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### **The effects of different approaches to reminiscence work with people with mild to moderate dementia living in care homes**

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**The effects of different approaches to reminiscence work with  
people with mild to moderate dementia living in care homes**

**Ponnusamy Subramaniam**

**Thesis Submitted to the University of Bangor in fulfilment of the  
requirements for the degree of Doctor of Philosophy at Institute  
of Medical Research and Social Care, University of Bangor,  
Wales**

**April 2013**

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## Summary

Reminiscence work has been described as the most popular psychosocial intervention for people with dementia. Despite its popularity, the empirical evidence that is available has been limited and inconclusive. The form of reminiscence work that is most associated with successful aging is integrative reminiscence work. For people with dementia, integrative reminiscence work using life story books appears promising but is lacking in empirical evidence. The first chapter provides an overview of reminiscence work. Some important issues and limitations that contribute to current work are highlighted. Chapter 2 is a systematic literature review of randomised control trials of individual reminiscence work for people with dementia. The findings highlight the psychosocial advantages of one to one reminiscence work, especially the life review/life story book approach and specific reminiscence work. The review concludes that the use of life review/ life story books with people with dementia merits further study.

Therefore in chapter 3, a preliminary randomised control trial with 23 older adults with dementia living in care homes is described. The main objective was to examine whether a life story book without a life review process has equivalent benefits to the combined approach that has previously been shown to have therapeutic benefits. The effect of intervention on relatives and staff was also assessed. The 23 participants were randomly assigned into two groups, life review and life story book as a gift group. The results indicated participants in one to one life review sessions showed significant improvement on key outcome measures evaluating quality of life and autobiographical memory. Participants that received a life story book as a gift showed improvement after receiving the book, even though they had not been involved in its creation, with no difference apparent between the groups at the final follow-up assessment. The findings suggest that a life story book developed either with or without involving the person with dementia, has therapeutic value and improvements in staff attitudes and knowledge suggest life story books can facilitate and promote personalised care. Relatives rated the quality of their relationship with the person with dementia as having improved following the introduction of the life story books.

With developments in technology, it is now possible to present a life story book in digital multi-media form, and this service is available from a number of organisations. In Chapter 4, a second systematic literature review is reported examining the application of Information and Communication Technology (ICT) to reminiscence work for people with

dementia. The findings support the feasibility of ICT based reminiscence work. Some personalized ICT based reminiscence work served as a replacement for paper based life story books. Some important issues are highlighted and discussed in this review article

Chapter 5, reports an original research study examining the usefulness and feasibility of ICT based reminiscence work. A multiple single case study approach was used to explore the idea. Both quantitative and qualitative methods were used to explore the results. The results indicated that the application of ICT based personalized reminiscence work in movie format was well received and associated with positive outcomes. The psychosocial usefulness and related issues of ICT based reminiscence work are discussed.

The last chapter presents an overall discussion of the findings and their implications. The limitations of the current research are discussed and further research directions highlighted. The chapter concludes with a discussion of the implications of the work for practice.

## Chapter 1: Introduction

## Introduction

Dementia is a huge and costly problem for society. The increases in the older adult population in the United Kingdom are due to increases in life expectancy. The average life expectancy in UK at birth (years) is 77.2 for men and 81.6 for female. Age is the main risk factor for dementia. The Alzheimer's Research Trust (2010) survey indicates that there are 821, 884 people with dementia in the UK and the estimated care costs are £23 billion per year. Numbers of people with dementia in the world will double every 20 years (Alzheimer Disease International (2009)). The prevalence of dementia among people in institutions varied little by age or gender, increasing from 55.6% among those aged 65–69 to 64.8% in those aged 95 and over. UK estimates have been made of the prevalence of dementia among all those aged 65 years and over living in 'EMI (elderly mentally infirm)' homes (79.9%), nursing homes (66.9%) and residential care homes (52.2%), (Alzheimer's Society, 2007). The increasing cost of care and prevalence of older adults with dementia living in institutional care settings, impose challenges to health sector workers at least to maintain the optimal level of quality of life for persons with dementia.

Dementia is an irreversible memory impairment disorder. The definition of dementia, according to World Health Organization (1993), in the 10<sup>th</sup> edition of its International Classification of Diseases (ICD-10), is:

...a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is impairment of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement. Consciousness is not clouded. The cognitive impairments are commonly accompanied and occasionally preceded, by deterioration in emotional control, social behaviour or motivation. This syndrome occurs in Alzheimer's disease, in cerebrovascular disease and in other conditions primarily or secondarily affecting the brain.

In general, it effects daily life functions, mood, behaviour and, communication ability. Though conscious, the person with dementia has impairments in short term memory leading to significant disturbances in daily living activities. Long term memory (for past events), usually remains intact for many years after formal diagnosis. The 'healthy' sections of cognitive function among people with dementia provide an incentive to develop strategies to keep them as healthy as possible. A detailed account of autobiographical memory will be provided in coming sections. However, as for definition, autobiographical memory is widely referred to 'as a type of episodic memory for both retrospective and prospective information



related to the self' (Schroots, Van Dijkum, & Assink, 2004: p. 70). The prospective information is the ability to plan or to do something for oneself in future e.g. one of the tasks could be a reminder to self to do something tomorrow (Schroots, et al. 2004). However, prospective information is not the focus of the present thesis. The main interest of the present research is retrospective autobiographical memory, which is the ability to recall past memories and experiences about one's own personal life history (Schroots, et al. 2004).

In treating dementia, drug treatment has received most attention but there is increasing evidence that psychological interventions may be equally effective. One of the psychosocial interventions often employed with people with dementia is reminiscence work. Reminiscence work requires participants to actively engage in recalling past memories, through retrieval of remote memories. Since the person with dementia typically has better remote memory compared with recent memory, reminiscence work was considered less challenging for those with impaired cognitive function compared with other therapeutic activity. Reminiscence work has been noted as the most popular psychosocial intervention in dementia care (Woods, Spector, Jones, Orrell, & Davies, 2005). Despite its popularity, research findings on the applications of reminiscence work as a therapeutic tool for people with dementia are still inconclusive. The need for vigorous research to test the usefulness of reminiscence work was well highlighted by Woods et al. (2005). This call was rooted in previous early-stage research findings that reported positive psychosocial benefits in reminiscence work for people with dementia and their family members and caregivers.

### *Reminiscence work with older adults*

The idea of reminiscence work as a therapeutic activity was proposed by Butler (1963) and for the first time tested with people with dementia by Kiernat (1979). Reminiscence work is highly flexible, ranging from very simple activity to highly structured activities. 'Flexibility' means that 'reminiscence work' encompasses a large variety of approaches with different aims, techniques and theoretical underpinnings. It has been used in group activities and in individual approaches in both community and institutional settings. The application of reminiscence work with people with dementia has ranged from simple, unstructured forms of reminiscence activities to highly specific structured forms of reminiscence work. As a therapeutic tool reminiscence is commonly used in group settings (Woods et al., 2005). Due

to its great flexibility, reminiscence work is also easily implemented with individuals (Douglas, James, & Ballard, 2004).

