

**The Experience Of Care Staff Delivering Reminiscence Sessions To
People With Dementia**

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Doctorate in Clinical Psychology

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I would like to thank all of my research participants.

Thank you for generously giving your time to carry out life storybook sessions and discuss your experiences with me. Your commitment and dedication to your work inspired me.

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Declaration:

I declare that this work is original and my own, and has not been submitted
for any other degree or to any other institution

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The Experience Of Care Staff Delivering Reminiscence Sessions To People With Dementia

Author: Susan Pullan

Thesis Abstract:

Literature review. A systematic review of the literature on the effects of reminiscence on communication with people with dementia was conducted. The focus was the impact of reminiscence on communication and implications for care improvement. Reminiscence can potentially improve communication with people with dementia in several ways. Evidence was strongest for improvement in content of communication, following life review interventions.

Research report. A qualitative study was carried out to explore the experiences of care staff delivering life storybook sessions to people with dementia. Eleven participants were interviewed, and Interpretative Phenomenological Analysis (IPA) used for analysis. Six themes were identified: Barriers to Personhood; Meeting the Person through Life Storybooks; Rehumanising the Person; Rehumanising the Professional; a Changed Relationship; and Plans for the Future. The starting context for many was a restrictive environment and a lost/hidden person. Participants were generally able to develop a more intimate connection with the individual person through delivering life storybook sessions. The experience seemed to rehumanise the person and the professional through the development of their relationship beyond formal staff-patient interactions. However, staff plans for future sessions tended to move away from that one to one relationship, perhaps to more effectively manage the complexity of the work. Links to literature on reminiscence, identity, social psychology and social defence systems are explored. Implications for clinical practice arising include involving care staff in delivering life storybook sessions, supported by clinical supervision. Areas for future research include evaluating changes in ward atmosphere and Dementia Care Mapping to explore care improvements from the care receiver perspective.

Critical appraisal. An in depth account of the researcher's reflections on the experience of the research process is provided. Her personal contribution to design, procedure and analysis, and learning outcomes are explored.

Part One: Literature Review

The Effect Of Reminiscence Therapy On Our Ability To Communicate With People With Dementia: A Critical Review

Target journal: Aging and Mental Health

The Effect Of Reminiscence Therapy On Our Ability To Communicate With People With Dementia: A Critical Review

Abstract

Objectives: A literature review examining how reminiscence therapy affects communication with individuals with dementia was carried out.

Method: PsychInfo, Medline and Web of Science databases were searched systematically. Thirteen articles met the inclusion criteria of empirical studies exploring the effects of reminiscence on communication with individuals with dementia.

Results: Positive effects of reminiscence on communication were demonstrated. Improvements were found in general communication and social interaction in some studies, with others showing improvement in specific aspects of communication, such as verbal behaviour, speech content or non-verbal communication. Evidence for life review and individual interventions was stronger than for general reminiscence. Individual reactions to reminiscence varied. Studies used a range of methodological approaches.

Conclusion: Reminiscence and life review can enhance communication with individuals with dementia. More research is needed to clarify which aspects of communication are consistently improved and how improvements generalise.

The Effect Of Reminiscence Therapy On Our Ability To Communicate With People With Dementia – A Critical Review

1. Introduction

Dementia refers to a group of progressive conditions affecting cognition. Symptoms often begin with mild confusion and memory difficulties, with other aspects of cognition and language deteriorating over time. Eventually the individual may depend entirely on others for care.

1.1. Prevalence Of Dementia

The number of people with dementia in the UK has been recently estimated at 600,000 (Knapp et al., 2007). The prevalence increases with age, rising from 1.3% in the 65-69 yr cohort to 20.3% in a cohort of 85-89 yrs. The increasing life expectancy throughout the Western world underpins the prediction of 940,110 people with dementia in the UK by 2011 (Knapp et al., 2007).

1.2. Dementia And Communication

People experience a range of communication difficulties, varying according to the person and type of dementia. In early Alzheimer's Disease, difficulties are subtle, often word-finding and semantic errors, and some difficulty understanding abstract concepts. In the middle stage people can struggle with staying on topic and cohesion, verbal fluency, empty speech, words lacking meaning, and some grammatical errors. The concepts of greeting and

turn-taking seem to be maintained, but people tend to take more shorter turns. In later stages speech often becomes less coherent, with poor comprehension, paraphasia, palilalia, and echolalia, sometimes progressing to mutism (Ripich & Terrell, 1988). In essence, communicating with a person with dementia usually becomes progressively more problematic.

1.3. Psychosocial Aspects Of Communication And Dementia

People with dementia gradually lose their independence as the disease progresses and one third of individuals with dementia move into residential care (DH, 2008). This usually happens in late stages of dementia, when communication difficulties are likely to affect the person's ability to build relationships and make their needs known. Frustration and confusion are likely to increase in a new environment (Kitwood, 1997), and could be compounded by difficulties expressing views and making choices. Improving communication could help reduce the frustration and enhance relationships.

Good communication is associated with high levels of well-being, and poor or neutral communication with low levels of well-being (CSCI, 2008). Quality of communication between staff and people with dementia living in care homes varies. A recent study found 22% of people with dementia, often those with most communication difficulties, remained withdrawn while activities were going on around them. However, examples of high quality care were also noted (CSCI, 2008). In another survey, residents spent only 14% of time communicating with others and 3% engaging in activities (Ballard et al.,

2001). Improving communication is important to people with dementia, staff and family carers (Train, Nurock, Manela, Kitchen, & Livingston, 2005).

Increasing the number and quality of interactions between care staff and people with dementia could potentially create more meaningful relationships.

Communication is fundamental to Tom Kitwood's person-centred view of dementia care (Kitwood, 1997). He highlighted practices including infantilization, labelling, stigmatisation, and ignoring the person, as creating a malignant social psychology. Improving communication could reduce these behaviours, enhancing interactions between people with dementia and care staff. A supportive social psychology could then evolve which Kitwood argues could potentially slow and even reverse disease progression. The social environment is therefore a powerful target for interventions.

1.4. Therapeutic Interventions For Dementia

A growing body of research evaluates therapeutic interventions for people with dementia, with outcomes ranging from improving cognition to increasing well-being. Despite the quantity of research, clear evidence of the superiority of any particular intervention for people with dementia is lacking. Cochrane reviews of Snoezelen Therapy (Chung & Lai, 2008), validation therapy (Neil & Barton-Wright, 2003) and reminiscence (Spector, Orrell, Davies, & Woods, 2005) for people with dementia failed to find sufficient evidence to recommend any particular approach. Another review found strongest evidence for behavioural, indirect and cognitive approaches, however called

for more research (Livingston, Johnston, Katona, Paton, & Lyketsos, 2005). There is therefore the need for a more detailed understanding of alternative interventions.

1.4.1. Reminiscence Therapy

Reminiscence is the re-experiencing and discussion of past events, in groups or individually, increasingly popular since the 1970s. Reminiscence was once seen negatively, with a view that older people, particularly people with dementia, were hiding in the past and should live in the present (Coleman, 1989). However Butler's (1963) concept of life review, a spontaneous process undergone by older adults integrating and accepting positive and negative experiences, gave reminiscence a theoretical basis. This inspired many therapists to use reminiscence with older adults (Viney, 1993).

However client responses to reminiscence vary. Older people show one of four responses to reminiscence: enjoyment; unproductive negative reminiscence; avoiding reminiscence to focus on present; and avoiding negative memories (Coleman, 1989). This suggests reminiscence is not a unilaterally positive experience, so should not be used as a universal solution.

Reminiscence is often used with individuals with dementia, perhaps because people with dementia often find it easier to communicate about the past. Potential benefits of reminiscence include coming to terms with the life lived, facilitating communication (Mills, 1997; Mills & Coleman, 1994), giving

support and facilitation to retain a narrative identity, and sharing that with others (Usita, Hyman, & Herman, 1998), and passing on values to the next generation (Gibb, Morris, & Gleisberg, 1997).

1.5. The Focus Of This Review

Reviews of reminiscence to date have been broad, giving an overview but not comparing different formats or specific outcomes. This might account for the mixed results. Despite suggestions that reminiscence could improve communication, reviews have not examined this area in depth. This review therefore aims to explore how reminiscence might affect communication. Given the potential effects of reminiscence on communication, it is hoped that the specific focus of this review will allow differentiation between reminiscence and other interventions.

Individuals experience dementia variably, depending on factors such as the disease progression, type of dementia, co-morbidity, personality, support networks, environment, life history and physical health. Conducting RCTs with this heterogeneous population is of limited utility, and alternative methodologies can offer increased understanding of potential benefits of interventions for some individuals. More qualitative research into effects of reminiscence for people with dementia has been recommended (Moos & Bjorn, 2006), and single case designs allow evaluation of individualised treatment approaches (Alderman, 2002). This review will therefore include empirical studies using any methodology.

Due to the importance of communication in facilitating relationships and improving person-centred approaches, this review will focus on the effects of reminiscence on communication. It will examine whether reminiscence really does impact on communication with people with dementia, and how. If reminiscence can affect communication with people with dementia, it will explore whether these improvements can lead to better quality care.

2. Method

2.1. Search Strategy And Search Terms

A systematic search was conducted of PsychInfo, Scopus and Web of Sciences databases and the British Library integrated catalogue. The search terms 'reminiscence', 'life review' and 'life storybooks' were paired with 'dement*' and 'Alzheim*'. Searches were restricted to studies since 1980 available in English. Secondary references from retrieved articles were followed up. Others researching life storybooks were consulted, and guidance was examined. Search criteria were amended to include terms from reference lists of other articles. The terms 'memory books' and 'memory aids' were sourced in the search and subsequently included, leading to a broader review of the literature.

2.2. Search Results And Inclusion Criteria

86 articles were retrieved and sifted manually according to the inclusion/exclusion criteria.

Studies were judged to meet the inclusion criteria if they:

1. were an empirical study
2. used reminiscence or a life storybook intervention
3. focussed on the area of communication
4. included participants with dementia

Literature evaluating memory books and memory aids was included, as the aids were comparable to a life storybook. The grey literature was searched to avoid publication bias, and an unpublished thesis included. Review articles were excluded. Some qualitative articles which briefly suggested improved communication after reminiscence, but did not explore communication changes in depth, were excluded. After this process, thirteen articles met the inclusion criteria and were selected for this review. Table 1 below lists selected articles with details of sample, focus and design.

Table 1 – Articles included in critical literature review

Reference	Sample	Design	Format of Intervention	Focus
Andrews-Salvia et al 2003	4 with severe dementia	Multiple baseline single case design	Individual sessions with memory books	Content
Baines et al 1987	15 with moderate to severe dementia	Controlled cross-over study	Reminiscence groups compared to Reality Orientation groups	Global
Bourgeois et al 2001	66 with dementia and 66 nursing aids	Experimental study	Memory aids compared to no treatment	Verbal
Bourgeois 1993	6 with moderate to severe dementia	Single case design	Conversations between dyads with or without memory aids	Content
Dijkstra et al 2002	66 with dementia	Randomised Controlled Trial	Individual sessions with memory books and training compared to no treatment	Content
Gee 1991	11 with dementia classified as "grossly impaired"	Within group design	Group reminiscence with discussion, stimulation and socialisation	Global
Haight et al 2006	31 with dementia	Randomised Controlled Trial	Individual sessions with life storybooks compared to no treatment	Global
Hoerster et al 2001	4 with dementia and nursing aids	Multiple baseline across subjects	Individual conversations with memory books compared to conversations without	Content

Moss et al 2002	15 with mild to moderate dementia	Within subjects design	Reminiscence group compared to diagnostic language group	Global
Okumura et al 2008	16 with Alzheimer's	Experimental between group design	Reminiscence compared to conversation group	Verbal
Smyth 2006 (unpublished thesis, University of East Anglia)	5 with dementia	Single case design	Individual sessions with life storybooks compared to general reminiscence and unstructured time	Global
Tabourne 1995	40 with AD or other cognitive disorder	Quasi-experimental between subjects design	Group reminiscence compared to no treatment control	Verbal
Thorgrimsen et al 2002	11 with dementia and 11 carers	Randomised Controlled Trial	Group reminiscence compared to no treatment control	Global

3. Results

Some studies examined communication in general, whereas others focussed on specific aspects, such as verbal fluency, or specific communication behaviours, such as on topic statements. The findings are presented below according to the communication area investigated.

3.1. Effects On General Communication Abilities

Studies used a range of scales to assess general communication abilities, including the Holden Communication Scale (HCS) (Baines, Saxby, & Ehlert, 1987); Thorgrimsen et al 2002), the Communication Observation Scale (COS) (Haight, Gibson, & Michel, 2006), and the NIH Rating Scale for Functional Communication Abilities of Dementia (Moss, Polignano, White, Minichiello, & Sunderland, 2002).

Baines et al.'s crossover study (1987) found Reality Orientation (RO) and reminiscence significantly improved communication over a no treatment control. A group receiving RO then reminiscence showed greater improvement in communication (27.4%) than a group receiving reminiscence then RO (11.7%). This demonstrates the complexity of comparing treatment interventions in this population, and suggests reminiscence can be more effective in certain contexts,

such as after an orienting intervention. Potential carry-over effects make results complex to interpret.

Thorgrimsen, Schweitzer and Orrell (2002) found a non-significant improvement in communication using the HCS in a group which received a manualised reminiscence intervention over a no treatment control. The study was a rigorous, well controlled RCT. The very small sample (n=11) renders significant results more difficult to achieve, and means results may not generalise to a larger population. The authors did not specify the statistical test used.

Haight et al. (2006) found a significant improvement in the COS in a group following a life storybook intervention compared to a no treatment control. The intervention was individual and existing staff delivered sessions, so carry over effects into care may account for greater improvements. Their sample was larger (n=31), however with no alternative treatment group, comparisons with other interventions cannot be made.

