

‘I’ve been thinking’: How Does Completing Life Story Work Affect People with Dementia?

Qualitative Information and Analysis for Service Improvement Assignment

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Title: “How Does Completing Life Story Work Affect People with Dementia?”

Abstract

Personhood is at the core of person-centred care for people with dementia (PWD) (Kitwood, 1997). Life story work (LSW) is one of the most commonly utilised tools to focus those who support PWD on their personhood. Despite a general consensus that life story work has the potential to elicit several positive outcomes for people with dementia, research in the area remains limited (McKeown et al, 2006). In particular, there is a gap in research that examines specifically how LSW affects PWD, this is the focus of this piece of research.

Using a case study approach and Interpretative Phenomenological Analysis (IPA) it was highlighted that LSW can affect mood, motivation and focus, realising ability over disability and eliciting feelings of pride. Most significantly it may assist PWD in realising their own personhood. This has important implications for service delivery and the utilisation of LSW.

Introduction

‘Dementia’ is an umbrella term used to describe a range of symptoms which occur through damage to the brain. The most common symptom associated with dementia is memory impairment, predominantly that of working or short term memory, however, people with dementia (PWD) can experience an array of additional impairments in cognitive functioning

such as difficulties with; communication, problem solving skills, logical reasoning, orientation, time keeping, visuospatial awareness, sensory abilities, and mobility, among others, this can make daily living more challenging for PWD.

The most common disease that damages the brain in this way is Alzheimer's disease; however, there are over 100 diseases and conditions which can lead to dementia including vascular dementia, frontotemporal dementia, dementia with Lewy Bodies and other rarer forms.

As indicated above; dementia is often discussed with reference to cognitive decline and functional disability with these being the primary focus of both diagnosis and treatment (McKeith & Cummings, 2005). However, Finkel et al (2000) posits that dementia cannot be fully understood by focussing entirely on neurological deficits alone and that more importance is now being directed towards the psychosocial factors that shape the person's experience of dementia.

From the point of diagnosis the person can be effected psychosocially; by being labelled as a PWD this can present a threat to the person's sense of self, or identity, and immediately establishes them with membership into a social group that is highly stigmatised (Harman & Clare, 2006, Katsuno, 2005). This sense of stigmatisation and fragmented sense of self can be exacerbated by the social context in which the PWD operates; PWD articulate this with the following examples:

'I went in _____ and came out someone with dementia' (A member of the Scottish Dementia Working Group discussing their experience of receiving a diagnosis with the researcher)

'it's a strange life when you 'come out'. People get embarrassed, lower their voices, get lost for words...it makes you feel quite alone' (Terry Pratchett, Andrews, 2015 pp 70).

'Dementia has changed how people treat me' (PWD discussing their experience of having a diagnosis of dementia, Harman & Clare, 2006, pp 12).

Norman (2006) adds to this by indicating that PWD can be ignored by nursing staff during hospital admissions.

This leads to the consideration that the environment in which a PWD finds themselves and the way in which people view them and act towards them can play a pivotal role in how a person may experience dementia. Woods (2001) echoes this ideation by indicating that relationships and social contexts can have the power to create and maintain personhood or diminish it. Woods (2001) is making reference to Kitwood's (1997) concept of personhood which is explained as:

'A standing or status that is bestowed upon one human being by others, in the context of relationship and social being' (Kitwood, 1997, pp 8).

The inclination that personhood can be maintained or diminished within relationships and social contexts (Woods, 2001) is clearly exemplified through Kitwood's (1993) notion of malignant social psychology which surrounds dementia. That is, through stigmatisation of those around them PWD can often be disempowered, infantilised, depersonalised and devalued through a predominant focus on negativity, deficit and disability. Additionally, when imbedded within such negative environments and social contexts PWD adapt their behaviour accordingly, this can be perceived as 'challenging behaviour', particularly in PWD with communicative impairments, for those who already have a malignant social psychology or hold a stigmatised view towards PWD this adapted behaviour may serve to solidify their negative view point, whereas in such circumstances it is more probable that the PWD is

communicating an unmet need, be this physical or emotional, and it is the observer who has failed to understand this (Woods, 2001).

This malignant social psychology or stigma can lead to a perceived greater or excess disability than the person may be experiencing through their neurological damage alone. Through this there remains a threat of a self-fulfilling prophecy.