### *Definition of Reminiscence and related issues*

There appears to be little consensus as to what exactly constitutes reminiscing (Merriam, 1980) and reminiscence has no standard definition in the literature (Bluck & Levine, 1998). The Cambridge English Dictionary defines 'reminiscence' as:

the act of remembering events and experiences from the past.

From the outset, experts have sought to define the meaning of reminiscence. Reminiscence is "the act or process of recalling the past" (Butler, 1963, p. 66). Havighurst and Glasser (1972, p. 245) define reminiscence as "dwelling on the past" and as "retrospection, both purposive and spontaneous". Romaniuk and Romaniuk (1981, p. 477) provide a general definition based on Webster's dictionary: "the process or practice of thinking or talking about past experiences". Wong and Watt (1991, p. 272) suggested reminiscence involves "personal memories of a distant past: long term memories of events in which the reminiscer is either a participant or an observer".

Woods, Portnoy, Head, & Jones (1992, p. 138) defined reminiscence as "vocal or silent recall of events in a person's life, either alone, or with another person or group of people" and this definition highlighted both internal and external process of reminiscence and well covered both individual and group reminiscence. According to Taft & Nehrke, (1995, p. 186), "reminiscence is a bridge between the past and the present and may be a mechanism that makes it possible for the elderly individuals to achieve ego integrity". Another researcher, Parker (1995, p. 517) defined reminiscence as "a selective process in which memories are evoked and reconstructed probably with varying degrees of intensity and emotional involvement".

Bluck and Levine (1998, p. 188) proposed a more comprehensive definition "Reminiscence is the recalling of personally relevant memories from the past. It can arise spontaneously in response to, for instance, a smell, a thought, or an image or it can be evoked intentionally in order to fulfil a particular purpose such as entertaining a listener or solving a problem. Stated in other words, reminiscence is the volitional or non-volitional act or process

of recollecting memories of one's self in the past". 'Reminiscence Therapy' was defined Spector, Orrell, Davies, & Woods (2000, p. 1) as follows: "Reminiscence Therapy (RT) involves the discussion of past activities, events and experiences with another person or group of people, usually with the aid of tangible prompts such as photographs, household and other familiar items from the past, music and archive sound recordings". However, although the focus in this thesis is indeed on reminiscence as therapy, it is important to be clear that reminiscence per se is a much broader construct. Even within the literature on the benefits of reminiscence, some researchers prefer the term 'reminiscence work' rather than 'reminiscence therapy'. Gibson (1994, 2004) stated the use of the term 'therapy' is misleading, implying illness and a required treatment or intervention from professionals who may produce a positive effect. On the other hand 'work' implies a joint enterprise of mutuality and, shared experiences and emphasises the positive rather than the negative aspects of behaviour. Therefore Gibson (1994) explained 'reminiscence work' as a mutual process and a shared journey between reminiscence worker and the older adult. The reminiscence worker would encourage the older adult to share and be enriched by their past experiences. She further added:

"Reminiscence work includes many different approaches depending on the level of knowledge, skill, confidence and experience of the people who use it. It is not a set of rigorously tested techniques. Instead it is a loose collection of ideas resulting in varied approaches, activities and practices that differ according to the specific objectives of the work and where it takes place". (Gibson, 1994, p. 17)

### *Reminiscence type and functions*

The applications of reminiscence work as a therapeutic utility are inconsistent and inconclusive (e.g. Chin, 2007; Pinguart, Duberstein, & Lyness, 2007). The variation in therapeutic usage, underpinning theoretical issues, operational definition, taxonomy and its functions are still being debated. Throughout history, reminiscence work has taken many forms and functions. Lin, Dai, Hwang (2003) argued that the many and varied concepts used in different reminiscence studies with older adults make the outcomes difficult to interpret together. Accordingly, existing reports of reminiscence work must be analyzed for differences in methods, variables and, processes, as well as outcomes (Haight, 1995).

A number of different types of reminiscence work may readily be identified in the literature. For instance, *specific reminiscence* refers to carefully selected, focused, precise use of specific triggers designed to be of immediate relevance to the people concerned (Gibson, 1994). It can be distinguished from other forms of reminiscence, especially general reminiscence work, where the triggers may not have direct personal relevance to the individual.

Many taxonomies for reminiscence work have been proposed, comprising between two and eight types of reminiscence (Beaton, 1980; Kovach, 1991; LoGerfo, 1980-81; Merriam, 1993; Romaniuk & Romaniuk, 1981; Watt & Wong, 1991; Webster, 1993). There is a fundamental distinction, of course, between social reminiscence, where the focus is on reminiscence in conversation and/or group activity (Cohen & Taylor, 1998) and private reminiscence, involving personal memories which may occur without any trigger or involuntarily, and which may remain internal and unspoken (Berntsen, 1996). McMahon and Rhudick (1964) identified three functions of reminiscence, namely storytelling, life review, and defensive reminiscence. Storytelling is the sharing of traditional values, culture and knowledge that are handed on to the next generation. Life review is to maintain identity, and is closely associated with Erikson's psychosocial development theory. Defensive reminiscence is to safeguard one's self worth by glorifying, boasting and exaggerating his or her past life experiences. Coleman (1974) highlighted the differences between simple reminiscence, informative reminiscence and life review. He likened simple reminiscence to day-dreaming, as a natural recollection of past memories. Informative reminiscence has the function of teaching and/or entertaining others. It is similar to storytelling as proposed by McMahon and Rhudick, (1967). The aim of informative reminiscence is for the older adult to transfer their life experience to others. LoGerfo (1980-81) introduced an additional type of reminiscence work, obsessive reminiscence. This refers to repeated recollection of negative memories of guilt and failure.

Since the 1990s, three main classifications of reminiscence type and functions can be identified, proposed respectively by: Wong & Watt (1991), Webster (1993, 1997) and Gibson (1994). Each will be described in turn.

i. *Wong & Watt (1991) classification*

This taxonomy of Reminiscence includes integrative reminiscence, instrumental reminiscence, transmissive reminiscence, escapist reminiscence or defensive reminiscence, obsessive reminiscence and narrative reminiscence. Wong & Watt (1991) elaborated on each type of reminiscence;

- The main function of integrative reminiscence is to achieve a “sense of self-worth, coherence, and reconciliation with regard to one’s past” (Wong & Watt, 1991: p. 273). Based on this definition, life review, as set out by Butler (1963) and Haight (1988, 1992a) can be seen as a particularly structured form of integrative reminiscence. Life review has been defined as ‘the process of reviewing, organising and evaluating the overall picture of one’s life’ (Woods et al., 1992, p. 138). Integrative reminiscence and life review are the main focus of this thesis and therefore both will be discussed in detail in coming sections.
- Instrumental reminiscence involves making use of past ability, skill or knowledge in order to face or overcome current challenges. It comprises three functions seen as facilitating healthy aging. The three functions are:
  - “(a) Access to problem-solving skills: Instrumental reminiscence ensures that one’s actions and decisions benefit from accumulated wisdom and experience in coping with the demands of everyday life,
  - (b) Search for realistic tasks: We learn what we can do and cannot do only by examining our track record. Learning to pursue realistic goals and activities not only frees us from unnecessary frustration, but also gives us a sense of competence, and
  - (c) Summarizing past achievements: Reviewing instances of successful problem solving and accomplishments provides a firm foundation of mastery and resourcefulness”

(Wong, 1995: p. 35).

