the past can still impact on the present" or "We believe that the life story approach should be the foundation of care and not just the 'icing on the cake'."

The conversations elicited by the life story telling approach might result in a book, photo album, DVD, one page profile or CD of music, or they might not result in anything so tangible. Any product that is an outcome of the work depends on the purpose and will depend on the setting - be that a mental health assessment ward (Chapter 9), a general hospital (Chapter 12) or a care home (Chapter 13). The main issue is that these stories should be used

therapeutically rather than gathering dust on a shelf. For sure, a patient could have the most beautifully bound photograph life story - but it is of limited value if it is not used. This book details how to initiate these vital conversations that honour a person, who they are and who they want to be, not just who they have been.

The whole area of art and dementia is a growing and flourishing one which can provide ideas about ways of engaging with people who do not rely on the written word. Maria Parsons describes some of these in more detail in Chapter 17 and her account will give the reader many ideas.

Life story work is not like genealogy, researching family history or drawing up a family tree; it is about helping people to tell their stories in whatever way is best for them, which may not result in an ordered chronological account that is factually accurate. It is important to know how to ask questions and to encourage people to respond. At the same time, it is helpful to know some of the known benefits not just for people with a diagnosis, carers and staff (Chapters 7, 8 and 9), but also in terms of the evidence and outcomes that can be achieved, so that the work is undertaken in the knowledge that it has validity (Chapters 5 and 6). By reviewing these benefits the authors intend the book to provide practical examples, ideas and suggestions that readers can adapt to their own particular circumstances.

Assessment and the biographical approach

It has been argued that all too often the assessment of an older person has been made from the viewpoint of the professional, with the emphasis being on identification of problems as opposed to strengths and capabilities. An alternative known as the biographical approach has been proposed. Central to this approach was the biographical interview in which older people were encouraged to reconstruct their past lives so that their current needs and preoccupations could be better understood. Johnson advocated that this approach would enable care to be planned with the person, preventing the assessment of the older person being made from the standpoint of the professional and therefore encouraging the recognition of strengths and capabilities as opposed to just problem identification. One can argue that this early work of Johnson helped to lay the foundation of the evolution of life story work with older people and people with dementia.

The use of life story work at the assessment stage promotes the concept of working with the person rather than the illness at the beginning of the therapeutic relationship, thereby instilling a collaborative relationship and ensuring that the individual is engaged and central to the process. This puts the relationship with staff on a more fulfilling, but sometimes challenging, footing as the work begins to understand the person as a unique individual. Listening to the individual story enables staff to increase their understanding of them and use this information as the

basis for person-centered intervention. Collecting biographical information can help to gain a more dynamic and complete picture and knowing the person's life story enables staff to find out more about residents' needs and behaviours. Adopting an approach based on the use of life story can also give an insight into how the person understands and make sense of their dementia in the context of their life history. Using life story at the assessment phase enables care to be planned *with* the person rather than *for* them.

The authors of this volume are clear that knowing the person, not just 'the patient', reduces negative labelling and stereotypical assumptions and encourages staff to undertake positive risk-taking as they have a greater understanding of the person in the context of their lived life, current situation and future hopes. It makes difficult conversations easier to initiate and sustain in the light of the person's background, history and known values. As they describe, life story work provides a framework to explore behaviours that are perceived to be challenging by staff. The experience of using this approach by care teams has resulted in: greater consistency of care; improving communication with the person and between team members enabling a greater understanding of why certain behaviour may be being displayed and what the person may be trying to communicate. There have been occasions when this has resulted in medication not being used as an intervention to help manage a behaviour as staff have understood the reasons why the behaviour is occurring and have been able to use non-pharmacological interventions instead. Increased understanding of why behaviours may occur and tailored individualised interventions aimed at meeting a person's needs also resulted in a reduction in the amount of reported incidents. The book illustrates how the use of the life story approach, in exploring behaviours that may be displayed by a person with dementia, have enabled staff to develop a greater understanding of the person and their lived life and how this may affect their present and future. It has also been found that life story work increase staff morale and motivation and increased job satisfaction. Staff have been heard saying proudly that they now know their patients as persons and therefore have a far greater understanding of who they are as individual people. They want to spend time with people to talk with them as part of their care and treatment plans, as opposed to just engaging in order to undertake task-orientated care.