Bryden (2002) suggests that the behavioural reaction of others and emotional impact that this has on PWD, such as depression and reduced self-esteem and self-confidence (Andrews, 2015, Bamford et al, 2004, Cotrell & Schultz, 1993), can have a more significant impact on the person than cognitive decline associated with dementia.

As a result of this PWD often develop maladaptive coping strategies such as denial, self-blame or perhaps more commonly social withdrawal (Bamford et al, 2004, Corrigan, 2004, Katsuno, 2005).

Social withdrawal in PWD is a maladaptive strategy that is frequently observed in professional practice. PWD indicate that this strategy is employed due to feeling embarrassed in social situations due to cognitive lapses and difficulty keeping up with conversations and/or activities (Ballard et al, 1996, Batsch & Mittelman, 2012). Furthermore, social withdrawal can become increased if PWD witness negative reactions towards them from others in social contexts, such as the experiences previously presented and the concept of malignant social psychology, and can serve to reinforce negative self-concepts (Batsch & Mittelman, 2012). This increased social withdrawal can increase feelings of social isolation, perpetuate negative self-concepts, increase depressive symptoms and worsen cognitive and functional decline (Alexopoulos, 2005). Herein lies the potential for a vicious circle to

perpetuate negative views held by both the social environment and views of the self that PWD may hold.

Through this short discussion it becomes clear that the experience of dementia is more complex than examining cognitive and functional decline in isolation and that it remains important to consider the complex interrelationship that these aspects have with the psychosocial impact of dementia (Woods, 2001).

This presents the negative impact that the social environment can have on people's experience of dementia, however, Woods (2001) did iterate that relationships and social context also had the ability to create and maintain personhood. Cheston et al (2003) and Woods (2001) suggest that by shifting focus away from deficit, loss and functional decline and placing attention on the person's abilities, while supporting opportunities for personal growth, there remains potential to elicit more positive ideations of the self, strengthen the sense of personhood for the person with dementia and possibly reduce disability.

To move towards this there needs to be an understanding of the person behind the illness and their life story (Woods, 2001). This concept and the ideation of promoting personhood is a fundamentally essential component in delivering person-centred care to PWD, reducing stigma and moving away from a malignant social psychology (Kitwood, 1997). Looking beyond the illness, changing people's perceptions of PWD and *seeing* the person behind the illness is central to this ideation (Kitwood, 1997). Of the practical approaches utilised to facilitate this, the most commonly utilised and discussed is life story work (LSW). LSW can provide concrete examples of significant aspects of the person's life and that they remain worthy of attention and value (Woods, 2001).

There is no commonly understood definition of LSW, however, for the purposes of this project life story work will be understood as:

'a form of intervention carried out in health or social care practices, and is an umbrella term, encompassing a range of terms/interventions, for example biography, life history, life stories. It is usually undertaken to elicit an account of some aspect of a person's life or personal history that goes beyond a routine health assessment undertaken to plan care and treatment, and aims to have an impact on the care the person receives' (McKeown *et al*, 2006, pp 238-239)

Killick and Allan (2002) clearly demonstrate the power that LSW has in facilitating the notion of personhood posited by Kitwood (1997) through reflective accounts of their initial experiences of engaging with PWD during the completion of a series of life story projects:

'They had suddenly become people in my eyes, and I was filled with empathy for them. Of course they themselves hadn't changed at all. It was my perception which had been profoundly altered' (Killick and Allan, 2002, pp 13-14)

This change in perception is immeasurably important and represents a shift from notions of a malignant social psychology (Bond & Corner, 2001, Kitwood, 1990). Other potential benefits can also ensue including improved assessment, the building of relationships between care staff and family carers, improved communication, the promotion of more individualised care for PWD and help reduce fragmented self-narratives for the PWD who complete life story projects (Bryan & Maxim, 1998, Clarke, 2000, Woods, 2001, Woods *et al*, 2009,).

Despite LSW being generally accepted as creating some level of positive outcomes for PWD, and those who are involved in their care, significant research in the area remains relatively uncommon (McKeown *et al*, 2006).

This remains evident as largely current research, although highlighting various potential benefits, predominantly focuses on the experiences of the staff who have been involved in LSW and the impact it has had on their practice and/or the experiences of the PWD's family members, with minimal attention paid to how LSW may affect PWD (McKeown *et al*, 2006).

Woods *et al* (2009) moves towards bridging this gap by identifying potential benefits in PWD's mood and cognition through the use of Reminiscence Therapy which shares some similarities with LSW and relates closely to McKeown *et al* (2006) ideation of LSW.