- The function of transmissive reminiscence is to pass on one's own culture, traditional values, life style and to leave a personal legacy (Wong & Watt, 1991). According to Sellers & Stork, (1997), transmissive reminiscence is "recalling past experiences for the purpose of sharing information or entertaining the listener" and it is similar to storytelling or oral history. McMahon and Rhudick (1964) described the important social function of storytelling reminiscence, not only in oral history but also in terms of enhanced self-esteem and positive benefits in adaptation.
- Escapist reminiscence is "characterized by a tendency to glorify the past and deprecate the present" (Wong & Watt, 1991, p. 273). It is reflected by boasting about one's past life, sometimes with the intention to return to the old life or the old days (Wong & Watt, 1991). It may be seen as involving an escape into a world of fantasy. LoGerfo (1980 – 81) referred to this function as defensive reminiscence. Wong & Watt (1991, p. 273) suggest escapist reminiscence "may provide instant relief from a painful present" but do not recommend it as a longer-term coping strategy.
- Butler (1963) identified that one of the outcomes of an unsuccessful life review can be obsessional rumination. Obsessive reminiscence is seen as occurring when a person has a tendency to become stuck on certain memories and starts to ruminate or obsess on that particular memory or memories (Puentes, 2008). According to Pincus (1970), obsessive reminiscence occurs in response to unmet needs or an ungratifying life situation. Wong and Watt (1991) suggest that, obsessive reminiscence is a sign of a person's failure to integrate his/her disturbing memories or experiences and these conditions leads to obsession with these problematic past events or memories. Wong and Watt (1991) further added that obsessive reminiscence is recognizable from a person's statements of bitterness, guilt and despair over the past. Wong (1995) identified this as a negative type of reminiscence and Kovach (1991) described a similar 'lamenting reminiscence'. Obsessive reminiscence is often viewed as related to unsuccessful aging and negative affect (Cappeliez & O'Rourke, 2002; Watt & Wong, 1991). For example, McKee et al (2005) showed high levels of reminiscence and the occurrence of regrets were closely related with negative psychological health in older people resident in care homes. However, other researchers (Goldfarb, 1956; Pincus 1970; Puentes 2008) suggest the content of obsessive reminiscence is

potentially useful in terms of resources, diagnostic clues and incorporating the problematic obsessive thought into any intervention plan designed to help older adults. Puentes (2008) further emphasises that, obsessive reminiscence may form an effective way to use memories to cope with anxiety and can provide a useful indication of the triggers of anxiety for people with dementia. For example, identifying a person's traumatic memories would help to understand the causes of his/her anxiety.

- Narrative reminiscence is a description of one's own recollection of the past. It is similar to informative reminiscence (LoGerfo, 1980-1981). It has two functions, providing biographical information and recounting events or incidents to the listener. Narrative reminiscence leads to the experience of positive mood and positive emotion for the story teller and others (Cappeliez, Guindon, Robitaille, 2008; Pasupathi & Carstensen, 2003). However Wong & Watt (1991) suggest there may be possible negative effects, perhaps producing high verbosity and perseveration. On the other hand, it may reveal the ability or resources to retain rich past memories.

ii. *Classification using Reminiscence Function Scale (Webster, 1993, 1997)*

With the development of the Reminiscence Function Scale (RFS), Webster (1993) took the work on taxonomy of reminiscence functions further forward. The Reminiscence Function Scale comprises 8 functions of reminiscence, including:, Bitterness revival, Boredom reduction, Conversation, Death preparation, Identity, Intimacy maintenance, Problem solving and Teach/inform.

Cappeliez et al. (2008) explained each of these reminiscence functions;

- Reminiscence for identity refers to the use of past experiences that are stored as memories to identify a consistent or coherent pattern in one's life and to find meaning and worth in life as it was lived.
- Reminiscence for problem solving is using past memories to overcome or solve current problems.

- Reminiscence for death preparation refer to using past experiences to come to terms with one's mortality.
- Reminiscence to teach/inform refers to sharing past experiences to transmit lessons or knowledge of life.
- Reminiscence for conversation refers to conveying information of personal past experiences in an interactive reciprocal context with no intention to appraise.
- Reminiscence for bitterness refers to ruminating on past experiences of negative or difficult life events or periods.
- Reminiscence as boredom reduction entails the use of past experiences to create or provide interest or stimulation.
- Lastly, reminiscence for intimacy maintenance is about reactivating past experiences with someone important in a person's life e.g. loved one (spouse) who may no longer be together with the reminiscing person, typically separated due to death.

Webster (1999) reported that older adults tended to score higher on the Teach/Inform and Death Preparation functions compared with young adults. Cappeliez & O'Rourke (2006) conducted more detailed work on this model of reminiscence and its association with well-being of older adults. A total of 412 older adults (167 men, 245 women) with a mean age of 61 years were recruited. In this cross sectional study, participants were required to complete the Reminiscence Functions Scale, Satisfaction with Life Scale, General Health Questionnaire and a Demographics and Health Questionnaire. Based on the findings, Cappeliez & O'Rourke (2006) developed a comprehensive model of the functions of reminiscence in relation to well-being in later life. The use of reminiscence for problem solving, death preparation and identity functions is directly associated with the psychological well-being of older adults. Reminiscence functions associated with a negative effect on psychological well-being in older adults comprise reminiscence for intimacy maintenance, bitterness revival and boredom reduction. However reminiscence for conversation and the teach-inform functions show no direct link with well-being in older adults.



### *iii. General vs. Specific Reminiscence Classification (Gibson 1994)*

Gibson (1994) draws out just two types of reminiscence work: - general and specific reminiscence. According to Gibson (1994) 'general' reminiscence work refers to creating and using a wide range of multisensory triggers to stimulate participants to engage in shared conversation on mutually agreed topics that relate to them to some extent, albeit loosely. Meanwhile 'specific' reminiscence work refers to precisely chosen triggers that are very closely related to a participant's detailed life history. Both types of reminiscence are suggested to be suitable for use in small groups or with individuals but 'specific' reminiscence fits well with an individual approach.

Life review (Butler, 1963; Haight, 1988, 1992a) can then be classified as integrative reminiscence (Wong & Watt, 1991), reminiscence for identity (Webster, 1993, 1997) and specific reminiscence (Gibson, 1994). In Wong and Watt's (1991) classification, successful aging was related to integrative and instrumental types of reminiscence and unsuccessful aging related to obsessive type of reminiscing. Integrative reminiscence (Wong & Watt, 1991) overlaps with reminiscence for identity (Webster, 1993, 1997) both serving to assist in the achievement of a sense of self-meaning, coherence and reconciliation of one's past memories. Specifically, a structured life review process (Haight, 1992a) has the ability to fulfil the function of integrative reminiscence. According to Wong and Watt (1991), 'regarding integrative reminiscence suggests that it is not the process of life review but the achievement of integrity in such a review that promotes successful aging'.