Smyth (2006, unpublished thesis) compared reminiscence, focused life review, and unstructured time. The case study design had a small sample (n=5). Staff rated communication with four out of five residents as easier during either reminiscence or life review. One participant was rated easier to communicate with during life review than general reminiscence, whilst another's

communication did not seem affected by the intervention. Individuality was considered, but a non-standard rating scale was adopted.

Tabourne (1995) found significant improvements in social interaction in a life review group over a control group. Improvements consisted of initiating conversations/ behaviour and responding to conversations verbally and non-verbally. 'Veterans' of previous groups showed additional benefits, initiating more conversations and two taking a semi leadership role. The design was quasi-experimental (n=40) and inter-rater reliability was high, however as rating took place during sessions, raters were not blind to condition. During the treatment period, participants from the experimental group engaged in more social activities on the ward than the comparison group, which could suggest generalisation of positive effects.

Moss et al. (2002) found a significant number of participants performed better in narrative production (n=10) and verbal behaviours (n=9) in a reminiscence group than in a diagnostic language session. Improvements were in narrative ($X^2=7.5$; $p<0.005$) and verbal categories of the scale ($X^2=4.8$, $p<0.025$). The narrative category included presenting a story appropriately, conveying information and varying conversational style; whereas the verbal category included complexity of phrases, volume and pitch of verbalisation. Improvements in conversation and non-verbal categories were not significant. This suggests

reminiscence groups can improve the quality of communication, perhaps by providing shared cues and memories. As performance was rated overall rather than scored, the magnitude of improvements cannot be judged. There was potentially some rater bias as raters were not blind to condition and session selection methods were unspecified.

3.2. Effects On Verbal Aspects Of Communication

Okumura, Tanimukai and Asada (2008) found a significant improvement in verbal fluency following a reminiscence group over a general conversation group. Verbal fluency was rated by a word generation task after the session, suggesting improvements could carry over from sessions. Performance of the reminiscence group improved after session 3, suggesting longer interventions may increase positive effects on communication. However effects on verbal communication, attention/interest and emotion as measured by the Todai-shiki Observational Rating Scale (TORS) did not show significant differences. Potential improvements over a control group were not explored. The process of randomisation is not specified, and inclusion of participants living in residential care and those living at home may have confounded results.

In summary, evidence suggests reminiscence can improve some aspects of communication (narrative production, verbal behaviours and verbal fluency) over other group interventions (Moss et al., 2002; Okumura et al., 2008). In contrast,

no significant improvement in verbal communication is shown (Okumura et al., 2008). RO followed by reminiscence may improve communication (Baines et al., 1987). Comparing specific aspects of communication may allow measurement of more subtle changes than using a global scale. Also, studies focussing on communication (Moss et al., 2002; Okomura et al., 2008) may measure more subtle changes than those investigating many outcomes (Baines et al., 1987; Haight et al., 2006, Thorgrimsen et al., 2002).

3.3. Effects On Content Of Communication

Bourgeois (1993) measured how memory aids improved the content of conversations between two people with dementia using single case methodology. On topic and novel utterances increased for 3 of 5 participants. Conversely, partners (member of dyad talking about other's book) made more on topic utterances without the aid, but fewer ambiguous utterances with the aid. Judges rated dyads better at staying on topic, conveying information, taking turns and responding appropriately. The author focuses on clinical significance, however statistical analysis would lend more weight to findings.

Andrews-Salvia, Roy and Cameron (2003) also showed an increase in on topic statements in four individuals with severe dementia, using memory books alone. Participants showed differences in which conversation topic generated more statements. Two participants required additional time to read material before

conversations. This was a case study, so does not claim to generalise, however suggests memory books can improve communication among people with severe dementia.

Hoerster, Hickey and Bourgeois (2001) compared conversations between nursing aids and people with dementia with and without memory aids. On topic statements increased in all residents, and off topic statements reduced in two participants when using memory aids. Participants made more detailed and novel statements using the memory aid. Individual differences were apparent, with some participants uttering more on topic statements, whereas others improved by reducing off topic statements. With this sample size (n=4), the influence of other factors such as environmental changes can have greater impact, and the number of conversations rated was limited.

Dijkstra, Bourgeois, Burgio and Allen (2002) found significant improvements in various aspects of communication following their intervention comprising a memory book and communication training for Nursing Assistants (NAs). This RCT had a reasonable sized sample (n=66). The treatment group showed significant improvements in: coherence; organisation of ideas; topic maintenance; the context of the conversation (global coherence); and, structuring of utterances (local coherence). There was a significant decrease in the number of indefinite or empty words, but an increase in repetitions post-treatment. Conversations rated

were short (5 mins) between individuals and NAs, and comparable to individual life storybook sessions. Individuals with severe dementia improved most, then mild, then medium. However as NAs received communication training, the findings may not be a result of memory books alone.

These results support the suggestion that significant improvements in certain aspects of communication can be achieved through using memory books.

Interventions were all individual, and the evidence is more consistent than in the previous section. Individual sessions were shown to increase the number of on topic facts (Andrews-Salvia et al., 2003; Bourgeois, 1993; Hoerster et al., 2001) novel utterances and words (Bourgeois, 1993), reduce off topic statements (Hoerster et al., 2001), and improve coherence (Dijkstra et al., 2002). One study showed increased repetitions following reminiscence (Dijkstra et al., 2002). Two case studies (Bourgeois, 1993; Hoerster et al., 2001) showed individual differences in response to reminiscence, however the overall positive effect in the RCT (Dijkstra et al., 2002) suggests that this intervention has potential for many people with dementia.

3.4. Effects On Non-Verbal Communication

Okumura et al (2008) found a significant difference in non-verbal communication following four sessions of a reminiscence group compared to a general conversation group. The effect was measurable on the non-verbal sub-scale of

the Todai-shiki Observational Rating Scale (TORS). The authors also informally noted an increasing interest in other participants in the reminiscence group, with participants nodding their heads in response to the comments of others.

Gee (1991) found a significant improvement in 'contact behaviour' following a group incorporating reminiscence, and no increase in 'withdrawal behaviour'. Elements measured as contact behaviour were mostly non-verbal communication behaviours such as eye contact, with some verbal communication. The design was within subjects, and rating was during sessions, introducing potential bias. The intervention involved stimulation, socialisation and the use of touch as well as reminiscence.

These studies (Gee, 1991; Okumura et al., 2008) found significant improvement in non-verbal communication following reminiscence. Both were group interventions, however one ran for five sessions (Okumura et al., 2008) and one for twenty-four sessions (Gee, 1991). Although general themes were provided, neither study used manuals to structure the group, again making comparison or replication problematic.

3.5. Effects On Staff Communication Behaviour

The Dijkstra study previously referred to (Dijkstra et al., 2002) using memory books also found significant increases in facilitative conversation of NAs when

speaking to people with dementia. This was measured during conversations following a treatment compared to a control group. NAs used more facilitative comments (facilitators), encouragement and cues. NAs talking to early stage dementia patients used more cues, those talking to medium stage used fewer questions, and to later stage used more facilitators and cues. This suggests memory books may encourage NAs to adapt their conversational style to suit the individual.

Hoerster et al., (2001) found that NAs reduced non-facilitative conversational behaviours when using a memory aid to talk to an individual with dementia. This study specifically targeted requests and assertions. Further training in addition to the memory books was needed to achieve this outcome.

Two studies suggest memory books can improve interactions between NAs and people with dementia (Dijkstra et al., 2002; Hoerster et al., 2001). Both studies are reviewed earlier in this paper. These results are clinically promising, however suggest that changing the conversational behaviour of NAs may require training in addition to provision of memory books.

4. Discussion

This current review aimed to be as systematic as possible. The literature in this area provides a complex overview as the types of study, interventions and

outcome measures vary. However, some conclusions can be drawn and specific elements of the results are discussed below in relation to the questions posed by this review.

4.1. What Effect Does Reminiscence Have On Communication?

This review found evidence that reminiscence can lead to improvements in communication with people with dementia. Studies suggest improvements can be seen in the content of conversation, and in non-verbal communication behaviours, which could also therefore indicate greater levels of engagement. Improvements were shown for participants with mild, moderate and severe dementia (Dijkstra et al., 2002). Both life review and general reminiscence were shown to improve communication, however, the number of studies and quality of improvements seemed stronger for individual life review/life storybook interventions. This supports Smyth's (2006) finding that focused life review is more effective than a general reminiscence group for this population. However, only this one study (Smyth, 2006) compared formats of interventions directly, so more research would be needed to support this argument.

These positive results contrast with the Cochrane review, which did not support the efficacy of reminiscence (Woods et al., 2005). This could be because examining psychosocial interventions generally did not allow detailed enough analysis to show how reminiscence affects communication. This focused review

highlighted quite subtle differences in communication behaviour, which might not show up on general outcome measures. Indeed, studies using global measures of communication did not all show significant improvement, and one study (Moss et al., 2002) showed improvement only on certain subscales of their measure, suggesting not all aspects of communication are improved. Additionally, studies showed improvement in different aspects of communication, suggesting particular forms of reminiscence could enhance particular communication behaviours. The strongest evidence is for on-topic statements, where several studies show improvement (Andrews-Salvia et al., 2003; Bourgeois, 1993; Hoerster et al., 2001) and no studies found otherwise.

4.2. How Might Reminiscence Improve Communication?

Reminiscence has been suggested to enhance the conversation of people with dementia, and lead to more facilitative communication by NAs (Dijkstra et al., 2002). The processes underpinning changes were not investigated directly, however there are some possibilities. Firstly, the clearest effect was shown in keeping on topic. People with dementia can make incoherent comments, and struggle to focus on a conversational topic. Studies showed on-topic statements can be increased using a memory book. The book may cue the person with dementia in to the topic of the conversation and provide subject matter for conversations. In this way the memory book can scaffold the communication ability of the person, allowing them to maximise their conversational skills.

Another area with promising results was non-verbal communication. Non-verbal communication can indicate level of engagement, and may reflect an increased interest or knowledge of the subject being discussed. The finding of Bourgeois (1993) that people with dementia discussing another's book made fewer on topic statements provides some support for this idea. In common with others, people with dementia have been shown to have access to more memories from early to middle life (Rubin, 2002), it would therefore seem likely that reminiscence would increase the accessibility of a conversation. This would seem to suggest that individual life review would be more engaging than reminiscence, which is supported somewhat by this review.

4.3. Can Quality Of Care Be Improved By Using Reminiscence?

This review suggests reminiscence improves communication by and with people with dementia. Reminiscence could therefore potentially enhance the social environment by improving the person's surrounding social psychology.

According to Kitwood's dementia experience model (1997), improving the social psychology would result in a more positive experience for the person with dementia. To achieve this, improvements need to generalise outside sessions. Improvements in verbal fluency were measurable after sessions in one study (Okumura et al., 2008), however, this was immediately after the sessions, with no indication of sustainability of improvements. Individuals from the

reminiscence group of another study (Tabourne, 1995) participated in more social activities outside sessions, a promising indicator of generalisation of improvements but not sufficient evidence in itself to establish a causal relationship.

Several studies showed improvements in NA communication behaviours, another potential source of generalising improvements. NAs comprise a significant part of the supportive or malignant social psychology surrounding a person, and often adopt non-facilitative, directive language when interacting with the people they care for (Baltes, Kinderman, Reizenzein, & Schmid, 1987). Two studies showed improvements in NA's interactions using a memory book (Dijkstra et al., 2002; Hoerster et al., 2001). The evidence is not unequivocal, since communication training was also required, although is clinically promising. Many interventions for dementia are limited in their potential for lasting change given the ongoing cognitive deterioration. Changes in staff interactions have potential to be maintained over time and to generalise to other people in their care.

4.4. Individual Differences

In the general reminiscence literature studies often failed to find differences between interventions (Baillon et al., 2005; Lai et al., 2004), instead reporting within group differences. In contrast, this review suggests reminiscence can improve communication over other types of conversation. Positive effects of

reminiscence are then not just increased attention and stimulation. However individual differences in reactions to reminiscence as identified by Coleman (Coleman, 1989) were apparent in the case studies reviewed. In one study, individuals with severe cognitive impairment improved less during reminiscence compared to those with mild to moderate impairment (Bourgeois, 1993). Another study found residents' communication enhanced in different ways, with more verbal residents decreasing off topic statements, and less verbal residents increasing on topic statements. Some participants needed additional time to process their utterances (Hoerster et al., 2001). This review suggests that reminiscence can improve communication, however individual reactions vary. It is important to remain mindful of ethical issues around imposing reminiscence on individuals for whom it is not a positive experience. In a client group whose cognitive difficulties affect their ability to express their views, this concern needs addressing.

4.5. The Literature

Sourcing articles for this review was problematic due to differing terminology; some articles refer to reminiscence or life review, others to memory books or aids. A strength of the review is compilation of research from various disciplines and methodologies. Comparing differing methodologies, in particular RCTs and case studies can be problematic. It has been suggested that these two methods contribute to knowledge in different ways, with the RCT showing general

benefits for a population of an intervention, and a case study giving an in depth look at the individual impact of the intervention, and evidence to support it's efficacy (Medical Research Council, 2008). The MRC suggests that case studies can demonstrate outcomes within and between participants, and test theory by manipulating variables to inform future trials. RCTs are considered to be higher up the evidence hierarchy than case studies, but this depends on the quality of the RCT or case study. This review has used data from case studies (eg. Hoerster et al., 2001) to provide insight into individual impact of interventions, and from RCTs (eg. Dijkstra et al., 2002) to suggest generalisable outcomes. Incorporating studies with varying theoretical bases and focus perhaps contributed to difficulty collating the information. Sessions varied greatly in length and focus, however all covered a person's life history or the past, and it may be concluded that this commonality outweighed any differences. Some interventions were very structured, whereas others did not specify content of sessions or how consistency was ensured. Some interventions were staff-patient conversations, which gave useful data on staff behaviour but introduced variability in patient experience.