McKeown *et al* (2010) have additionally added some rich data to this area of research, however, it could be suggested that accounts and participation from the PWD remain, to an extent, limited.

The majority of the cases discussed by McKeown *et al* (2010) include LSW projects that were led by family members rather than the PWD. It is acknowledged that this may have several benefits, i.e. if the PWD has significant memory impairment or is experiencing communication difficulties; however, it is also important to consider that the project is about the PWD's life and their experiences and that it would be beneficial, and where possible, more appropriate for the PWD to have a significant input and involvement throughout the process.

Furthermore, McKeown *et al* (2010) describe LSW as an opportunity for family members to 'show' the personhood of their relative. This remains a rich positive to culminate from LSW and enables care staff to appreciate the person behind dementia and improve their person-centred approach (McKeown *et al*, 2010), however, it may be argued that it is more important, and powerful, for the PWD to show their personhood.

Although McKeown *et al* (2010) interviewed key stakeholders and spent significant time in the field making observations and having conversations with PWD it could be suggested that certain elements of this process may present with some level of limitation. In particular, several of the semi-structured interview questions appear to be based more around the process of LSW rather than how the PWD viewed the experience or benefited from the experience, moreover the PWD appear to not have been involved in the interview process.

McKeown *et al* (2010) do make important contributions to the literature surrounding how completing LSW can affect PWD and highlight several aspects to how this may enhance person-centred care. McKeown *et al* (2010) present these under the headings of *From patient to person, can you hear me?*, and *Pride and enjoyment*. These indicate a changing perspective in care staff which enable them to see more clearly the person behind the illness, this altered their approach to the care they provided from being task orientated to more understanding and appreciative of the person's life history, furthermore McKeown *et al* (2010) noted feelings of pride and enjoyment from the PWD who completed LSW this highlights the importance of supporting PWD to participate in activities that are meaningful, provide opportunities for personal growth and promote feelings of achievement and identity (Cheston *et al*, 2003, Harmer & Orrell, 2008). This provides some supporting data of the benefits of completing LSW, or documents such as 'Getting to Know Me', for PWD, their families and care staff.

The purpose of this research project is to delve deeper and extrapolate how completing LSW affects the PWD themselves by directly interviewing a PWD, investigating how they

understand their experience of completing such a project. Additionally, key stakeholders will also be interviewed to investigate how they believe completing LSW has affected the PWD.

It is anticipated that some of the results will compliment and echo that of existing data but may add a richer account of how PWD experience completing LSW and how it may affect them. Additionally, it is envisaged that this may encourage and promote the completion of LSW with PWD, their families and carers, and voluntary, health and social care staff.

Aims & Objectives

Aim:

- Critically assess the affect that completing LSW has on PWD.

Objectives:

- Investigate retrospective accounts from a PWD who has completed a LSW project.
- Investigate retrospective accounts from family members and key workers of a PWD who has completed LSW.
- Make recommendations as to how life story work can affect people with dementia and how this may relate to service improvement.

Methodology

Design

This study is a qualitative case study explorative investigation on how completing LSW can affect PWD. The design of the current project is based around Interpretative

Phenomenological Analysis (IPA), therefore no hypothesis was stated as this is exploratory in nature. As this is a case study there may be limitations in the generalisability of results, furthermore consideration should be paid to the only PWD taking part in this research is male.

Participants

Participants consisted of one male (DR), who has a diagnosis of dementia with Lewy bodies and has completed a life story project. Dementia with Lewy Bodies is a form of dementia which is often linked to Parkinson's disease and may present with Parkinsonian symptoms, hallucinations and although memory can be impaired this is often not one of the early symptoms. Two females were also recruited, the gentleman's wife (MR) and his key worker from the day centre that he attends (EE).

Participants were recruited who were already known to the researcher, this was viewed as advantageous as a working relationship was already established which may allow the participants to feel comfortable leading to a more in-depth, relaxed and honest interview. It is acknowledged that this may influence the authenticity of the interview responses, efforts were made to reduce this by reinforcing that any information provided throughout the interviews would not affect any services or relationships that the participants are currently involved in.

Procedure

After receiving ethical approval from Alzheimer Scotland's Ethics Committee, participants were approached and asked if they would be interested in taking part in this research, information sheets (see Appendix 1.1) and consent forms (see Appendix 1.2) were provided to all participants. Participants were asked to sign consent forms before taking part,

consideration was paid to the PWD's level of capacity to consent to participate. The researcher, PWD and their wife were happy with their level of understanding and ability to consent of their own free will. The PWD's wife also signed as a witness for the PWD as their power of attorney.