Puentes (2002) argued that the underlying dynamics of these reminiscence classifications is much lacking in empirical evidence and unclear, except for life review. He further emphasised that particular types of reminiscence, other than life review, may produce both negative and positive effects.

In relation to people with dementia, since a person with dementia has progressive deterioration of memory, integrative reminiscence could be seen as having the potential to help them recollect and hold onto their memories to strengthen their identity as long as possible.

## Theoretical Background

### *Theoretical basis for Life Review as an Intervention Tool*

In general, no formal theory of reminiscence exists per se (Webster, 1999); nor is there agreement about the nature and concept of the operation and definition of reminiscence work (Webster & Cappeliez, 1993). Before 1963 reminiscence activity was typically viewed as an unhealthy phenomenon in the older adult. The concept of life review as a therapeutic approach for older adults was first introduced by Butler (1963). Butler (1963) defined life review as:

A naturally occurring, universal mental process characterized by the progressive return to consciousness of past experience, and particularly, the resurgence of unresolved conflicts; simultaneously, and normally, these revived experiences and conflicts can be surveyed and reintegrated . . . prompted by the realization of approaching dissolution and death, and the inability to maintain one's sense of personal invulnerability. (p. 66)

Butler further added that, by engaging in life review, people place their lives in the correct perspective, draw positive conclusions about the life they have lived and prepare to face their death with less conflict. He further explained that life review encourages older adults to express their thoughts and feelings. Life review helps people to look back at their lives, reach decisions and alter, restore or settle issues in their lives. Haight (1999) argued that people with dementia still have a chance to resolve issues with their remaining cognitive ability.

Life review is a particularly structured form of integrative reminiscence, drawing on Butler's (1963) life review theory of reminiscence and Haight's (1988, 1992a) life review models. According to Butler (1963) the aim of life review is to help the reviewer deal with Erikson's (1950) final developmental stage of 'integrity', since the main activity or events of old age are reflection on life. Therefore, life reviews are seen as a mechanism or tool for older adults to resolve old conflicts in this final stage, identified as the "Integrity vs. Despair" of Erikson's stages of psychosocial development. According to Haight (1988), the concept of Erikson (1950) and Butler (1963) is achievable by actively engaging older adults in the life review process to deal with this developmental stage. In this final stage, a person looks back on his or her overall life cycle, values it and may or may not achieve ego integrity. Erikson (1950, p. 268) defined integrity as, "the acceptance of one's one and only life cycle as something that had to be and that by necessity permitted no substitutions." Achieving

integrity means that a person has accepted his or her life cycle with significant others, and gained wisdom, happiness and the ability to face death (Erikson, 1968). If a person has failed or is unable to accept the life that has been lived then his or her life would end in despair. Although there is little empirical evidence to support Erikson's model it is a well accepted idea.

Table 1 Erikson's Stages of Psychosocial Development (Erikson, 1963)

Stage	Psychosocial Conflict	Activity	Successful Resolution Outcome
Infancy	Trust vs. Mistrust	Feeding	Learn to trust others by fulfilment of need from good parent care.
Early Childhood	Autonomy vs. Doubt & Shame	Toilet Training	Develop self-esteem, self-control and autonomy if provided with free choices and support.
Play Age	Initiative vs. Guilt	Exploration	Ability to set goal/idea and engage in planning and activities to achieve a purpose.
School Age	Industry vs. Inferiority	School	Achieve self-competency and personal and social skills from learning environment.
Adolescence	Identity vs. Role Confusion	Social Relationship	Able to develop own true 'self identity' as a unique person.
Young Adulthood	Intimacy vs. Isolation	Meaningful Relationship	Ability to form concrete, loving and romantic relationship.
Adulthood	Generativity vs. Stagnation	Parenthood & Career	Maturity and concern to guide and nurture family and next generation.
Old Age	Integrity vs. Despair	Reflection on Life	Harmony, wisdom, happiness and satisfaction with own life.

It is suggested then that a theoretical basis for life review can be identified in a combination of Butler's life review theory (1963), Haight's (1992a) life review models and Erikson's (1950, 1963, 1968) final development stage. Life review is seen as contributing to a person's sense of identity and is involved with preparation for death, as discussed by Webster (1997). Integrative and related types of reminiscence are concerned with issues of life's

meaning, coherence and continuity (Cappeliez, Rourke, Chaudhury, 2005). Integrative types of reminiscence have a greater intrapersonal focus, relating more to the inner self, rather than having an interpersonal function. This type of reminiscence is said to be associated with healthy and happy aging (Wong & Watt, 1991).

In practice, according to Woods et al. (2005, p.1) “Life review typically involves individual sessions, in which the person is guided chronologically through life experiences, encouraged to evaluate them, and may produce a life story book”. The life review process will help a person with dementia to record his or her life history in chronological order. This recording can be presented in the form of a life story book, photo album, scrap book or memory book. According to Garland & Garland (2001) life review is a highly structured form of reminiscence which, it is argued, allows the participant to ascribe meaning and value to his or her life, and to come to terms with uncomfortable issues. Hirsch and Mouratoglou (1999, p. 261) stated that, “the occurrence of a life review process involves emotional processing of events in the individual’s past. The occurrence of a life review is not necessarily easy to recognize. It can appear fragmentary, with key themes occurring in dreams, daydreams and more purposeful thinking”. Butler (1980-81) called for life review as a therapeutic tool for use with older adults. However, there were no directives or guidelines about how to implement life review in practice until 1992.

Haight (1988, 1992a) developed a strategy to help older adults resolve Erikson’s final stage conflict and achieve ego integrity by using the life review process. The implementation of life review as a therapeutic process for older adults was proposed by Haight and Dias (1992). The proposal was based on an experiment involving two hundred and forty older adults to establish the reminiscence modality that promotes well-being. They argued that the therapeutic way to maximise people’s reminiscing should involve (a) a structured and chronological order covering all the development stages from childhood to the current state, (b) analysis and evaluation, where people have the chance to elaborate and value important events related to their life, and (c) life review reminiscing in private and one-to-one sessions. They further explained that life review sessions should take place over eight weeks, with the first session and the final session as the opening and concluding sessions. The person acting as a life reviewer should employ Rogers’ (1980) counselling principles, such as being a good listener, non-judgemental, showing acceptance without conditions, empathy and so on. The reviewer should guide the older adult’s progress through the life review process by providing assistance, for example, by rephrasing and reframing life events when troubled memories occur or are triggered during the session. To conduct a life review session, Haight proposed

the Life Review and Experiencing Form (LREF; Haight, 1988), consisting of questions for the reviewer to ask in chronological order covering the entire life cycle (Appendix B). Haight proposed at least four important basic components that contribute to the effectiveness of life review reminiscence and which differentiate life review reminiscence from other types of reminiscence work: time (at least two months of interaction), individuality (one-to-one), structure (the entire life cycle, birth to present) and evaluation (analysing and reframing life events). These four proposed elements, which are based on research findings, are considered to be the 'magic' ingredients of life review as a therapeutic intervention tool (Haight & Dias, 1992).