There were various methodological concerns, supporting the finding of the Cochrane Review (Woods et al., 2005) that more rigorous research in this area is needed. The case studies offered useful indications of potential benefits, but cannot claim generalisable results. Although statistical tests are available for case study designs, none of those included reported statistical significance. Examining

one study in depth exemplifies many of the methodological concerns. Haight et al. (2006) carried out a randomised controlled study. The randomisation method was not specified. Researchers delivering measures may not have been blind to condition. There was no comparison treatment group. The sample was small (n=30), and severity of dementia was not reported. Different care staff delivered the intervention, so although a structured format was used individual interventions were likely to vary. The level of consistency between individual interventions was not reported. Relationship factors and differences between the six research sites were not reported. Also, between group designs do not show individual differences in reaction to the intervention. The RCTs (Haight et al., 2006; Okumura et al., 2008; Thorgrimsen et al., 2002) often had small samples, and only one study cited power of the effect. Lack of alternative treatment controls in some studies ruled out comparison reminiscence to alternative interventions. Participants had varying dementias and severity levels, resulting in a heterogeneous group. Only one study differentiated for severity of dementia (Dijkstra et al., 2002). The measures used varied. Two studies used the Holden Communication Scale (Baines et al., 1987; Thorgrimsen et al., 2002) but neither reported on its validity or reliability. The Todai-shiki Observational Rating Scale was developed to evaluate reminiscence sessions for people with dementia, and evidence cited of inter-rater reliability (Matsuda et al., 2001), however the validation sample was small (n=9). Other studies observed communication behaviours, capturing smaller changes but introducing potential rater bias.

4.6. Future Research

Much of the research reviewed was from an observational perspective, measuring changes in behaviours. Although these studies seemed rigorously implemented, they do not explore qualitative improvements in the life of the individual with dementia or in communication and relationships outside the sessions, such as would be reported by people with dementia and their carers. There was a lack of research into how reminiscence might affect relational aspects of communication, which might also address the question of how reminiscence impacts communication.

5. Conclusion

This review found reminiscence can improve various aspects of communication of people with dementia. Improvements were shown in overall communication, verbal communication, content and non-verbal communication. Evidence was not consistent regarding which aspects of communication were improved, and more research to investigate this would be beneficial. Changes in staff communication with individuals were found, and warrant more research. Individual differences in responses to reminiscence were evident in the literature, but no detrimental effects were found in this review.

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Part Two: Empirical Study

The Experience of Care Staff Delivering Reminiscence Sessions to People with Dementia

The Experience of Care Staff Delivering Reminiscence Sessions to People with Dementia

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Abstract:

Introduction. Despite cognitive deterioration associated with dementia, research suggests people can maintain 'personhood' with a supportive surrounding social psychology (Kitwood, 1997). Reminiscence is a popular intervention for people with dementia, which potentially improves relationships with care staff. The experiences of care staff delivering reminiscence sessions to people with dementia have not been thoroughly explored.

Method. Eleven participants delivered life storybook sessions to individuals with dementia. They were interviewed and transcripts analysed using IPA to explore their experiences.

Results. Six superordinate themes emerged: barriers to personhood; meeting the person through life storybooks; rehumanising the person; rehumanising the professional; a changed relationship and; plans for the future. For many, the starting context was a structured environment with a perceived lack of time or influence over the person's mood. Participants were often task-oriented and prioritised physical care. Life storybooks increased time spent with the person, connecting through shared emotional experience, although for some it was a frustrating experience due to limited interaction. Following the sessions, participants saw the person as more of an individual with a unique life history, rather than a passive care recipient. They experienced difficult emotions facing the person's losses, feeling inadequate to compensate, but their increased knowledge seemed to lead to care improvements. Participants intended to continue the sessions, having found them enjoyable and beneficial for the person with dementia.

Conclusion. Delivering life storybook sessions is an intervention with potential to effect broad systemic changes. Recommendations include creating life storybooks for people with dementia at the earliest opportunity, and offering clinical supervision to staff delivering sessions to support them in developing relevant skills. Areas for future research are suggested, including evaluating changes in ward atmosphere and Dementia Care Mapping to explore care improvements from the care receiver perspective.

1. Introduction

1.1. The Experience Of Dementia

Dementia is a group of progressive conditions affecting cognition with symptoms including confusion, memory and language difficulties. Depending on individual progression, people can eventually depend on others for care. Organic damage and general atrophy of the brain is often observable post mortem, however, no strong correlation between the severity of organic damage and dementia symptoms has yet emerged (Kitwood, 1987). The individual path through the disease seems to involve many factors including personality, environment and life history, with growing evidence that social environment can slow cognitive losses and improve well-being (Kitwood, 1997).

1.1.1. Prevalence Of Dementia

The number of people with dementia in the UK has been recently estimated at 600,000 (Knapp et al., 2007). The prevalence of dementia increases with age, rising from 1.3% in the 65-69 yr cohort to 20.3% in a cohort of 85-89 yrs. Life expectancy throughout most of the Western world is increasing, and this trend underpins the predicted rise to 940,110 with dementia in the UK by 2011 (Knapp et al., 2007). People with dementia typically lose their independence as the disease progresses and many individuals are moved into residential care once their family carers can no longer cope with their needs. Two thirds of people currently in care homes have dementia (DH, 2009). Quality of care was

evaluated as needing radical improvement in all private and NHS homes recently surveyed (Ballard et al., 2001). There is therefore a clear case for developing ways of working with dementia to maximise independence and wellbeing for the benefit of the individual and society as a whole.

1.1.2. Psychological Treatment For Dementia

Therapeutic interventions for people with dementia have been evaluated through a growing body of research, influenced by the dominant discourses surrounding dementia. Desired outcomes range from improving cognition and behaviour to increasing well-being. Reviews of Snoezelen Therapy (Chung & Lai, 2008), validation therapy (Neil & Barton-Wright, 2003) and reminiscence (Woods, Spector, Orrell & Davies, 2005) found insufficient evidence to recommend any one approach. A systematic review of reality orientation (RO) found improvements in cognition and behaviour, however, four out of eight trials included lacked treatment controls (Spector, Davies, Woods, & Orrell, 2000). Evidence for behavioural, indirect and cognitive approaches to dementia treatment is more robust but insufficient suitable studies were identified in the review (Livingston, Johnston, Katona, Paton, & Lyketsos, 2005). In summary, the evidence for psychological treatments for dementia is currently inconclusive. The National Dementia Strategy aims to fundamentally improve the lives of people with dementia in the UK through building services and early intervention,

supported by funding (DH, 2009). However, a clear evidence base is needed to direct funding to where it will be most effective.

1.1.3. Dementia And Person-Centred Care

The ideas of Tom Kitwood (1997) influence current approaches to dementia care. Kitwood argued for a person-centred view of dementia, highlighting differences in individual presentations and the potential for a supportive social environment to minimise cognitive losses, and possibly reverse symptoms. Improving the well-being of people with dementia has since become an important treatment aim, measured through Dementia Care Mapping, a systematic observation tool (Kitwood & Bredin, 1994). A person-centred approach, using knowledge of an individual's life history to interpret the communication underlying challenging behaviour, can lead to successful interventions (Stokes, 2000). One important change resulting from the take up of person-centred approaches to dementia treatment is to move the focus away from symptomatic improvement to enhancing quality of life for people with dementia. Measuring well-being is seen by many as the most suitable outcome matching this current understanding (Brooker & Duce, 2000)

1.2. Reminiscence

Reminiscence is the re-experiencing and discussion of past events, in groups or individually, and has gained in popularity since the 1970s. Once reminiscence

was seen as negative, with older people, especially those with dementia, encouraged to focus on the present (Coleman, 1989). However Butler (1963) created the concept of life review, giving reminiscence a theoretical basis. Butler's life review was a spontaneous process undergone in later life leading to integration and acceptance of positive and negative experiences. This inspired many therapists working with older adults to use reminiscence approaches. Butler drew on the work of Erik Erikson (1950), whose final developmental stages includes accepting the life lived. Benefits of life review can include: maintaining self-esteem in the face of losses of function, coping with negative feelings from losses, maintaining identity, and contributing to society (McMahon & Rhudick, 1964).

1.2.1. Reminiscence And Relationships With Care Staff

Evaluations have frequently found residents in care homes spend insufficient time interacting with others (Ballard et al., 2001, CSCI, 2008). Despite improvements, quality of care in many institutions is inadequate (CSCI, 2008). Interactions between staff and people with dementia seem to remain brief and impersonal, even with higher staffing levels (Kitwood, 1997). With the significant impact of staff on the lives of people with dementia, any intervention that increases staff-patient contact should improve quality of care. Reminiscence or individual life review offers one such intervention.

There are promising indications that reminiscence may impact on care staff working with people with dementia. Staff morale and attitudes can be improved where high levels of stimulating activity are planned for residents (Jones, 1988). This shows staff attitudes can potentially be changed through interventions. Life review sessions can reduce caregiver burden independently of whether the person cared for receives life review (Haight et al., 2003) and levels of stress in relatives may reduce following reminiscence (Thorgrimsen, Schweitzer, & Orrell, 2002). A reminiscence kit was rated above other activity kits for facilitating family visits to people with dementia (Crispi & Heitner, 2002) suggesting reminiscence offers a distinct contribution beyond other interventions. Staff also commented informally on their better understanding of the difficulties of people with dementia, and an increase in helpfulness and contact seeking in individuals following reminiscence sessions (Mills, 1997; Mills & Walker, 1994). These comments were not formally evaluated, but provide indications of potential changes in caregiver attitudes.

Evidence that life storybooks might help change attitudes of care staff towards care receivers, and improve relationships comes from a study by Clarke, Hanson and Ross (2003). Support workers produced life storybooks for older people in their care, resulting in an increased tendency to see the person beyond the patient, and reported improvement in relationships. Participants were not working with people with dementia, however, this study suggests life storybooks

can positively affect attitudes of care staff. Clarke et al. did not analyse staff experiences in depth, giving a broad overview of staff, people with dementia and family member views.

1.3. The Focus Of This Research

The progressive cognitive decline associated with dementia makes differentiating between interventions for people with dementia problematic. Positive long-term benefits from interventions are rarely demonstrated, and comparison studies have often found little to recommend particular interventions (e.g. Deponte & Missan, 2007; van Diepen et al., 2002). As people with dementia often lack stimulation, perhaps benefits of time and attention outweigh differences between interventions. However, there remains a need to prioritise and focus resources. This research was designed with the premise that reminiscence might offer a powerful method of indirect intervention, through improving the social psychology surrounding the person with dementia.

The literature suggests life storybooks can potentially improve the way care staff view the people they work with. Positive effects on staff attitudes towards older people have been shown (Clark et al., 2003), however no empirical studies were identified evaluating staff delivering sessions to people with dementia. Should life storybooks be shown to improve interactions and relationships between care

staff and people with dementia, quality of life for people with dementia should improve in the long term, through a positive social psychology.

The research will explore the experiences of care staff delivering reminiscence sessions to people with dementia. Further, it will examine how those experiences might alter their perceptions of and relationship with the person they work with, to look for any impact on care for the person with dementia.

2. Method

2.1. Design

Qualitative methodology seemed the most appropriate way to address the research questions, which focussed on subjective experience. With few prior studies in this area, testable hypotheses for a quantitative approach would have been more difficult to generate. Qualitative methods can facilitate a more exploratory, inductive approach to an area of study, allowing the subjective experience of the participants to be explored. Giving the participants an opportunity to tell their story generated valuable information about the processes underpinning life storybook sessions, not previously available.

There are numerous potential sources of qualitative data other than the traditional research interview. As this research enquired about participants' subjective experience of life storybook sessions, interviews were selected as the

most suitable data collection method. Interviews enabled participant accounts relating to areas of interest, such as how sessions affected their interactions with and views of the person, to be gathered.

2.1.1. IPA Methodology

Interpretative Phenomenological Analysis (IPA), as developed by Smith (Smith & Osborn, 2008) was selected as the most suitable methodology for this study after careful consideration of other qualitative methodologies, in particular Grounded Theory (GT). IPA was considered more appropriate than GT for several reasons: the research question related to the experiences and meanings of those to participants; there was a homogenous group of participants (in this case all caring for people with dementia in a particular setting); the focus was individual experiences, rather than to create a theory; and, IPA allowed the researcher to interpret the meanings of experiences to participants while acknowledging her own meaning making process. The researcher had undertaken a placement in the research setting so experienced alternative roles on site. IPA allowed her to remain mindful of these, while acknowledging their role in the developing story. In summary, IPA allowed the perspective of each individual to be explored and the emergent themes to build a picture of the experiences of all participants.

2.1.2. Selecting The Site

A psychology team working in an independent sector charity, specialising in secure care for older people with risky or challenging behaviour, wished to research the impact of life storybooks for their clients. The services were for older people including secure services, and specialist services for dementia and Huntington's Disease (HD). Some clients had a forensic history, some were detained under the Mental Health Act (1983), but others were informal patients.

Life storybooks had been used on site for five years, with many staff advocates; however, the psychology team wanted to consider their impact on client relationships, and to understand if it would be beneficial to involve more staff from various disciplines in delivering sessions.

2.1.2.1. Participants

Eleven staff members were interviewed, to gain a broad range of experience. Convenience sampling was used. This is generally used in IPA studies, which are taken from what is considered a homogenous group. Convenience sampling also met the practical requirements of this study, with potentially small numbers of participants available.