Other ethical concerns include discussing topics which may cause distress to the participants, such as discussing dementia and/or a reduction in a person's abilities. The researcher endeavoured to minimise such distress, in the event of such distress it was to be made clear that the interview could be stopped and the researcher would signpost the participants to appropriate services.

The life story project that the PWD had been involved in consisted of completing a life story book followed by a presentation event where the PWD presented their life story book to the rest of the services users that attend their day centre, his wife, son and local MSP also attended. The PWD was assisted by an Alzheimer Scotland Dementia Advisor (the researcher) throughout the project but was led completely by the PWD.

Semi-structured retrospective interviews, lasting a maximum of one hour, were conducted exploring how completing a life story project affected the PWD (see Appendix 1.3 for general interview guides).

Both the PWD and their wife were interviewed together at the participant's request. It is acknowledged that this may have affected the participant's responses as they may feel that they could not openly talk about the person while they are present, however, in respect of the participant's levels of comfort and support for each other it was viewed that the potential risk of this was justified.

Interviews were audibly recorded and securely stored on an encrypted USB drive for transcription and analysis.

Generated data was added to by the researcher maintaining a research journal throughout the process.

Data was transcribed, replacing participants' names with randomised initials to ensure anonymity, and analysed using IPA to focus on the participants' understanding of the experience.

Analysis

Data was analysed using a four level process, including providing a descriptive narrative regarding what the participants were saying, an analysis of the linguistic used by the participants, conceptual comments were made to highlight potential underlying themes and finally any points of significance were highlighted. The descriptive, linguistic, and conceptual comments were analysed and emergent themes were identified. Only the emergent themes which were viewed as the most significant are included in the results section and are labelled as recurrent themes.

Results

Throughout the analytic process it became clearly evident that completing a life story project had a profoundly positive affect on the PWD. This was evident through recurrent themes highlighting changes in mood, an increase in focus and motivation, and a prevailing focus on abilities leading to an increase in the person's self-confidence. These are all linked through a central narrative of a sense of identity or change in self-perception, achievement and pride.

Due to the complexity of dementia, individuality in general, and the developing support network that the PWD is currently engaging with it is difficult, and possibly inaccurate, to associate all the changes and affects experienced by the PWD solely to their experience of completing and engaging in a life story project. This is due to the PWD engaging in numerous activities and supports which seem to have had a beneficial impact on them, it has however been highlighted that the life story project was a key facet of this experience and the following results will focus specifically on this.

For ease of presentation results will be presented under the recurrent theme headings of *“I’ve been thinking”*: *Mood, Motivation and Focus, Ability not Disability, and Pride*. These themes will be discussed through a central narrative of changing self-perception and achievement.

Participants will be referred to with the initials DR for the PWD, MR for his wife and EE for his key worker.

“I’ve been Thinking”: Mood, Motivation and Focus:

Across the generated data it became clear that through the experience of engaging in a life story project there was a significant change in DR’s mood, motivation and focus, this is clearly exemplified in the following iteration:

MR: “he sort of ...came to life, kind of thing, sort of...eh...it motivated him, you know, it definitely did, he em...as I say before he would just kind of sit, he, he was going into a decline really...em...but... actually doing the book it just, the motivation was great and he...he took more of an interest in things, the book in itself you know, and he would talk about what he was gonna do in the next day he was at the club with the book...em it gave him a great interest...”

Possibly the most significant point in this discourse is the phrase “came to life”, this creates notions of energy, enthusiasm a coming back to life, or a claiming back of life and of identity for DR (this will be expanded upon in later discussion). This is reinforced by the pattern of discourse used by MR which creates a sense of energy and enthusiasm which reflects the affects she believes the life story project had on DR. Additionally, the repeated use of ‘he’ and ‘him’, which was used with greater frequency here than throughout other sections of the discourse, assists in giving the researcher a sense of DR’s identity, him as a person, coming back to the surface.

This is reinforced by an indication that MR felt that DR was going into a decline before and perhaps beginning to withdraw this is indicated through “came to life” and “before he would just kind of sit”, through engaging in life story work it assisted in bringing DR back, bringing back his interest and motivation again, by talking about what he would be doing the next day assists in solidifying these aspects of motivation, interest and focus.