Next, Haight (1988) conducted studies to investigate the utility of the Life Review and Experiencing Form (LREF) as an intervention tool with older adults. For example, she recruited 60 homebound older adults and divided them into three groups: an experimental, control and no treatment group. The experimental group received six sessions of the LREF approach. The results indicated an improvement in psychological well-being and life satisfaction which, according to Haight, was an indication of the achievement of integrity. Since no side effects such as depression were observed in this study, Haight recommended that the LREF approach should be used freely as an intervention tool (Haight, 1988).

Haight (1992b) conducted another trial using the LREF with 52 homebound older adults, again divided into three groups: an experimental, control and no treatment group. The experimental group received six life review group sessions compared with the control group which received six consecutive friendly visits. The aim of this trial was to ascertain the long term effect of life review using LREF. The results, indicating life satisfaction as measured by the Life Satisfaction Index (LSI-A) and psychological well-being as measured by the Affect Balance Scale, revealed that there was a significant improvement immediately post-intervention. However, no significant results were noted for measures of depression and activity of daily living. Interestingly, at one year follow-up the experimental group continued to report improvement in life satisfaction measures. Meanwhile, a declining trend was observed for all groups in the depression and activity of daily living scale. Anecdotal evidence at one year follow-up also indicated that participation in the life review process resulted in some psychosocial benefits, for example, increased functional ability, improved participation in life and positive general well-being. Again, Haight (1992b) concluded that the life review process has a long-lasting effect on life satisfaction and recommended to use the life review as a therapeutic intervention tool.

There are only a few studies in which the usefulness of life review with people with cognitive difficulties has been investigated. For example, Haight (1992a) conducted one to one life review sessions with a group of cognitively impaired older adults. The participants in this life review process showed an improvement in life satisfaction compared with the control group that only received friendly visits. Based on this study, Haight also recommended that structured life review may help older adults in dealing with stress and with current difficulties, and may facilitate the adaptation process, for example, when moving into an institutional care setting. In another study, Hirsch and Mouratoglou (1999) reported a single case study involving an 84-year old woman with high pre-morbid IQ. According to the Middlesex Elderly Assessment of Mental State (MEAMS), she had difficulties in word finding, orientation, learning, verbal fluency and spatial construction. After life review intervention, her life satisfaction and anxiety levels were both within the normal range and were stable at the one and six month follow-up assessments. Her depression level was outside the clinical range at one month follow-up compared to mild depression at baseline assessment. However, her depression level as measured by the Geriatric Depression Scale (GDS) was deteriorating and returned to the mild depression level at the six month follow-up assessment. Also her ego integrity scores, measured using a scale developed by Boylin, Gordon & Nehrke et al. (1976), showed an improvement from pre-intervention to one month post-intervention and at the six month follow-up assessment. These results are encouraging, but the positive changes observed in this study may not simply be a result of life review per se but also reflect other confounding variables, such as social contact with the participant.

Woods et al. (1992) tried to establish the feasibility of using the life review process with people with dementia. They recruited 20 participants with mild to moderate dementia (according to the Clinical Dementia Rating Scale - CDR), from two care homes. The research indicated that the participants enjoyed talking about their lives and looked forward to the sessions. Also, this research concluded that the life review process is a useful tool for people with mild to moderate dementia. However, Woods et al. (1992) highlighted that as a reminiscence approach the life review process is not as easy for people with dementia as simple reminiscence. They further added that the life review process requires more insight, cognitive effort and guidance for people with dementia.

Haight, Gibson, & Michel (2006) conducted an experimental study with 31 participants with mild to moderate dementia living in a residential care setting. Participants were randomly allocated to two groups. The experimental group received eight sessions of life review based on LREF and the production of a life story book. The control group received

‘treatment as usual’. The data was collected pre- and post-intervention using the mini-mental state examination (MMSE), Cornell Scale for Depression, Alzheimer’s Mood Scale, Functional Independence Scale and Memory and Behaviour Problems Check List. The results showed that the participants who were receiving life review as an intervention had a significant improvement in their depression, communication, mood and cognitive functions compared with residents who received ‘usual care’ as a treatment. Haight et al. (2006) recommended conducting MRI mapping to fully understand the effects of the life review process and indicate whether life review can produce a substantial effect. Recently Morgan & Woods (2010) conducted a randomised control trial using life review/life story book. The results further supported the psychosocial benefits of life review and strengthened the case for life review as an intervention tool. This particular research work is closely related to the project for this thesis and will be discussed in more detail in the following section.

### *Theoretical Background of Autobiographical Memory*

The development of autobiographical memory is closely related to the study of oral traditions (Rubin, 1995). Baddeley (1992) stated that autobiographical memory is concerned with the capacity of people to recollect their life stories. He further added that the term ‘autobiographical memory’ is used in at least three different ways: (1) as a specific memory system with a separable neurological base, (2) as a term describing the knowledge and schemata that form the memorial basis of the self, and (3) as the study of the processes and mechanisms whereby people recall and recognise the events they have experienced in their lives. Greenberg and Rubin (2003) defined autobiographical memory as memory of a personally experienced event that comes with a sense of recollection or reliving. From the neuropsychological perspective, autobiographical memory may be seen as comprising two main independent components: personal incident memory and personal semantic memory (Baddeley, 1992; Kopelman, Wilson, & Baddeley, 1989, 1990). Personal incident memory refers to specific personal events (e.g. holidays, births, marriages) where there is detailed information and a richness of the specific story including place, date, other significant person’s behaviour and so on. On the other hand, personal semantic memory refers to personal information or facts which are not event based (e.g. name of neighbours, childhood friends, name of teachers). Autobiographical memory is a very useful memory for everyday functioning. Kopelman et al. (1990) developed a semi-structured interview assessment tool to

evaluate both components of autobiographical memory – the Autobiographical Memory Interview (AMI) Scale. The development of the AMI made it possible for researchers to measure autobiographical memory in a scientific way.