Participants were members of care staff working at the selected site who consented to participate. Participation was invited from all staff who potentially

delivered life storybook sessions, except psychologists, as it was judged that their investment in the success of life storybooks would have influenced their experience of delivering sessions to an unhelpful degree for this study.

2.2. Procedure

Participants were selected, delivered sessions, and were then interviewed about their experiences. Volunteers were recruited by sending information via email about the study to staff. Interested staff members were invited to discuss participation with the researcher or a member of the psychology team. After consent had been obtained, a Consultant Neuropsychologist oversaw the recruitment and allocation of one individual with dementia on their ward for each participant. Copies of the information leaflet and consent form used are in Appendices 5 and 6. Following a refresher training session, participants delivered five reminiscence sessions of approximately 30 minutes to that individual.

Twelve participants agreed to take part in the study, from four different wards. One participant withdrew due to an extended absence from work; therefore the final sample was eleven. Participants were drawn from qualified and unqualified nursing staff, and the allied health professions of occupational therapy, physiotherapy and social work. Table 1 shows most participants were female, due at least in part to higher numbers of female staff in the population on site. They were paired with people with varying types and severity of dementia. The

responsible Consultant Neuropsychologist estimated dementia severity using criteria set by Folstein (1975).

Participant	Gender	Age	Profession	Ward	Diagnosis of person	Severity of Dementia
1	F	55 - 60	Allied Health Profession	1	Alzheimer's & Vascular Dementia	Severe
2 (did not complete)	F	50 - 55	Nursing Profession	1	Fronto-temporal Dementia	Moderate
3	F	40 - 55	Allied Health Profession	1	Pre-senile Dementia (Alzheimer's Type)	Severe
4	F	35 - 40	Nursing Profession	2	Huntington's Dementia	Severe
5	F	50 - 55	Nursing Profession	2	Huntington's Dementia	Severe
6	F	30 - 35	Nursing Profession	2	Huntington's Dementia	Severe
7	F	50 - 55	Nursing Profession	2	Huntington's Dementia	Moderate
8	F	25 - 30	Allied Health Profession	3	Fronto-temporal Dementia	Severe
9	F	45 - 50	Nursing Profession	3	Frontal Lobe Dementia	Moderate
10	F	55 - 60	Nursing Profession	3	Vascular Dementia	Severe
11	F	50 - 55	Nursing Profession	4	Frontal Lobe Dementia	Moderate
12	M	25 - 30	Allied Health Profession	4	Frontal Lobe Dementia	Moderate

Table 1: Participant Details

Ten participants conducted five sessions, however one had only completed one very brief session. This participant agreed to talk about her difficulties delivering the sessions. Interviews lasted for approximately one hour, and were audio recorded. The researcher personally transcribed the recordings.

2.3. Analysis

Manual analysis was used to allow the researcher to actively work with the transcripts. IPA is a structured approach to data analysis, involving several key stages. The first transcript was coded entirely with key emerging themes drawn out and organised and a master table of themes produced. Subsequent transcripts were approached using this master table, actively seeking new codes and developing existing codes. This method of analysing group data was selected to allow thorough coding of a large number of transcripts for an IPA study. The researcher sought out new or discordant views to those already stated within the following transcripts, for example Anne's interview represents the experience of someone who did not complete the sessions. In keeping with the comparative nature of IPA, the final master table of themes was used to reconsider all transcripts, and represent the collective story of individuals.

Notes of areas of interest from left margin	Excerpt from transcript	Emerging codes from right margin
Enjoyment of time spent with person Doing more than usual Some hesitation to say frustrated	"Erm, (.) In fact, I enjoyed it because, erm, I was spending individual time with, with him which as I say I wouldn't normally do on, for that length of time"	Having one to one time with the person

Table 2: Illustration of coding process used

2.3.1. Ensuring Rigour Throughout The Research Process

A range of approaches to ensuring rigour in qualitative research has been suggested (Elliott, Fischer & Rennie, 1999; Meyrick, 2006; Morrow, 2005; Yardley, 2000). This research was conducted using criteria suggested by Yardley (2000) to enhance value in qualitative research. These principles are: sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance.

Sensitivity to context was shown by grounding the research in the theoretical literature and the clinical needs of people with dementia. An example of this is the decision taken to not interview people with dementia about their experiences, on the basis that this would be repeating previous studies.

Commitment and rigour is exemplified by the depth and breadth of the analysis, also the use of a reflexive diary to gauge what the researcher brought to each stage of the process. An extract from the diary is reproduced in Figure 1 below, illustrating reflection on both content and process of interviews. Feedback from peers and supervisors was also sought on coding to ensure it was representative and thorough. For example, the themes of 'the depersonalising nature of institutional care' and 'the lost/hidden person' were grouped under a new overarching theme of 'barriers to personhood' following a discussion in supervision.

"I was very concerned though that the interview seemed very short. It would have been shorter, but I thought of extra questions to ask. I think I worry about missing something, or not doing a good enough interview, I also find it personally challenging to manage people who don't talk very much. Have reflected that although short, there was a lot of information there. Am also very excited that my research has already resulted in a direct improvement in the life of one person."

Figure 1: Extract from research diary.

Transparency was demonstrated by saving the master table of themes after each transcript was analysed, with example quotes showed transparency, it also demonstrates the fluid nature of the analysis as it developed throughout, for example the theme 'feeling important to the person' emerged as an aspect of 'a changed relationship' late in the coding process. Coherence is demonstrated by

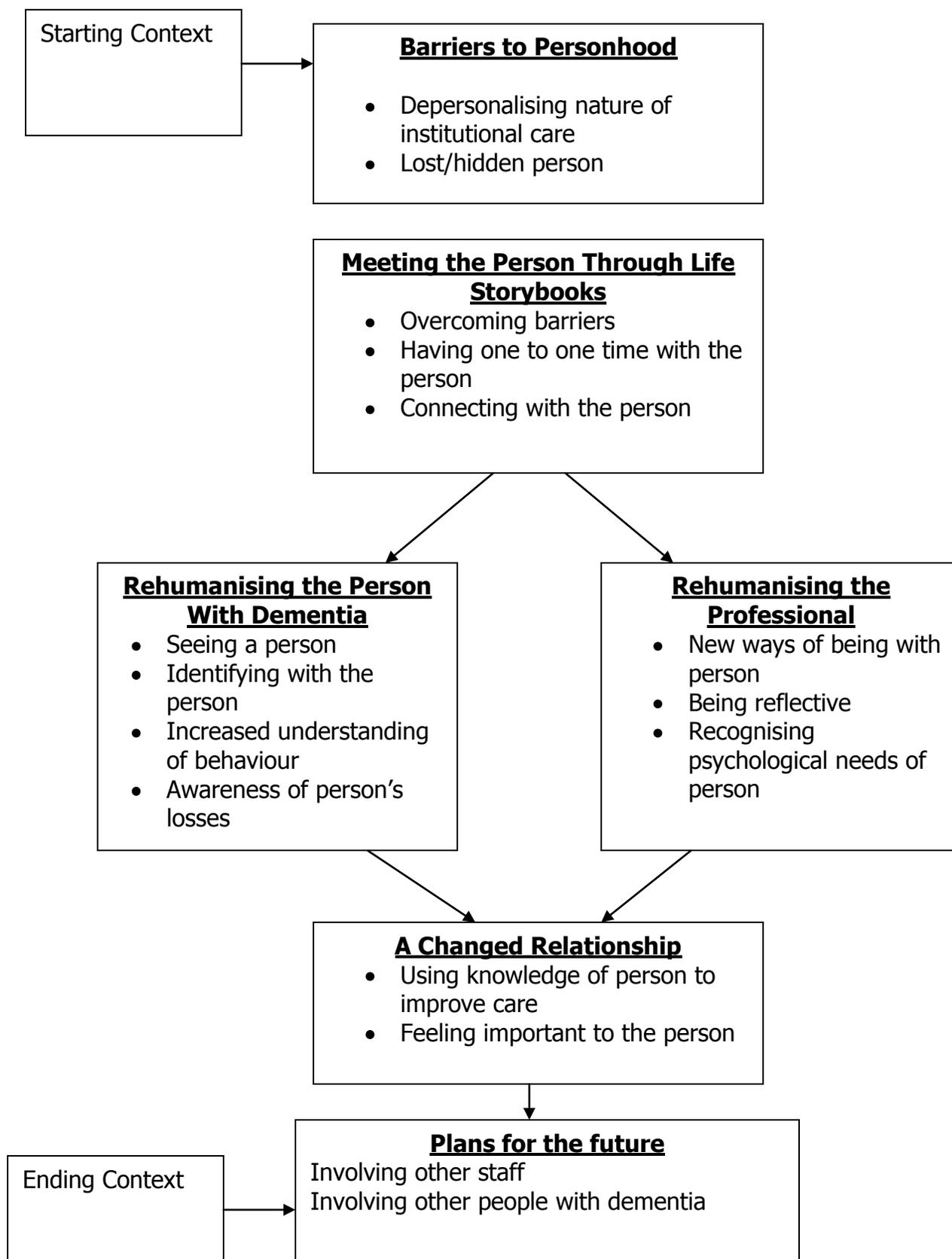
how the analysis resonates with both the existing literature and the experiences of the psychology team on site.

Impact and importance is demonstrated on two levels. The research impacted directly on ward practices, and this process will hopefully continue through feedback of results on site. Additionally, dissemination through a community of interest and academic publication will be sought. The results of the research are important to clinicians in the field, and may provide an enriched understanding of processes taking place during reminiscence.

3. Results

The analysis will be presented according to the six superordinate themes which emerged from the data: barriers to personhood; meeting the person through life storybooks; rehumanising the person; rehumanising the professional; a changed relationship, and planning for the future.

Figure 2. Illustration of themes: experience of care staff delivering reminiscence sessions to people with dementia



3.1. Barriers To Personhood

This theme refers to the context before sessions took place. When describing their working life, two main barriers to personhood emerged from participant accounts. Barriers arose from the working environment, the 'depersonalising nature of institutional care', and the interpersonal difficulties and uncertainty experienced around caring for 'a lost/hidden person'.

3.1.1. The Depersonalising Nature Of Institutional Care

Participants described how institutional care for people with dementia presented major barriers to seeing the person. There were several aspects to this theme, which are explored separately below.

3.1.1.1. Structure And Imposed Limits.

Participants described ways structure limited the care they could provide to people. They felt limited by time, work requirements, the person's condition and their needs. A lack of time came up in most accounts.

"You want half an hour really, don't you really? [YEAH] Really yeah to sit with her without being disturbed and that's what you

need [MMM] but you couldn't do this this morning there'd be too much you know there's a lot to do this morning."

Anne, 171

This captures Anne's feeling of lacking sufficient time to sit with the person. Participants talked about struggling to find times when patients are receptive and juggling competing requirements. Ward life is extremely busy, with patient days fairly structured. Nurses are left prioritising physical care and very task focussed.

"You know what I mean, you kill two birds with one stone [YEAH] sometimes, when you get the patients up and you're washing them and you're bathing them [MMM] so you use that opportunity to talk to them"

Jane, 25

As Jane describes, communication with patients often takes place during routine physical care. The sense of moving from task to task, and being constantly busy pervades accounts. Participants described prioritising physical care, as tasks involved in physical care are visible and obvious.

"I think sometimes you can tend to think that not it's wasted time but there are other things I could be doing [MMM] yeah?"

*[YEAH] And so you think like if I get them done then I'll know,
then it looks like I've done something and I've and it's done
[MMM] whereas you can't see that <Ange>'s had ten or fifteen
minutes or <Bianca> has or whatever [MMM] but they're reaping
the benefit and you're reaping a lot of that."*

Tracy, 787

Tracy introduces another key concept to this category, that of obligation to the team. Participants felt they must complete tasks or let their colleagues down and feel guilty. One participant, Anne, felt so guilty about leaving her colleagues to cope that she did not complete her sessions. As well as meeting obligation to colleagues, participants talked of their difficulty meeting the diverse needs of the individuals they care for.

3.1.1.2. Roles Restricting Relationships.

Participants' professional roles were experienced as a barrier between them and people they cared for. Being a nurse seemed to mean for some that they should not have feelings.

*"you always have to remember that you are a nurse and they
are a patient and, and although you can't help but maybe*

sometimes develop a liking for them, you know I think it's a human thing isn't it?"

Jane, 68

Jane's account here captures the dialectic between her human response and how she feels she ought respond as a professional.

Participants also referred to how adopting a professional role allowed participants to control their feelings, inhibit their reactions to aggressive incidents, and withhold personal information.

"you have a good day and a not so good day but that in a professional level you override that. You have to I mean you know some patient might have (.) lashed out at you and you think "I didn't need that today" but it happens."

Gail, 605

3.1.2. A Lost/Hidden Person.

Participants described difficulty reaching the person with dementia. Aspects of this theme were difficulty knowing the person, seeking to understand, and a one-sided relationship.

3.1.2.1. Difficulty Knowing The Person.

Participant accounts were full of uncertainty and the difficulty this state of not knowing engendered.

"you don't really know if they actually happy, I mean she'll be smiling for you as if she's feeling happy [YES] but she doesn't sort of erm explain things ... quite a few patients that won't talk I think I find it really difficult because I would never know exactly what they are thinking "

Jane, 684

Communication difficulties were a common factor behind the uncertainty participants felt.

"I thought well is it that she doesn't like talking about her past [YEAH] maybe it's upsetting the fact that you know once ... she had a full-time job she had a family and, you know an active lifestyle, and now she's here in a home and dementia."

Carla, 129

Carla struggled to interpret a lack of response from the person she worked with.