Of notable interest through analysis of the researchers research diary it becomes profoundly evident that a key phrase is continually iterated by DR: “I’ve been thinking...”. This was said by DR at the beginning of the majority of each meeting with the researcher, and often when DR and the researcher met in passing through the day centre. This highlights the level of focus and interest that DR had in engaging with this activity and led the researcher to conclude that DR’s life story project remained a focus of his thoughts out-with the allocated sessions. This level of thinking and interest ensured that DR controlled and guided this project completely and creates a sense of control, or a reclaiming of control, that has possibly been absent from DR due to difficulties that he is experiencing as a result of his illness. This is clearly exemplified in the following quote from DR:

“I was thinking I should maybe give you, I was thinking that I’ll maybe give you something to make sure you are doing it right”

This notion of a reclaiming of control relates succinctly to the next recurrent theme.

Ability not Disability

During analysis it became intrinsically pertinent that the most significant theme spanning the entirety of DR’s experience is that of self-perception or more accurately a change in self-perception for DR which highlights his personhood and takes focus away from his dementia and other ailments and places focus towards what he can do as opposed to what he cannot. Throughout this process clear references were made to an increase in confidence of self and abilities as well as self-value for DR.

Elements of this were illustrated distinctly by MR who expressed:

“It does seem to give him a new interest in life other than his ailments, he...it brought him out, it definitely did...”

This clearly indicates a shift in focus for DR from his ailments, or what he finds difficult, to what he can do, what he is capable of, who he is, having a “new interest in life”. Through this short discourse there remains frequent uses of “him”, “his” and “he”, this assists in reinforcing this sense of focal change towards DR himself and not his ailments. Of particular interest, or power, is the phrase “brought him out”, through analysis this caused the researcher to envisage bringing someone out from somewhere dark, from somewhere where DR was trapped, it “brought him out” from dark to light, DR could be seen now where he could not be seen before. This recapitulates this sense of identity or change in self-perception for DR.

Through this there appeared to be an increase in DR's confidence in his own abilities, this was most pertinent during discussion of when DR presented his life story book to the other services users who attend his day centre. Through analysis of the research diary of particular interest is how DR would refer to the day of the presentation, DR repeatedly referred to it as "The Event" and this is what it became known as during the planning stages and now through discussions in retrospect. The significance of this is encapsulated by EE when discussing "The Event":

EE: "The Event' he always kind of billed it, like... as the event of the year....but it was for DR...he was just so proud of the whole thing..."

Through EE's expression that DR's presentation was, for DR, "the event of the year" it creates a sense of importance or a mark of achievement attributed to it by DR, it gave DR an opportunity to show his identity through sharing periods of his life, but perhaps more importantly it became viewed as a demonstration of what DR is capable of. This is further reinforced by EE also referring to DR's presentation as the "book ceremony" which during analysis created a sense of occasion akin to an award ceremony.

DR elaborates on this postulation when discussing "The Event" by indicating that:

"...it was something I had never done in my life and I'm doing now... I didn't want to miss that day that I was going to the club and make sure that everyone was there...I wanted to see if I could do it..."

This clearly illustrates a change in DR's self-perception and an increased confidence in his own abilities. The use of the word "life" along with "I'm doing now" adds a sense of almost disbelief in DR that presenting to an audience in this manner is something that DR had not even considered doing in his past. The emphasis on "now" is particularly pertinent and reinforces the inclination that despite being advised that there are several things that he is not capable of doing, DR is almost proving this wrong by the fact that he is standing up and presenting to an audience now despite his difficulties. During analysis "The Event" becomes a pronounced moment where DR almost viewed this as a moment or vehicle pushing him to realise that he is still capable of many things, this is highlighted by the end of this dictum "I wanted to see if I could do it".

Additionally, noted through the research diary are occasions where DR discussed a desire to see what he could next and that he was writing a list of things down that he wanted to achieve, DR did state that he had already achieved most of them, but this does add to the notion of an increase in confidence and desire to continuing growing.

There are clear themes of emerging identity, personhood and a realisation of skills throughout this section, which attaches a sense of value to life story work and "The Event" in particular, this creates an impression of pride which flows through discourse from all participants.