### *Conway's Theoretical Model of Autobiographical Memory*

Conway and Pleydell-Pearce (2000) proposed a conceptual framework for autobiographical memory based on a hierarchically arranged concept called the self-memory system (SMS). This consists of two important components: the autobiographical knowledge base and the working self. The SMS is a conceptual framework about the relationship between memory and self, with this self-memory model seen as explaining the 'interconnectedness of self and memory' (Conway, 2005). Conway's (2005) key idea is that a person's cognition is goal-oriented, therefore memory is motivated. The autobiographical knowledge base contains and provides information about one's own self with retrieval involving a hierarchical process. The three broad levels within the autobiographical knowledge base, organised hierarchically, are: lifetime period, general events and event-specific knowledge. The hierarchical order places lifetime period at the top, followed by general events, with knowledge about specific episodes at the bottom (Schulkind, Rahhal, Klein, & Lacher, 2012). The three SMS concepts of Conway and Pleydell-Pearce (2000) can be explained as follows:

- i. Lifetime Period – involves abstract and general knowledge (e.g. activities, common locations, goals, other important people) which are characteristic of a period. This knowledge is arranged according to thematic and specific time periods, for example, a period spent at school (school theme). Lifetime periods have a clear beginning and end but they may overlap with one another. Some researchers refer to a lifetime period by different terms such as 'chapter' (Thomsen, 2009; Thomsen, Pillemer, & Ivcevic, 2011), 'mini narratives' (Robinson, 1992) and 'extendures' (Linton, 1986).
- ii. General Events – refer to extended, repeated or related events that happen over a certain period of time measured in months, weeks or days. They are more specific than lifetime periods and involve specific representations of events. These events may be grouped into similar themes and linked to each other as a common theme. Therefore, when one event is recalled, this will trigger or act as a cue for the recall of



other related events (e.g. all achievements while studying at university) and extended events (an event over a certain duration such as conducting and completing a PhD project).

- iii. Event-specific knowledge – involves specific incidents or events with fragmentary detailed information which includes visual imagery, colour, sensory details and feelings about event-specific memories (e.g. feeling at the first date or kissing). A person retrieves event-specific knowledge via thematic frameworks.

According to Conway and Pleydell-Pearce (2000), the information stored in the lifetime periods area contains triggers or clues to the general events area and the knowledge stored in the general event area will act as a stimulus or trigger to event-specific knowledge. The autobiographical memory is formed when all the knowledge is available based on the activation of a cue evenly within the autobiographical memory-based hierarchy. The life story of a person is formed from all of these three areas of the autobiographical knowledge base (Conway, 2005).

The purpose of the working self is analogous to working memory, as outlined by Baddeley & Wilson (1986), which consists of sets of control processes that regulate goal-directed activity (Williams et al., 2007). The working self is a complex hierarchical system that controls access to the autobiographical knowledge base and organises sets of personal goals and self-image that are referred to as the 'self'. The working self regulates cognition which results in behaviour that helps a person function at the best level in his or her social context and environment.

### *Theoretical Function of Autobiographical Memory*

Bluck, Alea, Haberman, & Rubin (2005) described three functions of autobiographical memory based on the available literature and empirical evidence:

- i. The directive function – uses past experience and information to guide and solve current and future challenges. Autobiographical memory enhances the development of attitudes and new ideas (Cohen, 1998) and updates, plans and predicts future events and behaviour (e.g. Baddeley, 1987; Lockhart; 1989; Robinson & Swanson, 1990).

- ii. The self-representative function – uses preserved personal memory and experiences to maintain the continuity of the sense of self (e.g. Brewer, 1986). This includes the development of self (Conway, 1996), maintaining a coherent self over time (Barclay, 1996), help for the self in adverse conditions that need self-change (Robinson, 1986) and the preservation of self-concept (Wilson & Ross, 2003).
  
- iii. The social function – uses autobiographical memories that enhance the development and maintenance of social bonds by providing sufficient material to improve communication and social interactions (Pillemer, 2003). Personal memories enable understanding and empathy for others (Cohen, 1998) through the sharing of similar life experiences (Pillemer, 1992) and the promotion of intimacy and bonding (Fivush, 1996). Impairment of autobiographical memory will disturb social relationships (Robinson & Swanson, 1990).

The possible fourth function of autobiographical memory is an adaptive function (Williams, Conway, & Cohen, 2008). Basically, the adaptive function of autobiographical memory is to regulate mood, that is, to maintain a wanted mood and adjust an unwanted mood (Robinson & Swanson, 1990). This is quite similar to Pasupathi's (2003) idea of emotional regulation. This function enables a person to cope with negative moods (Williams et al., 2008).

#### *Autobiographical Memory Impairment in a Person with Dementia*

Neuropsychologists have long been interested in the autobiographical memory performance of older adults. This is because, in general, autobiographical memory is an important indicator of memory functions in the older adult. The link between impairment of autobiographical memory and memory or cognitive performance of people with dementia has been well established (e.g. Addis & Tippett, 2004; Graham & Hodges, 1997; Greene & Hodges, 1996; Irish, Lawlor, O'Mara, Coen, 2011; Jetten, Haslam, Pugliese, Tonks & Haslam, 2010; Leyhe, Muller, Milian, Eschweiler, Saur, 2009). The impairment of autobiographical memory is viewed as an early indicator of dementia. The impairment of personal incident memory (e.g. Addis & Tippett, 2004; Dorrego et al., 1999; Graham & Hodges, 1997; Greene, Hodges, & Baddeley, 1995; Kopelman, 1989) and personal semantic

memory (e.g. Addis & Tippett, 2004; Greene et al., 1995) are well documented in people with dementia. There is also empirical evidence that people with dementia perform poorly compared with normal older adults in autobiographical memory (e.g. Addis & Tippett, 2004). People with dementia perform better at recalling remote memories, such as childhood memories, than they do in recalling recent memories, such as memories of late adulthood, but perform worse than normal older people at each time point. The temporal gradient of the decline of the autobiographical memory with people with dementia has been well documented (e.g. Addis & Tippett, 2004; Kopelman, 1989), and like older adults they show relatively poor memories for the middle phase (Morris, 2008).

It is widely agreed that life stories are based on a person's autobiographical memory (Conway, 2005; Habermas & Bluck, 2000; McAdams, 2001). Reminiscence, including life review as proposed by Butler (1963), is one way to access and use the information stored in the autobiographical memory (Bluck & Levine, 1998). In other words, reminiscence work involves recalling and reconstructing a person's life history which is stored in his or her autobiographical memory. However, the link between reminiscence work and autobiographical memory is less studied (Webster, 2003).

### *Autobiographical Memory and Identity in dementia*

The evidence of a connection between self-identity and dementia has been relatively inconclusive. Some studies have suggested that dementia imposes great challenges to and changes in a person's sense of identity (Cohen & Eisdorfer, 1986; Cohen-Mansfield, Golander, & Arnheim, 2000). Loss of autobiographical memory would reduce cognitive abilities, contributing to a loss of personal identity strength, which reduces a person's social function and affects his/her wellbeing (Jetten et al., 2010). However, a recent review concluded that some components of identity are well preserved in people with dementia even at a severe stage (Caddell & Clare, 2011). A case study demonstrated how sense of identity can improve quality of life (Cohen-Mansfield et al., 2000) and also improve wellbeing (Cohen-Mansfield, Parpura-Gill, Golander, 2006).

Empirically, Addis & Tippett (2004) investigated the level of autobiographical memory impairment and its connection with changes of identity. A total of 20 participants with dementia and 20 age-matched controls were recruited. The assessment tools used in this study was AMI, TSCS-II and Twenty Statement Test (TST) by Kuhn & McPartland (1954).

Interestingly, the study showed the autobiographical impairment associated with changes in identity: to be more precise, the childhood and early adulthood section of AMI, associated with changes in the strength and quality of identity. Further, Addis and Tippett (2004) concluded, autobiographical memory has an important role in a person's identity and impairment in autobiographical memory would lead to significant disturbance in identity.