3.1.2.2. Seeking To Understand

A strong urge to understand the person permeated accounts, arising from a combination of not wanting to upset the person, and uncertainty about signs of distress. Lacking confirmation, participants relied on their own interpretations, but questioned these.

"You know because as I say, because he's very much difficult to understand, well words are basically unintelligible most of the time, but there is the odd word that you can pick up. [MMM] But what – you know if you're trying to listen to what somebody's saying you'll probably pick up on a word that's related to what you'd like to think it was."

Karen, 143

In the context of communication difficulty, responses from the person are questioned and sometimes discounted, such as in Karen's case, as wishful thinking.

With the person unable to share their story and maintain their own narrative identity, the role of others becomes vital to hold this on their behalf. Many people do not have this support from family and in a sense lose their identity altogether.

"I know one particular patient has a brother and it's very difficult to get information from him because he has, er mobility problems and early onset dementia, so if we were to do her life story book I know it would be very difficult to get information"

Carla 732

This sense of a lost identity comes through in Carla's account, as the family members who could fulfil that role are losing their ability to do so.

3.1.2.3. A One-Sided Relationship

Difficulty reaching the person seemed to leave participants feeling responsible for managing the health, behaviour and emotions of the people in their care.

Relationships seemed very one-sided, with participants giving but not experiencing any sense of reciprocity from the person with dementia. They did not seem to feel important to the person or find their companionship rewarding.

"Er, yes you do speak to other patients but when they can't hold a conversation it is very one sided and it's very hard. [YEAH] Whereas when you've got the two way thing, it's much better. "

Tracy 457

Tracy's account illustrates her experience of this one-sided relationship.

Although participants seemed to feel they were unable to affect the mood of the people they cared for, they seemed to believe that they needed to be kept cheerful at all times.

"I think it's nice looking back erm, with <Donna> she looks at it like it's happy, she you know I've never found, times before, I've never found it's upset her [NO] whereas you'd think that probably that would. [MMM] Because that's what I was afraid of, I think to myself "oh, it could be upsetting looking back", and that which is quite natural."

Anne, 276

Anne's account demonstrates her feeling of responsibility for the emotions of the person she worked with, and the avoidance of negative feelings present in many accounts.

Participants seemed to feel that the person they cared for did not notice their individuality, that carrying out tasks was more important than their personal contribution to care.

*"I think it could have been me, or it could have been somebody
else going through this book with her, you know."*

Helen, 406

As Helen demonstrates, for many an aspect of relationships seemed to be a feeling of not being special to the person.

3.2. Meeting The Person Through Life Storybooks

This second over-arching theme describes a journey to meet the person through the life storybook sessions. The starting point of this journey was overcoming specific barriers to the sessions themselves. Changes were experienced in perceptions of the person through first by simply being with, then by connecting with the person.

3.2.1. Overcoming Barriers

In order to deliver sessions, participants overcame a number of specific barriers. These included their own expectations of sessions; judgements about the person, and making time to do the sessions.

3.2.1.1. Expectations

Some participants had negative expectations of the sessions or worries. They often expressed concern about the concept of sessions, practical considerations, or having a poor experience of the person they were allocated.

"I wouldn't like to you know continue. [MMM] Because I would think you know maybe it's just opening up her (.) old wounds really."

Jane, 662

Like Jane, some participants started with a negative view of reminiscence as potentially harmful.

"You know, he'd consistently for a couple of years been refusing to see me despite needing sort of ...intervention."

Gordon, 21

Sometimes worries about the sessions were based on prior interactions with the person.

3.2.1.2. Awareness Of Judgements About The Person

Participants changed their ideas about the person they worked with and seemed to increase their awareness of how these judgements were formed. Prior to sessions, information available about the person was from reports or any forensic history, or reactions of other staff members. There was a feeling that people shouldn't be pre-judged, but it was inevitable.

"It's finding that little bit more other than what's written in his erm folder. [MMM] See the life history book is is about their life what they did before they came here [YEAH] whereas we just get what they've done wrong. We don't get what they've done right.

Gail, 821

Participants talked about their understanding of people's conditions. For some, the condition had taken the person away, whereas others saw the condition between them and the person.

"when I started doing the life story book with her it was really strange because then I began to see her in different light you know it was like behind the patient and HD condition is somebody totally different, who's kind of I don't know in a way

*been transformed by her condition into someone totally different,
if that makes sense?"*

Jane, 86

Jane's understanding of the person has changed, and she now seems to see the patient, the disease and the person as three separate entities.

3.2.1.3. Making Time

Participants made the time to do sessions. Following the sessions, participants conversely saw it as not a big task and often wondered why they hadn't done so before. This suggests there is actually time in the working day for interaction, which doesn't happen usually for other reasons.

"Because actually you're actually taking time to sit and listen to him aren't you, sit and listen to what he's got to say (.) that was quite good because it was erm (.) and I also found that I made time to spend with him ... But because I knew we was doing these sessions and I needed to get I made the time and (.) yeah it was really good."

Laura, 184

Participants expressed the idea that time was made because they had committed to take part in the research.

3.2.2. Having One To One Time With The Person

There was importance and personal reward from simply being with the person. Even when the person they worked with didn't show a response, participants felt being with them was giving comfort.

"I think he enjoyed it because obviously he'd got contact and all, most of the time I was sort of, I was talking to him, I touched his hand several times obviously to make sure he's still you know, he's still with me sort of thing."

Karen, 173

Karen's partner showed little response, however she felt satisfaction from having been with him. Most participants enjoyed the sessions personally.

"What was good? [YEAH] I enjoyed the time with her. [YEAH] It was nice just to have half an hour with <Bianca> as I said we had fun [YEAH] and er, yeah it I enjoyed it and I think I think because she did as well. [MMM] So it was a nice half an hour."

Tracy, 640

*"I'd say do you want a cigarette and then some girlie time, we'll
have a little catch up [YEAH] you know, just something like
that."*

Tracy, 285

Tracy and another participant conceptualised sessions as "girlie time" demonstrating a fundamentally different approach to interactions than the professional approach described previously.

3.2.3. Connecting With The Person

Through being with the person, participants described connecting through the shared experiences. There were two sub-themes to this theme, striving to make a connection and making a connection. These are conflicting experiences, seeming to relate to different levels of response from the person with dementia.

3.2.3.1. Striving To Connect With The Person

This sub-theme shows the frustration of trying to get a response from somebody faced with seeming indifference. Some participants felt unable to establish a connection given this lack of response. The life storybooks have given the

participant responsibility for trying to connect, which perhaps they usually avoid doing during everyday patient care.

"I felt this need for her to sort of recognise a, er a name that I said or you know places that she used to go to that sort of thing, and there was just absolutely nothing. [RIGHT] You know, so it's frustrating on my part because there was just nothing there, yeah."

Carla, 49

Carla's frustration at not being able to connect did not stop her trying, and her perseverance comes through in the above extract.

3.2.3.2. Making A Connection

This conflicting theme relates to experiences of participants who able to make a connection during sessions. Many were pleasantly surprised by the response generated, particularly how much people both remembered and were willing to share with them.

"I thought you know she was going to tell me bits about what's written down you know but she actually elaborated on everything [MMM] that was there. ... It makes you feel that

these people, they're not just patients they're people who live in this world you know they have the same problems as we have and they've dealt with it in their lives as well."

Helen, 126

The contribution from person she worked with pleasantly surprised Helen, and the elaboration of stories from the person seemed to enhance the connection.

"somebody could write oh, yeah you know about a bottle of perfume and say you know smelt this and this and this you can just only imagine it based on what you smelt before but when they actually spray it on you and you smell it [YEAH] it's a totally different, different experience so looking at her and going through those pictures with her and learn, you know knowing her from the life story book obviously not really going to know her 100% but you know it's kind of an eye opener, really."

Jane, 124

The experiential aspect of the learning other aspects of the person, which Jane describes above, seemed to be the ingredient allowing a deep connection to be made. Merely reading the information from the book would not have had the same impact on Jane.

"I wouldn't mention his wife that has passed because I know it's a very sensitive subject, but with the book it just opens up many more possibilities so I just just a great erm conversation tool, it was excellent so. And in the sessions that I do with him now I remember things that were in the book and then so we can still have that good conversation."

Harriet, 82

Participants found books opened up conversations on subjects they previously avoided, primarily about negative life experiences. People seemed mostly happy to discuss those experiences, and participants felt more confident to broach these subjects outside sessions.

3.3. Rehumanising The Person With Dementia

A strong theme running through almost all accounts was seeing the person as a person, rather than a patient. This theme demonstrated how life storybooks penetrated the barrier of the patient role, allowing a person to emerge. Aspects of this theme were: seeing the person; identifying with the person; an increased understanding of the person and an awareness of the person's losses.

3.3.1. Seeing A Person

Participants described how their daily work could leave them seeing the person as a passive care recipient, but the life storybook helped them see a person beneath.

"But one of the, one of the strangest things and I think this sounds in some ways it sounds awful and in other ways probably not, erm doing the life story book with her made me see her as, I know that this sounds awful but made me see her as a human being [YEAH] and I er, I'm probably not using the right words here because obviously I saw her as a human being before [YEAH] but I think when you're so busy doing other things you see the patients as (.) service users, patients that need your care [YEAH] and you forget that they had a life before they came here you sometimes forget that [MMM]. And I suppose the life story book has sort of helped me sort of realise, not not realise I'm probably using the wrong words here because obviously I know that she had a life before she came here but [MMM] you forget don't you, you sort of go through your life and you do different things and you go through your job and you forget that this lady was married, had children, had a job and did things that we do now."

Carla, 443

Carla's quote illustrates how exploring the person's life helped participants to regain the view of the patient as a person. Carla had not experienced response from her person, but still felt the powerful effect of her life story. Participants were ashamed of having lost sight of the person, and Carla struggled to express this.

Knowing the person's life story led participants to feel they knew the person much better. Participants thought they knew the person before sessions, however felt they now knew them deeply.

"Suppose you get to know, you know the, I got to know her more [MMM] you know [MMM] more than I knew her. I thought I knew her, but after a while then I realise I know, you know what I mean?"

Sasha, 134

"Erm, I suppose somebody coming in cold would find it very difficult, I don't really know. [YEAH] But because I know the gentleman quite well, well I think I do, erm, I suppose I (.) I was forearmed or forewarned what the expectations were."

Karen, 575

Participants often stressed the importance of their prior knowledge of the person enabling them to deliver the sessions.

3.3.2. Identifying With The Person

Through seeing the person, there was a growing realisation of a similar life lived to their own. Participants often talked about the person with dementia in their prior roles of caring for others, increasingly comparing their life experiences.

*"It makes you feel that these people, they're not just patients
they're people who live in this world you know they have the
same problems as we have and they've dealt with it in their lives
as well."*

Helen, 132

As participants increasingly identified with the person they were working with, conversations could become more reciprocal, covering shared life experiences.

"Well we even spoke about our marriages"

Tracy, 175

Tracy's excerpt contrasts with the professional barriers expressed before sessions, as during sessions she shared information about her personal life with her partner.

With this growing sense of similarity seemed to come a realisation that anyone could experience dementia in the future.

"you know is is just you kind of think when she's shouting and screaming and I think oh gosh, you can see (.) you know, I would probably be worse."

Jane, 109

Participants put themselves in the patient's position, often suggesting they would behave in more challenging ways.

3.3.3. Awareness Of Person's Losses

Sessions also increased the participants' awareness of what the person lost from their life, and the restrictive nature of institutional care.

"Because you're thinking "wow", you know, she was like an outgoing person and she had lots of friends, she was quite a

girlie girl actually, you know and all of a sudden all that's been taken away from her by the condition."

Jane, 100

Sadness at the person's losses and externalising this to the condition seemed to lead to increased empathy for behaviour, which was now conceived as expressions of distress.

"I can't imagine what it must be like, it must be dreadful it must be horrendous. How can you suddenly have so much and then you're confined [MMM] because of your illness. It must be absolutely (.) well I can't imagine what it must be like. It must be soul destroying it really must be."

Gail, 696

Gail had discussed the person in a very matter of fact way, but then experienced a strong emotional impact when his losses are brought into her awareness. Some aspects of participant accounts may be an attempt to defend against the strong reactions inherent in this theme.

"It was well, it was lovely, she told me all about <Jim> and how much she loves him, how much he cares about her and how

*lucky she is to have him [MMM] and she also talked about erm,
being here [MMM] and I asked her how she felt about being here
and then it was erm, she told me she felt safe here [AH] that,
you know it is nice here."*

Helen, 101

Conversely, awareness of losses brings awareness of the valuable aspects of participants' lives, as in Helen's description of the loving relationship experienced by the person she worked with.

3.4. Re-Humanising The Professional

This theme refers to changes in the professional, who seemed to undergo a process of increasing the humanity of their approach to work, contrasting with the professional barriers described at the beginning. Sub-themes were: new ways of being with the person, being reflective, and prioritising the psychological needs of the person.

3.4.1. New Ways Of Being With The Person

Participant accounts were permeated with their experiences of new ways of being with the person. These incorporated emotional ways of being and a more collaborative style.

An important aspect of many participants' experience was emotions raised during the sessions in themselves and the person they worked with. Bearing in mind the context, where negative emotions are avoided as much as possible, experiencing emotion with people they worked with was a new and very powerful experience for many.

"But a lot of it, some of it made me a bit sad because (.) because you know it I don't know some of it was just he did he did have a good life but (.) when they're sad you get a bit sad don't you?"

Laura, 71

Laura expresses how her mood was affected by the mood of the person she worked with.

"it's not just conversation it's actually reminiscing about when he went away with her and how they met and and it's all positive that he was saying to me in the life storybook there was no, no tears he was a bit down a couple of times but he was (.) it was a good kind of down because it was good reminiscence"

Harriet, 102

The attitude towards sadness experienced by the person Harriet was working with shows her construction of this apparently negative emotion as cathartic.