Pride

All participants made clear reference to a sense of pride instilled within DR generated through the completion of his life story project. This was demonstrated by DR by stating:

"I was telling everybody about it...ha (laughs), I was probably getting a nuisance"

By laughing during this section of discourse it emphasises that DR, although being aware that he may have been repeating himself to people with regards to his life story project, and

perhaps generating a level of annoyance in them, this was of little concern, his level of pride overruled this and would not discourage him to continue to mention it. This relates extremely closely to the above recurrent theme and during analysis directed the researcher towards the postulation that not only was DR proud of his completed book and “The Event” but also of his abilities. This is further reinforced by EE:

“there’s times that you know you will talk about achievements in your life and what you’ve done and DR will bring up...about his book event”

In reviewing DR’s life story book it becomes clearly evident that he has had many accomplishments throughout his life, the above dictum emphasises the value that DR has attached to his life story project and what it has meant to his ideation of self-perception, expressed through feelings of pride.

Discussion

The aim of this piece of research was to critically assess the affect that completing LSW has on PWD. This aim was identified predominantly through reviewing the current literature in relation to LSW and PWD and extrapolating that there remained limited data examining specifically how LSW affects the PWD themselves, with focus predominantly being placed on how it may affect staff, how they work with PWD and family members (McKeown *et al*, 2006).

This aim was attempted through recruiting a PWD who had been engaged in a life story project and key stakeholders including the PWD’s wife and key worker with focus being placed entirely on the affects this had on the PWD.

Through close analysis of the generated data, a point which remained constant across all participants was that the experience of completing a life story project had a positive affect on the PWD. Although numerous interesting and complex themes emerged, which co-existed and interrelated creating a web of rich data, several key themes appeared to stand out and were presented under the headings of “*I’ve been thinking*”: *Mood, Motivation and Focus, Ability not Disability, and Pride*, these were discussed through narratives of achievement and change in the PWD’s self-perception.

Improvements in the PWD’s mood, motivation and focus were reported which may lend some additional support to Woods *et al* (2009) supposition that reminiscence therapy can improve mood and cognition in PWD. Through the current data this was illustrated succinctly by MR indicating that the PWD “came to life”, “before he would just kind of sit” and the PWD repeatedly iterating “I’ve been thinking”.

This change in mood, motivation and focus, also represents an almost coming out, a movement away from withdrawal, this again is indicated through the statements of “came to life” and “before he would just kind of sit”. This may lend some support to the concept that PWD can develop maladaptive coping strategies such as withdrawal due to a malignant social psychology (Kitwood, 1993) and a focussing on their disability by themselves and others (Bamford *et al*, 2004, Carrigan, 2004, Katsuno, 2005). However, it may additionally support the notions of Cheston *et al* (2003) and Woods (2001) that social contexts have the power to create and maintain personhood and by shifting focus away from deficit, loss and functional decline and placing attention on the person’s abilities. This can begin to bring the PWD’s personhood to the fore but is made more solid by supporting opportunities for personal growth, this may create the potential to elicit more positive ideations of the self, strengthen the sense of personhood for the person with dementia and possibly reduce disability (Woods,

2001). The process of completing a life story project, in this research, appeared to help the PWD move towards this.

It is important to consider that of central importance to this process is perhaps the eliciting of a sense of control. This becomes paramount as dementia, although associated with many aspects of deficit and loss, a loss of control may be one of the key components leading to feelings of depression, withdrawal, fragmented self-concepts and perceived excess disability (Aminzadeh *et al*, 2006, Katsuno, 2005). A sense of control for the PWD involved in this research was evident through the PWD remaining the driving force through their life story project and their increased feeling of control appeared throughout the data namely stating that they wanted to make sure those who were supporting him with the project were “doing it right”.

The taking of control and moving towards a realisation of personal ability for the PWD was perhaps most prominently exemplified in the current data through ‘The Event’, this seemed to represent an emergence of the PWD’s personhood, for the PWD and those around him.

These elements are foundational concepts of person-centred care for PWD, *seeing* the person behind dementia and bringing them to the fore (Kitwood, 1997).

This has powerful implications for caring for PWD and the potential for moving towards an increase in quality of life and possibly a reduction in disability, or perceived disability not only for those within the PWD’s social context but also in themselves (Woods, 2001).

This lends some supporting data to possibly strengthen McKeown *et al* (2010) concept *From patient to person* where the completion of LSW enables those around PWD to better understand the person which facilitates improvements in the care and interactions that they are involved in. This whole concept centralises around an altered perception of the PWD. The

data generated in this research represents an additional possibility in that the PWD may realise their own personhood. The completion of LSW represented, in this data set, a journey of altering self-perception for the PWD which highlighted their abilities and seeing themselves as someone who can still achieve things; this led to an increase in self-confidence and pride.