Naylor & Clare (2008) aimed to examine the relationship between autobiographical memory, identity and awareness of memory function among people with early-stage dementia from a local memory clinic. A total of 30 participants were recruited, 29 of whom completed all the assessments. Measurement tools used included the Autobiographical Memory Interview (AMI) by Kopelman et al. (1990) and Jones & Woods (2006) and the Tennessee Self-Concept – Second Edition (TSCS-II) by Fitts & Warren (1996). However, the results showed no significant relationship between AMI and TSCS-II. In addition, Naylor & Clare (2008) argued, many participants found the TSCS-II questionnaire too demanding.

Caddell & Clare (2012a) explored the relationship between identity, mood and quality of life. The measures used included AMI to assess autobiographical memory, TSCS-II for identity, QOL-AD by Logsdon, Gibbons, McCurry, & Teri (2002) for quality of life and the Hospital Anxiety and Depression Scale (HADS) by Snaith & Zigmond (1994) for mood. A total of 50 participants over 60 years old with early-stage dementia were recruited for the study. The findings showed that none of the correlations between measures were statistically significant. Additional analysis indicated that depression and QoL significantly predicted a modest proportion of variance from different aspects of identity.

In another recent study, Caddell & Clare (2012b) examined the association between identity measured by TSCS and autobiographical memory measured by AMI. A total of 50 participants with early-stage dementia were recruited. The result indicated that no significant correlation was observed between TSCS and AMI. Further analysis to predict the AMI's contribution to the variance in identity was carried out. A higher positive identity score was predicted by higher AMI total score. However, only a very small amount of variance in TSCS from the AMI total score was noted. Therefore these researchers concluded that there is no straightforward relationship between identity and autobiographical memory. The challenge may be how best to evaluate 'sense of identity' in the context of dementia.

### *Kitwood's Person-Centred Theory*

The introduction of Kitwood's (1997) person-centred dementia care theory was a significant milestone in the progress of dementia care. This triggered a major shift in the dementia care culture which for the first time placed the person with dementia in the front line of care and marked a new 'person-centred' approach. The idea of the person-centred approach originated in Carl Rogers's counselling theory (Rogers, 1961), and it was later introduced in the field of dementia care by Tom Kitwood. The new culture involves placing the person first: 'PERSON with dementia' against the old view of 'person with DEMENTIA'. Care workers need to view the person beyond the clinical disease. In other words, the person is the main focus and not the person's illness, which is dementia. According to Kitwood (1997), 'Personhood is a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being'. Kitwood (1993) explained that the condition of a person with dementia is influenced by various factor, as shown by the following equation:

$$\begin{aligned} \text{Dementia Presentation (D)} &= \text{Personality (P)} + \text{Biography (B)} + \text{Health (H)} + \\ &\text{Neuropathological Impairment (NI)} + \text{Social Psychology (SP)} \\ \text{D} &= \text{P} + \text{B} + \text{H} + \text{NI} + \text{SP} \end{aligned}$$

Kitwood (1990, 1996, 1997) argued in his personhood model for the importance of relationships and interaction in enhancing a person with dementia's enjoyment and in upholding their personhood. In order to maintain the personhood, a care environment should provide comfort, attachment, inclusion, occupation and identity. Kitwood also coined a term 'malignant social psychology' to describe negative behaviours that are the opposite of personhood and cause harm to persons with dementia – this is described in terms of 'depersonalizing tendencies'. The term 'malignant social psychology' refers to a social situation where the negative interaction and communication patterns diminish the personhood or are not supportive towards the personhood. The malignant social psychology can occur in the social environment with the person with dementia either intentionally or unintentionally due to lack of awareness. The depersonalising tendencies can create a devaluing environment, which includes 17 ways of interaction with the person with dementia and their environment: disempowerment, treachery, infantilisation, mockery, disruption, withholding, imposition, ignoring, objectification, banishment, invalidation, disparagement, labelling, outpacing, stigmatisation and intimidation.

A person is still a person despite the loss of memory and other cognitive functions (e.g. Brooker, 2007; Dewing, 2008; Kitwood, 1997). Many researchers have suggested that a person with dementia still has the ability to have a good quality of life, enjoy life and maintain functional abilities. The concept of person-centred care is increasingly well recognised in the field of dementia care.

According to Brooker (2004) person-centred care has four essential elements:

- i. Valuing people with dementia and those who care for them (V)
- ii. Treating people as individuals (I)
- iii. Looking at the world from the perspective of the person with dementia (P)
- iv. Providing a positive social environment in which the person living with dementia can experience relative well-being (S).

Therefore the idea of person-centred care (PCC) can be expressed in terms of = V + I + P + S. A positive care environment created according to the person-centred care concept will enhance well-being for people with dementia.

Thus, it is clear that good care practice for a person with dementia is highly associated with implementing Kitwood's personhood theory (1997). The aim of personhood is to recognize the uniqueness of a person beyond his or her illness, the dementia. The care provider should attend and focus on personhood and not on the dementia and its treatment alone. The person's biography is seen by Kitwood as being an essential component of the presentation of dementia, and so a biographical approach, such as life story work, and the psychosocial aspect of the life experience of persons with dementia is receiving more attention (Sabat, 2001) and is strongly associated with a person-centred care approach. Treating people as individuals also contributes to person-centred care (e.g. Brooker, 2004; Cobban, 2004; Moniz-Cook, Woods, & Gardiner, 2000; McKeown, Clarke, Ingleton, Ryan & Repper, 2010). One-to-one life review sessions can be viewed as an individualised approach that supports personhood (e.g. Haight et al., 2006) and an opportunity for person-centred care. This idea was highlighted by Woods (2001), who recommended that, in order to understand a person with dementia, the life review method should be adopted as a tangible aid for facilitating the construction of the life story. This also directly helps to preserve the identity of persons with dementia. The sense of identity of people with dementia living in a residential care setting has long been recognised as being under threat (e.g. Townsend, 1981). The carer can recognize the 'self' of the person with dementia by practising the person-

centred care approach (Kontos & Naglie, 2007). The exploration of the remaining self in the person with dementia is a vital part of personalised care.

### *Continuity Theory*

Continuity Theory was formally introduced by Atchley (1971). The theory argues the existence of patterns of stability in older adult's behaviour, activities, traditions, beliefs, habits, attitudes, relationships, and thinking despite growing older. The continuity involves both internal structures (e.g. beliefs, personality) and external structures (e.g. relationships, activities) throughout the life cycle. Atchley (1989) defined internal continuity and external continuity as;

‘Internal continuity is defined by the individual in relation to a remembered inner structure, as the persistence of a psychic structure of ideas, temperament, affect, experiences, preferences, dispositions, and skills’ (p. 184)

‘External continuity is defined in terms of a remembered structure of physical and social environments, role relationship, and activities’ (p. 185)

According to Atchley (1989) continuity is a strategy for older adults to cope with changes in middle and later life stages. The main idea of continuity theory is that older adults would use adaptive strategies which were acquired through past experiences to understand and adapt to current conditions (Atchley, 1999). The aim of adaptive strategies is to attempt to maintain this sense of continuity. Usually, in order for a person to deal with changes or a new environment, he or she will try to familiarize the new changes by seeking linkages and familiarity with past experiences. Typically, the adaptive strategies to maintain continuity involve recalling past experiences which is a cognitive process, mainly involving autobiographical memories. Parker (1995) clearly stated that individuals must be involved in this process of recall to maintain continuity. She further highlighted, reminiscence as a very useful tool to create this sense of continuity.