"Well I think the, the first time I did it it was with this enthusiasm (speaks in a falsely positive voice) "ah so <Clare> let's see the, lets see your book", you know you know but then after the first session before the second time it was like oh, I was dreading it thinking "oh do I have to do that again, I know I'm going to be upset" and then I approach it with caution and then from then on you're kind of cautious but you kind of know what you felt before and then eventually you sort of develop certain skills perhaps, you know to talk to her and then you know towards the end when you're talking to her you're just approaching her as a different person, for for certain, totally different."

Jane, 199

Jane describes her own emotional journey very eloquently. Her initial reaction to being upset is avoidance, but she persevered and came to feel she developed skills. This extract illustrates how sessions seemed to overcome defences.

Not all negative emotions seemed to be productive. One participant found that the person she worked with became extremely upset by a traumatic memory triggered in a session.

"I read something that disgraced my, erm client, [OK] and she ended up in tears, [OK] so erm, yes... she really went on and erm I felt so bad like the other time it was before, I was about to hand over to the next shift so when they come in she was crying, [AH] so I had to say why she was crying and ah you know, it was a bit hard."

Sasha, 41

Sasha was very upset that she was re-traumatising the person, and guilty for causing more work for her colleagues.

An important aspect of the sessions for many seemed to be the collaborative nature of sessions. The person with dementia was able to choose whether to engage in the session, and guide the content of sessions.

"Well there was one where I went and it only lasted five minutes [RIGHT] because then she er told me to f off (laughs) she wasn't, you know I think she wasn't in a very good mood [MMM]"

and they is one where she was really dancing, you know and she was happy and it was "mmm, yeah" and she was you know chatting away."

Jane, 306

Jane's experience echoes that of many participants who responded to the reaction of the person to guide them in whether to proceed with a session, and when to change topic.

3.4.2. Being Reflective

Following sessions, participants described becoming more reflective and questioning their working practices. This theme is complex, as participants were sometimes left in a difficult place, however feelings of personal achievement seemed to lead to improved job satisfaction.

Participants felt more aware of their own prejudices and described being less judgemental and more open-minded.

"I think it's quite good because it's made me aware of my own yeah, my own feelings about things and my own prejudices and you know made me, made me think you know in a different way, so that I'm less prejudiced about things and a bit more open-

*mindful and more wanting to explore things before I I just come
to a certain you know conclusion"*

Jane, 584

An important factor in forming more balanced judgements about people seemed to be the difference in information from life storybooks to usual sources of information about the person, such as reports.

Connecting with the person on an emotional level, and increasingly aware of their losses, participants were sometimes with difficult feelings.

*"Yes, yes it was quite sad and she just you just think you know
when you're going home thinking my job is fulfilled and that you
know I'm doing a good job and I looked after this patient, er and
all of a sudden it was an awful feeling [YEAH] because although
you're doing what you're doing for them, you know really they
were much much better before they had this condition. [MMM]
do you know what I mean? And whatever I'm doing can never
ever match how she lived her life before [MMM] and it can never
be back you know"*

Jane, 142

Jane demonstrates how job satisfaction could be affected through feeling unable to measure up to the previous life of the person.

so she always seemed the same and during the same, and afterwards she seemed the same"

Carla 293

Carla's sense of inadequacy seemed to come from trying but not making a difference.

Conversely, some participants described feeling more personal satisfaction in their work, and an increased sense of achievement.

*"So yeah, that's when she said that she felt safe here. [MMM]
Which it's quite nice to hear someone saying that, because it makes what we do worthwhile, doesn't it?"*

Helen, 300

Helen's extract shows how sometimes conversations about current care could be opened, giving positive feedback.

3.4.3. Prioritising The Psychological Needs Of The Person

In contrast to the task-focused prioritisation of physical needs permeating earlier descriptions, a new awareness of psychological needs seemed to arise following the sessions. Participants seemed to appreciate the benefits of interacting with people both for mutual enjoyment, and prevent the person from needing to attract their attention by extreme behaviour.

"You know as I say it's 24/7 be nice to erm have ten minutes here and there wouldn't it for goodness sake it's not too much to ask...as I say yes lots of time we've been short but like I've just said is it the end of the world if the stock isn't put away? Is it the end of the world if the towels aren't in the bathroom? Yes, it makes life easier but then we could have an hour when <Ange>'s really settled. [YEAH] Without her screaming, and then we don't get anything done anyway."

Tracy, 772

Tracy's extract demonstrates her reprioritisation of spending time with the person over physical tasks.

3.5.A Changed Relationship

These two aspects of the re-humanised professional and the re-humanised patient seem to enhance the relationship between them. This theme captures the end a journey of psychological change and shared experience. The sub-themes are using knowledge of the person to improve care, and feeling important to the person.

3.5.1. Using Knowledge Of The Person To Improve Care

Participants felt they used increased knowledge of the person to improve the care they offered. Better care resulted from improved engagement and the ideas inspired by the person's interests. They had gained confidence in their ability to influence the person's mood and behaviour.

"(.) I suppose in a way it's good for (.) for the clients (.) because even though we sit with the clients every now and again, erm, if I do, like, personal hygiene now and again it's lot more better, more social., I let her get on with what she's doing, and this gave me the opportunity to, you know engage more, you know, and erm (.) and more one to one you know."

Sasha, 329

For Sasha, the changed relationship carried over into routine tasks such as physical care.

"I'd think well I'll offer him coffee because that's what he's got in his book [YEAH] whereas I didn't know that previously. [YEAH] I don't think it's made any difference otherwise."

Karen, 398

The magnitude of the change varied. Participants who struggled to get a response felt the sessions had not affected their relationship, although small changes still came through, such as in Karen's account above.

"Erm, well we've seen him subsequent times and he's actually agreed to come out for a walk with me since which is something that he's not agreed to do before"

Gordon, 31

Gordon describes how engagement in life storybook sessions led to the person engaging in other activities.

"I do take the care plan approach but I put my emotion and feeling for her I know why now."

Jane 443

Like Jane, participants talked about putting more of themselves as people into the care they provided. Interestingly, Jane no longer seems to see the structure and her individual contribution as incompatible, she aims to use both.

Participants also seemed to have gained more confidence approaching the person they had worked with. There was a sense of being able to manage their mood.

"I think it is good, it's more strong I must say. [MMM] Yes, because I mean at times, like what I say, she's got quite a strong willpower [MMM] and, erm, when she's crying I can sort of erm (.) give her reassurance basing on things that I know now [MMM] You know, like, erm you like these things, or let me put this DVD, remember, you saw it this and that, you know (.) things. You used to like it. [MMM] At least I've got something to ... that I truly know she likes."

Sasha, 203

Sasha's account demonstrates how she felt an increased ability to improve the mood of the person she worked with based on their shared experiences.

3.5.2. Feeling Important To The Person

Elements of their experience delivering the sessions seem to have balanced the relationship with the person with dementia, which became more reciprocal. In particular, participants felt the person they had worked with trusted them and special to them. This contrasts directly with the unequal relationship described prior to sessions, where the person with dementia was seen as indifferent to the care provider.

"It was nice to be able to get close to someone, because er I've only managed to do that with one other patient on here, be the only person that they would open up to [YEAH] and that was er, I felt quite proud of that, and I felt quite proud at the end of the sessions that she was ready to talk to me and wanting to do it again, you know that she didn't feel like she'd been pressured into anything."

Helen, 519

Helen's account captured how rewarding participants found it when the person they worked with opened up and trusted them. The experience seems to have been enhanced by a sense that people had the chose to share their personal stories, and an element of exclusivity.

3.6. Plans For The Future

Participants all planned to use life storybooks in the future, including those who had experienced difficulty getting a response and had found the sessions frustrating. Some planned to continue sessions with the same person, but there was a tendency to involve more staff and more patients. This could be a wish to share benefits with others, or perhaps enables increased distance from an uncomfortably intimate care relationship.

"Erm, (.) I didn't want to give up, [MMM] I wanted to keep going just in case [YEAH] and it's funny because even though I've done the, the five sessions part of me still wants to continue on with this life story book [YEAH] and sort of, to see if I get something [YEAH] do you know what I mean?."

Carla, 199

Carla's account illustrates how participants were sometimes determined to persevere and try to make a connection. Others who did not get a response from the person they worked with planned to seek out a more responsive person.

"the patient wants to get that one to one session with whoever because the books are in the room anyway [YEAH] and we can use that and she didn't say otherwise. Mmm-hmm."

Sasha 453

Sasha's extract exemplifies the feeling throughout accounts of wanting to involve other staff members and patients in sessions. Often plans for the future moved away from one to one relationships to any member of staff delivering a session to any patient. This may be a response to the intimacy and difficult feelings aroused by sessions.

"Because we've had that one on one, now we're like that (crosses fingers) do you know what I mean? [YEAH] And I don't mean that in a bad way but it can be dif – it is a bit claustrophobic. You know it seems as though it's always my name [MMM] cause I tell her I'm going to change it and I've left the island and that is it [MMM] erm perhaps it's because, erm,

*she did get my that attention and because she wants that place
again, I don't know."*

Tracy, 109

Tracy's account exemplifies this wish to move away from a one to one relationship, with a sense that exclusivity can be stifling.

4. Discussion Of Results

This section aims to summarise the results of the current research in relation to relevant psychological literature and theory, including the reminiscence literature, identity, social psychology, and social defence systems. Clinical implications are explored, the study critiqued, and recommendations for future research suggested.

4.1. Interpretation Of Results

The results suggest life storybooks can potentially effect powerful systemic change. Six key themes were identified: barriers to personhood, meeting the person through life storybooks, rehumanising the person, rehumanising the professional, a changed relationship, and plans for the future. The theme 'Barriers to Personhood' described their starting context, working within institutional constraints, where time and a feeling of powerlessness in the face of overwhelming need could lead to a task-oriented culture. Within this setting,

participants could struggle to connect with a lost/hidden person. They experienced uncertainty in establishing people's needs, and monitoring their reactions. This difficulty contributed to a seemingly one-sided relationship where the person with dementia lacked opportunity to reciprocate.

The next theme, 'Meeting the Person Through Life Storybooks' describes a journey of discovery. Participants' initial expectations were often negative, however many experienced enjoyment through simply being with the person. Participants whose partner gave fewer verbal responses experienced frustration, striving to make a connection. Through sharing experiences participants often connected with the person and experienced emotionally rich sessions.

'Rehumanising The Person' captures the experience permeating participant accounts of starting to see a person behind the patient. Participants became aware of the person's losses, and increasingly identified with the person.

'Rehumanising The Professional' captures corresponding change in participants. Reflexivity appeared to increase as participants described tolerating difficult emotions and uncertainty. However, this could be a difficult place professionally, particularly participants who felt unable to compensate for the person's losses. 'A Changed Relationship' showed how relationships could be enhanced, with more confident professionals using increased knowledge of the person to interpret behaviour and improve care. 'Plans For The Future' showed participants all planning to continue with the sessions, however moving from the exclusivity of

one to one sessions, which some found stifling, towards using books more generally.

4.2. This Research And The Reminiscence Literature

This research adds an important aspect to the reminiscence literature, supporting the idea that life storybooks can enhance staff attitudes towards people with dementia, and improve their relationships. Although this research does not claim to transfer to all care staff in all settings, the results appear to complement those of Clarke et al. (2003) who found similar benefits in staff developing life storybooks for older people. Clarke et al. found biographical approaches helped nursing staff see the person behind the patient, and improved relationships. Their sessions did not suit all older people, contrasting with these results where sessions were felt to have benefited all, even those who experienced negative emotions or showed no response. Anxieties which Clarke et al. report in their participants before the sessions were lack of time, and the possibility of upsetting patients. Participants in this worried about the same things, as well as their prior experiences of the patient, perhaps due to their history with patients.

Another interesting comparison is implementation. Clarke et al. found strong barriers to implementation, with staff members saying they could not make time for the sessions. Eventually, a dedicated support worker was recruited, and her positive experiences interested others. This researcher anticipated but did not

experience implementation difficulties. This might be due to cooperation between participants and the psychology department, or perhaps participants felt an obligation, knowing the research was for a qualification. The positive history of life storybooks on site may have helped. Participants in this study also seemed to pass their enthusiasm onto others, and enjoyable aspects of the sessions seemed to lead to a wish to continue. The experience seemed necessary for benefits to be fully appreciated, however, staff anxieties such as those expressed before sessions may prevent some from taking up the approach. This research also supports the finding among community nurses, who were concerned that implementing life review could be harmful if negative emotions were triggered, and requested qualified support (Trueman & Parker, 2006). This research has suggested a potential route to increasing the well-being of people with dementia. If changes described by participants carry over to improve care, they may account for some improvements in the well-being of people with dementia following reminiscence sessions.

4.3. Life Storybooks And Holding Identity

The experience of dementia can profoundly impact on person's identity, exemplified by the theme a lost/hidden person. Participants describe trying to connect with a person who struggles to communicate their preferences and emotional responses, and where they often question the nature responses. Participants seemed to cope with their frustration and uncertainty by

concentrating on attainable physical care tasks, and denying the person's psychological needs.

The fragile identity of the person with dementia also came through in accounts of trying to develop life storybooks for people with no family involvement, where the only source of information is professional reports or case notes. There was a sense that sometimes, the story of the person was lost before a book was produced. Through the sessions, the identity of the person in the context of their life story and their preferences was revisited. Participants often expressed surprise at the person's ability to remember and elaborate their story, and how much they learned about them. From an understanding of why someone was a boxer, to knowing someone hates her hair being washed, the person re-emerged. Maintaining identity had previously been suggested as a potential benefit of life storybooks (Surr, 2006). These results suggest that through exploring the life story of a person with dementia, staff could potentially hold and maintain their narrative identity.