This has important implications for service delivery and the use of LSW by emphasising that not only will the PWD's personhood be identifiable to those who support the PWD but may also highlight their own personhood to themselves.

LSW may have the ability to reduce withdrawal, increase motivation, self-confidence, create a sense of control and pride. Of additional importance the completion of a life story book can also be utilised as a resource which accompanies the person throughout their journey of dementia and may assist them in showing their personhood to others in their social environment when they may have difficulty in doing so themselves. This may be of particular importance during hospital admissions (Norman, 2006) and in additional care environments.

It is hoped that this may encourage the completion of life story projects or at the very least documents such as 'Getting to Know Me' as this can have the power to help staff (McKeown *et al*, 2010) but the actual process of completion for the PWD may elicit more profound benefits for the PWD which may remain after the project is completed, such as pride, a sense of control and realisation of their own personhood.

It is important to consider that everyone is different, and indeed dementia affects everyone differently, with this in mind it may be unreasonable to conclude that completing a life story project will have the same positive outcomes for every PWD, or any other one activity for that matter. The essence of person-centred care is to put the person at the centre and assist

and engage with them in things that are important to them, that is, activities or support which addresses their psychological and social needs (Harmer & Orrell, 2008).

Nevertheless, LSW has the potential to elicit several benefits to both PWD and those involved in their care and is something that is worthy of considerable thought when supporting someone with dementia.

“They had suddenly become people” (Killick and Allan, 2002, pp 13-14).

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Appendices

Appendix 1.1

Information Sheet

TITLE OF THE RESEARCH STUDY:

“How does completing life story work affect people with dementia?”

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the study is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Why is this study being carried out?

The following study is being carried out to fulfill the course requirements of the Practitioner Research Outcome & Partnership (PROP2) course that I am currently participating in and is aimed at enhancing current knowledge and understanding regarding life story work and how it can affect people with dementia. It is anticipated that findings from this research will be used to increase knowledge in this area and help inform future practice and care for people with dementia.

Why have you been chosen?

The following study seeks participants with dementia who have completed a life story book, their family members and professionals involved in their care and you have been identified as fulfilling one of these requirements.

Do you have to take part?

You are free to decide whether or not you wish to take part. If you do decide to take part, you will be given this information sheet to keep and you will be asked to sign a consent form. If you do decide to take part, you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect you in anyway.

What will happen if you take part?

A researcher, Iain Houston, who is a dementia advisor at Alzheimer Scotland and is studying a Practitioner Research Outcomes & Partnership course at the University of Edinburgh, will arrange a suitable time and venue for you to take part in a semi-structured interview. Before the interview starts you will be asked to read and sign a consent form indicating that you are

willing to take part in the study, you are still free to withdraw after you have done this if you wish.

You will then be interviewed for no more than 1 hour with a range of questions regarding your experiences of life story work and dementia; you can see the interview schedule before the interview if you wish. The interview will be semi-structured in nature and be more like an informal chat where you will be encouraged to do most of the talking.

The interview will be recorded audibly (if you completed a life story book and have it with you may be asked if your interview can also be recorded visually). This is done so the interview can be transcribed and later analysed to identify any recurrent themes across all interviews.

Anonymity will be ensured by replacing your name with a randomly assigned name and all recorded and transcribed data will be securely stored on an encrypted USB drive. Access to this data will only be granted to Iain Houston and his supervisor Dr Stuart Muirhead. Upon completion of the study and after it has been formally written up all data will be destroyed. It is important to understand that some extracts from the interview may be used in the written section of the final report which may be put forward for publication, however, as previously stated your anonymity will be guaranteed as your name will be replaced with a randomly assigned name.

Findings from this study will be formally written up and may be submitted for publication in a peer reviewed academic journal. Findings may also be presented at appropriate conferences and events, and shared with peers, other professionals and the general public in a variety of means. However, as previously stated your anonymity will be guaranteed.

How long will it take?

The interview will take 1 hour maximum.

What will happen to the information that you give?

The interview will be recorded for later transcription and analysis. Excerpts from the interview may be used in the final write up. Your anonymity will be guaranteed by replacing your name with a randomly assigned name. All data will be securely stored on an encrypted USB drive with access only granted to the researcher (Iain Houston) and the research supervisor (Dr Stuart Muirhaed). Following formal write up of the study (approximately July 2015) all data will be destroyed.

Will you benefit directly from this research study?

Although you might not benefit directly, we hope that this evaluation will enhance current knowledge and understanding regarding the importance of life story work and dementia.