The authors explain how listening to the individual's story enables staff to increase their understanding of the people they are caring for and enables them to use this information as the basis for person-centered intervention. For example, staff using the approach in one nursing home reported that collecting biographical information helped gain a more dynamic and complete picture and that knowing the person's life story enables staff to find out more about residents' needs and behaviours. Adopting an approach based on the use of life story can also give an insight into how the person understands and makes sense of their dementia in the context of their life history.

A Life Story Network conference in Leeds which was attended by 250 people saw life story work as a valuable tool that could help them provide dignified, respectful care

based on knowing individual needs, preferences and aspirations - enabling them to understand their local Dignity Campaign.

Life story work enhances person-centered care by allowing nurses to make the link between past and present, which can promote understanding of the person's preferences for care. It can also help in understanding the meaning behind what people say and how they behave, re-inforce identity and facilitate communication. Life stories can provide a valuable insight into the life of someone, especially when they have difficulty in sharing this information themselves. Knowing how to use information from the person's biography to help stimulate and provoke memories to calm the individual can be particularly helpful in unfamiliar situations.

Conclusion

One of the great strengths of the book is the style of writing. The authors are clearly addressing their thoughts to people working with people diagnosed with dementia. This includes quotations from practitioners explaining how life story work with patients makes their as practitioners work more rewarding as their relationships with residents and patients improves.

As the authors describe, the use of the life story approach when working with people with dementia may initially seem to equate to extra time and work. However, experience leads people to believe that this is time well spent. Adopting a life story approach has the potential not only to have a positive effect on the person with dementia, but also to bring numerous staff benefits. Having a greater understanding of the person people are looking after, rather than seeing them only as a set of symptoms or problems to be dealt with, leads to greater job satisfaction and a belief that the care being delivered is valued and having a positive impact. Challenging staff assumptions about the person with dementia can lead to a change in staff attitudes. In the long term, the use of life story work can save time for staff as it enables care and interventions to be planned with the person in the context of their lived life. As a result, there is a greater chance that interventions and care packages would be acceptable to the person and tailored to their needs. This may therefore reduce the amount of time spent on reviewing in effective interventions and care packages.

Life story work ensures that care and treatment decisions remain in the context of what the person would want, where they are in the illness trajectory and what is in their best interests. It can facilitate the use of creative approaches to care that also promote people strengths. Additionally, staff knowledge of the patient enables them to engage in conversation based on what is meaningful to the person. This in turn can help reduce the resistance to care often encountered when supporting people with advanced dementia. Life story work has the potential to improve therapeutic relationships with the individuals being cared for, making interactions and interventions more positive and enjoyable from the perspective of both

the individual and the staff team. There is therefore the potential to reduce complaints as care interventions are planned with greater understanding of the person, an important consideration since complaints are known to reduce staff morale and motivation. Similarly, life story work enables the improved involvement and relationships with relatives and carers, which can increase their confidence in the care that their loved ones are receiving.

The authors have identified the benefits of adopting the life story approach through the above phases of care. It will enable needs to be assessed, care to be planned and interventions to be delivered in the context of the person and their life, challenge staff assumptions about the person to help change attitudes, promote the person and not the illness, identify strengths, hopes and dreams to counterbalance deficits, needs and lost losses that we normally focus on. It will also reduce task-driven care, promote an understanding of an individual's behaviour and presentation, which in turn may reduce the need to resort to medication and increase the use of non-pharmacological individualised interventions. This approach also improves the caregiving relationship as staff will know more about the person. It provides opportunities for engagement, meaningful conversations and shared enjoyment and most importantly of all it keeps the person at the centre of care.

In conclusion, this book is highly recommended to all those practitioners and carers who care for persons living with dementia.

Conflicts of Interest

The author declares no conflicts of interest.