Life storybook sessions can also be understood as the person with dementia having an opportunity to pass their wisdom to others. Sharing a narrative identity with others is valuable to people with dementia (Usita, Hyman, & Herman, 1998) as is passing on values to the next generation (Gibb, Morris, & Gleisberg, 1997). Many participants planned to continue developing books,

reflecting their growing realisation of the value of capturing experiences for future reminiscing.

4.4. Life Storybooks And Creating A Supportive Social Psychology

The starting context, a depersonalising institution and a lost/hidden person, seemed to echo Tom Kitwood's (1997) ideas on how a malignant social psychology is inadvertently created. In particular, the phenomenon of labelling, where a person's behaviour and needs are explained by their condition, came through in participant accounts of seeing people as patients and forming judgements from past histories. The responsibility participants took for the actions and mood of the person may lead to inadvertent infantilisation, where the person is patronised. Most powerfully, participants could be seen as inadvertently invalidating, through their avoidance of negative feelings, the actual lived experience of the person.

The results suggest life storybooks can possibly improve some of these problematic care practices. Sessions appeared to directly reduce invalidation, as participants engaged with emotive aspects of the person's past and present experience. The theme 'seeing a person' could demonstrate a move away from labelling. Life storybooks seemed to allow participants to see the person as an individual in the context of their life story. Importantly, participants often saw the person they worked with had life experiences very similar to their own. Following

sessions, people seemed to understand behaviour in relation to the losses people had experienced distress caused by their condition. This increased consideration of potential processes underlying behaviour shows a promising move away from simplistic labelling.

Sessions also increased aspects Kitwood (1997) associated with positive social psychology, including: recognition, negotiation, play, celebration and facilitation. The theme 'seeing a person' demonstrates powerfully how recognition could be improved through sessions. Negotiation was shown by the choice the people were given about engaging in and content of sessions. Participants described sessions as enjoyable, fitting with the aspect of play. The joyful moments described, like when <Bianca> was "really dancing" seem to fit with celebration. Finally, participants and the books were facilitating conversations with people with dementia, which they may have been unable to structure themselves.

When examining the results then, there is support for Kitwood's theories on the effect of social psychology on personhood, and the possibility of improvement through life storybooks.

Kitwood's work has been criticised as placing unattainable expectations on staff and family caregivers, who are powerless in the face of the deteriorating self of a person with dementia (Davis, 2004). Davis argues from sociological and

philosophical perspectives that the nature of dementia is a fundamental attack on the person's being. These results support Kitwood's view that a supportive social psychology can help to continue the sense of self, and seem to offer a hopeful view of what good dementia care can achieve.

4.5. Social Defence Systems And Life Storybooks

The journey undertaken by participants can be understood in terms of alteration of defence systems. Menzies-Lyth (1988) wrote powerfully on how staff working in stressful inpatient environments spontaneously develop social defence structures to help them cope with emotional strain. Menzies-Lyth described how depersonalisation, and a task-focussed environment could be social defences. Menzies-Lyth understood social defences as serving the same purpose as psychological defences, guarding against intolerable negative emotions, on a systemic level. Participants in this research employed several strategies that could be understood as defences: they avoided negative emotions, and were focussed on achievable physical care goals. Through the sessions, being confronted with difficult emotions in themselves and the person they worked with challenged these defences. An example is the increasing awareness of the patient's losses leading to feeling inadequate as a carer. If avoiding losses allowed care staff to maintain job satisfaction, this defence served an important function. Other defences may protect staff against emotional investment in people who experience deterioration over time and who will eventually abandon

them by dying in their care. Interestingly, participants' future plans for sessions seemed less personal, involving more staff members and patients. This could have been an evolving defence to the difficult emotions experienced in sessions. If care practices that inadvertently reduce personhood serve to defend staff from negative emotions, there is a need to provide alternative approaches to managing the distress that accompanies the improvement of the care environment through this type of intervention.

4.6. Clinical Implications

Part of the clinical relevance of this research is in generating recommendations for future interventions for people with dementia using life storybooks. This research illustrates the experiences of several care staff delivering life storybook sessions to people with dementia, and some degree of transferability might be expected to other similar settings.

4.6.1. The Role Of Negative Emotions

The role of experiencing negative emotions as part of life review should be considered carefully. As this research demonstrated, staff often viewed their role as keeping the person happy, which conflicted with expectations that negative emotions would be experienced during sessions. Participants were therefore not always equipped to process negative emotions in themselves or contain them in others. Life review incorporates revisiting and accepting positive and negative life

experiences, however, people with dementia may need facilitation. Some empirical evidence for life review with dementia comes from Marie Mills (Mills, 1997; Mills & Walker, 1994), who facilitated people with dementia to carry out life review using reminiscence. However, Mills is a skilled counsellor, and neither nursing staff nor allied health professionals have necessarily developed counselling skills.

One participant was concerned that being reminded of a past traumatic event did not seem beneficial for the person she worked with. This is a concern when working with people unable to give informed consent to revisit experiences. In this situation, the researcher informed the Consultant Neuropsychologist of the problematic reference in the life storybook. The clinical team could then choose to remove the reference, and consider whether future sessions were appropriate. This suggests teams need to be fully involved in selecting individuals for life storybook sessions, and monitoring their content.

4.6.2. Critique

This study was constrained by time limitations and practical issues around recruiting participants who would commit to delivering sessions. For these reasons, a convenience sample was used. The sample was a homogenous group of care providers to people with dementia, however does not claim to be representative in terms of length of service, age or ethnicity. It is possible that

volunteers for the study were those most motivated to deliver quality care. The experiences of less dedicated staff members may therefore not be represented, so if life storybooks were implemented as a blanket solution in a similar setting, implementation issues may be very different.

More participants were recruited than required to allow for an anticipated high drop out rate. However, only one participant dropped out, so eleven interviews were completed. This has resulted in more of a general account than an individual focus. Although the researcher attempted to give flavours of individual experience and differences, it was difficult to fully represent each individual with this sample size.

Finally, the researcher's position as a former member of the psychology team on site is relevant. Participants may have seen her as invested in a successful intervention and may have been less positive with another researcher.

4.6.3. Recommendations

The following recommendations arise from this research:

1. Life storybook sessions, when delivered by staff involved in the care of people with dementia, have a potentially powerful effect. They can alter perceptions of the person, judgements of behaviour, and lead to improved relationships. In this study, sessions seemed to lead to care

improvements. However, the story of a person with dementia can be lost before a life storybook is created. It is therefore recommended that life storybooks are developed for people with dementia as early as possible, ideally before any move into residential care (if necessary).

2. Care staff should use life storybooks in regular one to one sessions with people with dementia, to promote person-centred care. Individual differences in reactions to reminiscence do need to be taken into account. Decisions about who to deliver sessions to, and content of books, should be agreed within the multi-disciplinary team, in consultation with family if possible.
3. The impact on staff of delivering sessions was apparent on a personal and professional level. While increased reflexivity and being more human with people seem positive outcomes, participants experienced a sense of inadequacy. They were confronted with negative emotions, but did not always have skills to process these and to determine whether negative reactions were therapeutic or harmful. Staff will therefore need to be supported to deliver life storybook sessions to people with dementia they develop their reflexive skills to be able to tolerate and manage difficult emotions. They will also need to retain a sense of job satisfaction to prevent potential burnout. It is suggested that support and regular supervision is offered to staff delivering sessions, either individually or in

groups. This supervisory role should be undertaken by psychology, and offered on a pro-active rather than reactive basis.

4. This research suggests life storybooks can potentially overcome some barriers to personhood arising from the nature of institutional care. Care staff made time to do sessions, and moved away from prioritisation of physical care tasks. Staff seemed to make time to do sessions because they had made a commitment, suggesting sessions may be easier to implement if timetabled. The monitoring of psychological well-being as a daily care task might usefully remind staff of the person's psychological needs.

4.7. Future Research

This study shows promising results for changes in staff attitudes and ward ethos. As an inductive study, some understanding of processes underlying preservation of identity and improved relationships with care staff has been offered. This study was limited by focussing on staff experiences to improve care for the person with dementia. Measuring the change in relationships from the perspective of the person with dementia was outside this study's scope, but would help confirm that changes in relationships effect genuine rather than perceived care improvements. This could be explored either through interviewing people with dementia, or observational measurement of quality of care from the person's perspective, using Dementia Care Mapping (Kitwood & Bredin, 1994).

These results suggest implementing life storybooks in this way may change a ward ethos, however, future research could investigate how improvements in care practice might generalise. In particular, quantitative methods would allow measurement of ward atmosphere before and after implementation of life storybook sessions. A questionnaire measure used on a larger sample of staff delivering sessions investigating changes in attitudes and attributions might demonstrate whether these results might generalise.

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Part Three: Critical Appraisal

1. Introduction

Through the process of carrying out this research, I have developed my knowledge of both the clinical area and research processes. It is important when carrying out qualitative research to remain mindful of the contribution of the researcher to the research findings (Elliott, Fischer & Rennie, 1999). This critical appraisal considers the research process chronologically, from the initial concept to the final writing up, in terms of what I have learned and how my personal position has impacted on my findings.

2. Evolution Of The Study

The contribution of the researcher to the process begins at the initial stage of conceiving a study. The starting point of this section reflects on my epistemological position, leading to the selection of a research topic, forming the research question, and the choice of methodology.

2.1. Epistemological Considerations

The need to reflect on the epistemological position of the researcher is widely acknowledged by the qualitative research community (Willig, 2008). I considered carefully my epistemological position before commencing my study, which was influenced by my developing understanding of the nature of knowledge, and fitted with the qualitative methodology selected. My understanding is that knowledge is fluid, and to a certain extent constructed by social processes. I

recognise that we cannot directly access the reality of lived experience, such as we could through a video recording, as we process and make sense of the world through the lens of our prior experiences. An extreme relativist social constructionist viewpoint, such as discourse analysis would argue that our experiences are actively constructed by discourse, and that there is not necessarily a relationship between our talk about the world and the world itself (Burr, 2003). For this reason, discourse psychology generally involves the study of language and interaction itself.

As I grappled with epistemological issues, I found the distinction between the nature of reality and the nature of our knowledge of reality offered by critical realism helpful. Parker (1992) adopts the position that there is a physical reality which both restricts some possibilities and opens others, and that our ideas are socially formed within these structural limitations. This position resonated most strongly with my current personal position. My clinical and life experience have given me a profound belief in the ability of the individual to reconstruct their experience in more helpful ways, but also an appreciation that life circumstances restrict the options available.

My own belief in the nature of lived experience also meshed well with the choice of IPA methodology. With its roots in symbolic interactionism, IPA adopts three basic premises: people interact with things according to the meanings that they

hold about them; these meanings are developed through interaction with others and society; and, the meanings are modified through a process of interpretation. The researcher's meaning making therefore forms a second layer of interpretation. Through this process, I brought my own meanings to the meanings and interpretations with which participants understood their experiences. The possibility of being able to "bracket off" my personal contribution to this interpretative process, seemed to me to be illusory, since the very nature of my understanding is formed by my position. IPA's acknowledgement of the integral role of the researcher in their interpretation offered a way to use this understanding to further the research process. My analysis should then be understood in the context of this interpretative process, and my personal position as explored within this critical appraisal.

2.2. The Choice Of Research Question

The undertaking to evaluate life storybooks came from the Consultant Clinical Psychologist from the research site, and was presented by her at our research fair in the first year of my clinical training. I was immediately interested in following up this idea, for several reasons, not all immediately apparent to me. Initially, I was attracted by the idea of working with life storybooks, as I had used them in the first therapy sessions I had delivered on my placement on site. My personal experience was of an initial reaction of fear and revulsion to working with someone with a significant forensic history. Through making his life

storybook with him, I came to value and like him as a person, and felt honoured when he actually learned my name despite his difficulty in retaining memories. My personal experience then, showed me that life storybooks are a powerful way to overcome prejudices formed about someone's history and to build a positive relationship in the present. I believe this to have been the basis of the way I decided to explore the question from a staff member's perspective once I had become familiar with the literature and seen this was an omission.

Working with people with dementia has interested me from my early days on placement, and I explored my own experiences of my grandmother having dementia in supervision. I experienced first-hand my grandmother's change in personality, confusion and difficulty dealing with everyday matters, which began shortly after she came to live with us during my teenage years. My reaction at the time was that of annoyance and some apprehension about what she might do next. It was only later, when the family made the reluctant decision to move her into a care home that I connected with my guilt at being unable to help. I am quite sure that my interest in improving the quality of care for people with dementia in care homes stems partly from this experience. I also think the guilt about not being able to help her probably influenced my choice of career, in particular my wish through my clinical work and research to allow people to maximise their independence and achieve a quality of life.

The final research question came from a starting point of wanting to improve the quality of life for people with dementia. One way to achieve this seemed to be through indirect working, and seeing whether my personal experiences in using life storybooks and anecdotal evidence from my research supervisor's experiences would be similar to those of my participants.

2.3. Methodology

I considered carefully the question of methodology, in particular how to measure the changes in quality of life I was hoping would come from life storybook sessions. I was extremely interested in using Dementia Care Mapping (Kitwood & Bredin, 1994) to chart the quality of interactions between care staff and participants during sessions then comparing to during unstructured time. Quite early in my research planning though, I sourced a thesis from the University of East Anglia, where this methodology had been used to evaluate life storybooks, with very promising results (Smyth, 2006). Wishing to add something to the body of knowledge in this area, I considered how I could investigate the effects of life storybooks on relationships with people with dementia. Investigating the subjective experiences of staff through qualitative methods seemed to be a way to explore the processes occurring during sessions, as well as the effects on attitudes and relationships. If life storybooks were found to have a powerful impact on how staff perceive people, then this was a way to explore participants' experience of that change. This area was also under-represented in the

reminiscence literature, which seemed to me an important omission. When staff had been involved in studies, it tended to be as an additional measure (Haight Haight, Gibson, & Michel, 2006; Thorgrimsen, Schweitzer, & Orrell, 2002), or informally reported (Mills, 1997; Mills & Walker, 1994) rather than their experiences being explored as valuable sources of information in their own right.