What to do now

If you would like to take part or would like any more information, please contact either:

Iain Houston; 0141 410 5309, 07787 448 519, ihouston@alzscot.org or Stuart Muirhead
stuart.muirhead@iriss.org.uk

Thank you for taking time to read this information.

Appendix 1.2

Consent Form

TITLE OF THE RESEARCH STUDY:

“How does completing life story work affect people with dementia?”

I,.....(put your name in here),
agree to take part in the research study being carried out by Iain Houston at Alzheimer
Scotland, as part of his Practitioner Research Outcomes & Partnership (PROP2) course. I
have read the information sheet and have had a chance to discuss it.

I understand that:

- I do not have to take part in the research if I don't want to.
- If I change my mind and decide to withdraw from the research at any stage after signing this form, I can. I do not have to give a reason or sign anything to do so.
- If I decide to withdraw from the research study, this will not influence any help or treatment I get in any way.
- The information kept on me will be treated as strictly confidential and will be stored securely.
- Any information I give will be used for research only and will not be used for any other purpose.
- I agree to having any interviews that I take part in as part of this study being visually and audibly recorded.
- Anonymity will be guaranteed with my name being replaced with a randomly assigned named.

SIGNATURE: _____ DATE: _____

WITNESSED: _____ DATE: _____

Appendix 1.3

“I’ve been thinking”: How does completing life story work affect people with dementia?

Interview Guide: Questions I would ask PWD

This is just a rough guide of the sort of things I will ask about, but it will really be more of an informal chat than an interview

- Go through what project is about, give information sheet and consent form
- **Start Interview:** Ask participant for verbal consent, reinforce that all the information that they give will be completely anonymised ask them if they would like to come up with their own pseudonym.
- Begin with general question to start interview, tell me a little bit about your life story book.
- What was it like putting this together?
- How does it make you feel when you look through the book?
- I know that you sent copies of your book to other family members and people have asked to look at the book, how does that make you feel?
- What was it like when we did ‘the event’? Maybe show a video clip or some photos from it, you had told me you were nervous on the day, why was that? How did it feel to tell other people your stories?

“I’ve been thinking”: How does completing life story work affect people with dementia?

Interview Guide: Questions I would ask PWD’s wife

This is just a rough guide of the sort of things I will ask about, but it will really be more of an informal chat than an interview

- Go through what project is about, give information sheet and consent form
- **Start Interview:** Ask participant for verbal consent, reinforce that all the information that they give will be completely anonymised ask them if they would like to come up with their own pseudonym.
- Begin with general question to start interview, can you tell me a little bit about DR.
- What was DR like when he first started putting the book together? Did you notice any difference in him?
- Does DR ever mention the book or what he was up to at the club?
- How do you think it makes DR feel when looking through his book?
- I know that you have sent copies of the book to other family members and people have asked to look at the book, how does DR respond to that?
- DR organised ‘the event’ which you came along to, can you remember what he was like leading up to the event?

- Tell me a little bit about what the event was like?
- How do you think it affected DR doing the event? What was he like after it?
- How do you think the overall experience of putting this together has affected him, both good and bad (I know that people can sometimes find it difficult to look back & reminisce about the past).

“I’ve been thinking”: How does completing life story work affect people with dementia?

Interview Guide: KEY WORKER

- Go through what project is about, give information sheet and consent form
- **Start Interview:** Ask participant for verbal consent, reinforce that all the information that they give will be completely anonymised ask them if they would like to come up with their own pseudonym.
- Begin with general question to start interview, tell me a little bit about what you do at the centre.
- What is DR like in the centre? Can you remember when he first started?
- DR started putting his book together quite a while ago can you remember how he was when he first started putting it together?
- Did you notice any difference in him? Expand with tell me more about that, what do you mean by that?
- Does he ever mention the book?
- Do you or other staff ever look through the book with him? What is this like, how does it affect him? How does he react?
- How do you think it affects him when he comes through to work on the book? Would you say there is any difference in him after we have spent a session working on it?

- DR organised 'the event' which you helped with, can you remember what he was like leading up to the event? He asked for a meeting with you...
- Tell me a little bit about what the event was like?
- How do you think it affected DR doing the event?
- How do you think the overall experience of putting this together has affected him, both good and bad (I know that people can sometimes find it difficult to look back & reminisce about the past).
- Would you say he is different at all? Has it affected him in any way?
- Has the book made any difference in how you work with DR?