Having selected qualitative methodology, I needed to select a data collection method. There are numerous sources of qualitative data over and above the traditional research interview, and the tendency of qualitative researchers to carry out interviews without considering alternatives has been criticised (Potter & Hepburn, 2005). I considered observations, research diaries or case notes as potential alternatives. I selected interviews due to their value in accessing participants' experiences and exploring the subjective meanings of those experiences. Interviewing participants also allowed me to follow up areas of specific interest. There were also weaknesses of the other potential methods. Observations of sessions would not allow access to the thoughts and feelings of the participants. Research diaries or journals would have the same potential weaknesses as interviews and I was concerned that under pressure in a busy ward, participants would be likely to fill them in late or potentially not at all. Case notes are often brief, and may not have captured the reflections of participants, as in my experience they had tended to focus on practical issues.

From the social constructionist perspective of discourse analysis, interview data is seen as co-constructed, and is constructing the phenomenon rather than exploring the experience of it. The interaction of the interview is seen as vital, and the data merely a product of the context (Potter & Hepburn, 2005).

Although the critical realist approach of this research does fit with the use of interview data, an awareness of constructionist arguments emphasised to me the importance of acknowledging my part in allowing the person to discuss their experience in particular ways, thereby potentially shaping the story. The series of interviews undertaken for this research tell a story about the experience of this group of participants at this time, however, I do not claim that all care staff delivering life storybook sessions will have an equivalent experience. Indeed, the experiences of individuals in this study vary.

I wondered whether people would come to interviews having already processed and started making sense of their experiences, however this did not seem to be the case. Although participants had been told that the focus of the research was on their experiences, they still seemed surprised when that was the subject of the interview. Some participants had stories about the person that they were keen to tell in the interviews, and seemed to have been processed in advance, but these were relating to the life story of the person, rather than their own subjective experience. There is evidence from many of the interviews of the consideration of novel ideas, suggested by pauses in the account and people

trying out different words to fully explain a concept. There are several examples showing the development of a spontaneous narrative, such as in the extract from Helen's interview below:

"I think they've made me a bit closer to her [MMM] made me understand her a lot more. I think it, it sort of civilises things doesn't it, they're not just a patient they're a person a person that's erm I don't know. I'm not very good at explaining these things."

Helen 309

2.4. Choosing Who To Talk To

I deliberated the question of who to interview over several months, weighing up the pros and cons of interviewing people with dementia as well as staff members in supervision. My final decision to only talk to staff members caused me some uncertainty. My concern was that by not talking to people with dementia about their experiences I was marginalizing and disempowering them. This concern made the decision not to interview them very difficult, however, I eventually decided not to for several reasons. Firstly, there is a need to consider carefully before subjecting somebody to a research interview, which they might find distressing. My research question evolved to specifically relate to staff experience, a very important and under-researched area, particularly in the

reminiscence literature. I would have been interviewing the person with dementia unnecessarily for this question. Additionally, the experiences of people with dementia receiving sessions had already been explored by other studies (Mills, 1997; Mills & Walker, 1994) and so repeating this would not be adding to the body of knowledge. I was encouraged during supervision to reduce my original proposal, being supported to explore how the scope of my project could be wider than necessary, to contain my anxiety about producing a good research study. I read the Clarke, Hanson and Ross (2003) study with interest, and felt that the results were weaker for not focusing on one group's experiences. Added to these issues was my knowledge that the process of obtaining ethical approval for interviewing people with dementia would have been long and more complex than for interviewing staff members.

3. Reflection On Data Collection

3.1. Participants

Potential participants were approached because they worked at the research site, and would be in a position to deliver life storybook sessions to the people with dementia in their care. However, the route by which they were contacted should be considered. Participants were contacted via internal email and indirectly through line managers. Although I used University of Leicester headed paper, approaching participants in this way was likely to create assumptions that I was part of the internal team. These assumptions came through in the accounts, as

some participants clearly identified me as part of the psychology team on site. There was also a natural tendency to link me with life storybooks, which came through in some participant accounts.

"Erm, hmm. I don't have that much really, I have to be honest with you, I mean erm apart from doing the life story books, you know when we first started the life story books [YES]"

Carla, 25

This extract from Carla's interview demonstrates our shared experience of implementing life storybooks when I worked on the ward, and her placing me as part of the team. My affirmation would have confirmed her placing of me in this context.

My field supervisor and I planned the research procedure carefully to try to maintain the distinction between the life storybook sessions themselves, which were an integral part of the care approach on site, and my research. As delivering sessions was something staff were encouraged to do, it was included in the regular training offered by the psychology team on site. Most participants recruited were new to delivering sessions, so refresher training was offered, delivered by the psychology team. I maintained responsibility for the research elements alone, and we hoped in this way to minimise my perceived stake in the

success of the intervention. Working with the psychology team in this way was extremely rewarding, however, the relationship did require management. For example, at one stage there was wait of several weeks for refresher training. I avoided this situation in the future by copying training requests to the Consultant Neuropsychologist.

Additionally, I took care to explicitly request negative aspects of the sessions in interviews, to try to avoid accounts developing that were focussed on trying to please me. In the event, accounts seemed to cover all aspects of the experiences, and people seemed to be open about their difficulties, although it is possible that negative aspects were downplayed in order to create a more positive account. Throughout the accounts, participants also showed their awareness of me as a researcher. Unlike much qualitative research, participants in this study were required to carry out an intervention prior to interview. The very experience of delivering an intervention could have made them more invested in the success of that intervention. The nature of the research is also likely to have had an impact on how participants viewed me during the interviews. Some confirmation of this comes from the many references in accounts to having done extra for the research, such as the extract from Karen below.

"YEAH, BUT MAYBE YOU PRIORITISED THIS ONE TO ONE A LITTLE BIT MORE BECAUSE YOU'D MADE THE COMMITMENT. Yes, yes. But as I say when I've done them, probably better to do them (laughs) [YES] So I er, if you want some more research done then (laughing, can't hear three words) I'll do it again, give me an excuse to do it again (laughs)."

Karen, 478

3.2. My Prior Roles On Site.

My first placement during clinical training was at the research site. It was from my experiences on placement that my interest in this area of research developed. Returning to the hospital to recruit and then to interview participants meant that some of the participants had worked with me directly when on placement. I felt very comfortable, and a sense of belonging on site. In some cases, I felt that people may have agreed to take part in the study because they wanted to help me to complete my research. In some cases, the people who sessions were delivered to were known to me. This can be seen as a positive aspect of the interviews, as a prior relationship between researcher and participant can facilitate greater discussion and reflexive commentary (Burman, 1994). The interviews were likely to differ from those that would have been carried out by a researcher without any prior contact with the site. There was certainly a sense with many participants that I was part of the team, and would

understand their experiences and working practices. Terms such as 'constant' were used without explanation, backing up this sense of shared understanding which participants may have felt. Given the emotive nature of the interviews, and the scope of topics covered, I feel that my prior relationship with some participants did allow for a deeper conversation. It is also important to note that accounts were very consistent between participants, regardless of whether they were previously known to me.

3.3. Development Of The Interview Schedule

The interview schedule developed over the course of the research, with changes after most interviews. Although I was using semi-structured interviews to allow me to follow up areas of interest, I was still adding questions after most interviews. I was aware that I found interviews personally very challenging where participants gave brief answers and needed prompting to elaborate. I also had a worry about missing important issues, and this concern prompted changes to the interview schedule. This was helpful as I was able to explore a wider range of topics with more participants, although as a result some interviews took over an hour to complete. After the first interview, which was much shorter than I anticipated, I added a warm up question regarding the person's role. Although this was a warm up question, the information people gave provided useful insights into the context they worked in, and I decided to include those answers in the analysis. This potentially led to the creation of more themes than just

including material on life storybooks alone, however seemed to provide a rounder picture. I tried to keep questions open, but was mindful of needing to be attentive to and explore for ambivalence and negative impact. I felt participants were unlikely to offer this voluntarily, considering me invested in the success of the intervention.

3.4. What I Brought To The Interview Process

I was aware during the interview process of the conflicting pressures generated by my need to complete interviews to tight deadlines and my need to carry out good quality interviews, with adequate time for reflection and development of the interview schedule. My interviewing experience included research as well as clinical interviews, however, I had been developing my clinical interviewing skills over the preceding two years of clinical training and felt more confident in my clinical interviewing skills. I was aware of feeling uncertain about my interview technique, and felt there were some difficulties with my initial interview. In line with IPA methodology, my interviews started with an open question, then points of interest were followed up. During my initial interview, the participant gave very brief answers, which led me to doubt this technique. I subsequently developed additional prompts for interviewees, and a warm up question about their role, collecting more information about initial context than I had originally intended to. It could be considered that the answers researchers receive will depend on the questions they ask (Burr, 1995; Charmaz, 2006), in this sense

then, the context may not have emerged in the same way without this particular question. I believe including the context was useful to the analysis, allowing a deeper exploration of structural systemic change.

4. Reflection On Data Analysis

I was aware during the period of data analysis of how events in my own life were echoed in the emerging themes. In particular, my son was unwell for an extended period of time, and I was going through a period of uncertainty and seeking answers. These aspects emerging from participants accounts mirrored my personal experiences. Throughout the data analysis, I remained mindful of the need to interpret only what was in the accounts, and went back to transcripts regularly to check that my interpretations fitted with what participants actually said. Using IPA, I was not attempting to avoid interpretation, but to be aware of how my own biases were affecting data analysis. It is generally acknowledged that different researchers will arrive at results with a different emphasis in qualitative research, due to the interpretative nature of the processes involved.

I was also aware of some of my ideas about participants which were challenged and changed during the data collection process, mirroring their experience of overcoming prejudice against people they cared for. My initial expectation was that participants could spend the time with people, but didn't choose to. On

reflection, I felt that my experiences working on site of the tensions that can exist within an MDT had contributed to this view. During the interviewing process, I was struck again and again by the commitment people showed to their work and the people in their care. I moved away from my quite naïve starting position to one where I could appreciate the perspective of the participants, and their genuine reasons for sometimes avoiding engagement.

5. Reflection On Write-Up

5.1. Write-Up As Part Of The Analysis

I found my write up to be an essential part of tightening and trimming my analysis. During write up, and in particular when I produced the illustration of themes for the main paper, I needed to consider titles of themes and found I was able to merge some sub-themes even at this late stage. It has often been suggested that researchers pick two or three themes to analyse in depth (Smith & Osborn, 2008), and I wondered whether I should take this approach. I took this question to supervision and gave it serious consideration, however, finally realised that for me the story of the analysis was that of the journey, which ran through all of the themes. I could not remove one and adequately maintain the coherence of my interpretation. I was left with what felt like a quite unwieldy analysis, which through the process of write up I continued to condense and represent as best I could. I believe that this process was an important part of shaping the final analysis, with the summary section at the beginning of the

discussion added to enhance the coherence of the account. Themes were finally formed at this stage, and summarising them clarified them in my mind. I took a conscious decision to end the analysis there. Although working to the word limit was extremely challenging, the hardest part was trimming the quotes, as I wanted to allow participants their voices.

5.2. What I Brought To Writing Up

Having examined lots of example papers using IPA, I was left confused about how best to represent the overall analysis while retaining the voices of individuals. I felt over-whelmed by the number of stories I wanted to tell, and had to accept that I would not be able to represent them all fully, merely give a flavour. This was the hardest part of writing up the paper for me, as I moved between telling the general experiences and showing the individual variation within that. I hope that in the final version I have represented the general and the individual.

6. My Use Of Supervision

6.1. Research Supervision

I had the benefit of two extremely dedicated supervisors – a field and an academic supervisor, both committed to a good quality piece of research being produced. Initially, I worried about the possibility of conflicting advice, having experienced difficulties during an experience of two clinical supervisors, so took

steps to pre-empt any such difficulties. In the event, my supervisors offered complementary expertise, and I approached each with their personal expertise in mind. My field supervisor was an expert in the field. Our supervision sessions often included prolonged discussions about clinical implications of the research and the background literature. I found on many occasions I was able to express and develop my thinking through these conversations in new and exciting ways. She commented that I was able to express things verbally very well, but often struggled to be so eloquent in writing, so I tried to capture some of these ideas as we talked. My academic supervisor was knowledgeable about methodology, epistemology and academic requirements. As someone not familiar with the field, he was also able to feedback on my synthesis of the literature from a different perspective. These two positions complemented each other well, and I feel I made good use of supervision throughout the research process.

7. A Final Thought

8. I have learned a great deal through the process of conducting this research, developing my research skills and knowledge, and questioning my whole view of research. At times, learning more about methodological weaknesses, and believing strongly in the strength of formulation over diagnosis – that is for approaching each individual and understanding their personal story rather than allocating interventions based on diagnosis – at times I became very uncertain of the value of research. At the end of my

personal journey though, I have gained a balance and can see the equal value of understanding the position and potential needs of a population, and valuing and approaching the individual with an open mind. I consider my approach to this research to have been a way of blending the group and the individual, by asking how a group of staff can be affected by connecting with individual people through their life stories. I am left feeling enthusiastic about research, and wanting to build on what I have achieved during this piece of research in my clinical work.

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