Thus engaging in reminiscence activity would allow a person to maintain continuity. The sense of continuity may help the older adult to adapt and cope better in a new

environment. Atchley (1989) argued a person with dementia would be unable to use memory to maintain continuity. Therefore impairment in memory as experienced by people with dementia would have a negative effect on maintaining self-continuity. However, there is increasing evidence that suggest reminiscence activities could help to preserve and maintain identity and improve psychological well-being (e.g. Clarke, Hanson, & Ross, 2003; Murphy, 2000). Whitbourne (1985) in Parker (1995, p. 521) explained;

‘...the use of “life stories” to facilitate a sense of continuity. Individuals build life stories as they age, and these stories incorporate past events into an organized sequence, giving them a personal meaning and sense of continuity. The term “story” is used to convey that its retelling by individual to the self and to others cause it to take on a rehearsed quality that eventually becomes stylized. Life stories are altered throughout the life span; they change as details are forgotten and as certain scenes are highlighted. These biases may be selective mechanisms designed to preserve identity’

Reminiscence work especially life story work would then give a tangible sense of continuity for persons with dementia. Recording the life stories of a person with dementia may facilitate the continuity process and support psychological well-being. As argued by Parker (1995) the creation of life stories could provide a sense of continuity.

### *Previous Literature Reviews on Reminiscence Work*

Only one high quality review paper about the effectiveness of reminiscence work with people with dementia was available at the time the work in this thesis commenced. The Cochrane Review identified four randomised controlled trials (RCTs) showing an improvement in cognition and mood after treatment among individuals with dementia participating in reminiscence therapy (Woods et al., 2005). However, the conclusion is based on both group and individual reminiscence work, and out of four research papers only two were about individual reminiscence work (Lai, Chi, & Kayser-Jones, 2004; Morgan & Woods, 2010). This review concluded with the potential psychosocial benefits of reminiscence work and called for more rigorous research. This review also highlighted that no harmful side effects had been reported. Since the Cochrane Review was last updated by Woods et al. (2005), many more studies of group reminiscence work for people with dementia employing a randomised controlled trial design (e.g. Ito, Meguro, Akanuma, Ishii, & Mori, 2007; Takada



& Kanagawa, 2007; Wang, 2007) and a few on individual reminiscence work (e.g. Haight et al., 2006; Haslam et al., 2010; Morgan & Woods, 2010) have been published.

Other systematic reviews on the use of group reminiscence therapy (GRT) indicate that there is evidence of support for an improvement in functioning among individuals with dementia (Kim, Cleary, Hopper, Bayles, Mahendra, Azuma, & Rackley, 2006). The same review with six research papers highlighted the preliminary positive evidence for improvements in communication and cognition and recommended the use of GRT as a cognitive-linguistic intervention for people with dementia (Kim et al., 2006). Another review of seven randomised control trials indicated that reminiscence therapy can improve mood and cognitive abilities. However, this review again mixed both individual and group reminiscence work (Cotelli, Manenti, & Zanetti, 2012). Another systematic review of the effectiveness of psychosocial interventions concluded that reminiscence work promotes interpersonal connections for people with mild to moderate dementia (Kasl-Godley & Gatz, 2000). A systematic review of the effectiveness of psychological intervention for the better management of the neuropsychiatric symptoms of dementia noted the lack of high quality research into reminiscence therapy with differing conclusions about its effectiveness (Livingston, Johnston, Katona, Paton, & Lyketsos, 2005). However, in Livingston et al.'s (2005) review, only one of the five published reminiscence works was an individual reminiscence study by Haight et al. (2003). A narrative review by Scott and Clare (2003) also reported difficulties in reaching firm conclusions about the evidence for the effectiveness of psychological intervention, including reminiscence work on a group basis, and it recommended further better quality research and the selection of appropriate outcome measures. It is important to note, as indicated in Kim et al.'s (2006) systematic review and Scott and Clare's (2003) narrative review about group reminiscence work, that there are no systematic reviews specifically designed to evaluate the effectiveness of reminiscence work in an individual setting. Therefore, there is a clear need to conduct a systematic review on individual reminiscence therapy, and such a review forms part of this thesis (Chapter 2).

### *Life story book as an Intervention Tool*

Life story books could be seen as a specific sub-type of the tangible memory triggers and external memory aids which have long been associated with people with dementia. These might include a memory box, a memory book, a memory wallet and other forms of external

memory aid such as diaries. Bourgeois (1990, 1992, 1993, and 1996) reported several positive outcomes for memory books and memory wallets as external cognitive aids among individuals suffering from Alzheimer's and dementia. However, all the Bourgeois studies focused on memory books and wallets as a tool for improving the communication abilities of people with dementia rather than as an aid to reminiscence. Mcpherson et al. (2001) replicated Bourgeois' intervention studies with five people with severe dementia and concluded that memory aids are helpful to some people with severe dementia. Andrews-Salvia, Roy, & Cameron (2003) investigated the effect of memory books based on three topics (day, life and family) with four individuals with severe dementia from a care home. The outcome showed that improvement appeared to depend on the topic and the amount of time spent with the memory book. They concluded that with a few cues, and without intensive training, the memory book has the potential to enhance communication skills even for people with severe dementia.

Initially life story books or scrapbooks were created for childcare work and after some years the concept was adapted for older adults (Gibson, 1994). Researchers have been arguing for the use of the life story book for people with dementia (Parker, 1995). The current situation is that the idea of the life story book for the older adult with dementia has been well received and it is getting good attention from various organizations in the UK. For example, the First National Life Story Conference took place on 25 February 2010 (see [www.lifestorynetwork.org.uk](http://www.lifestorynetwork.org.uk) ) and the UK's Department of Health has also trained 500 people to carry out life story work with people with dementia (see [www.lifestorynetwork.org.uk](http://www.lifestorynetwork.org.uk) ). Whitbourne (1985) argued for the usefulness of the life story book in providing a sense of continuity. Parker (1995) explained that the book has numerous therapeutic benefits as a tangible self-reminder, which helps the older adult in adaptation, and as a self history, which helps to maintain a sense of continuity for people with memory difficulties.

Haight (2003) linked the life story book with the life review process, seeing the book as a tangible outcome. She further emphasised that the use of the book should be directed by the persons concerned who are given their own freedom to choose and select the contents of the book, for example, pictures, words, props and so on. In her view, the book is about the person's life and created by their choice of pictorial items that they have viewed and rated as relevant and significant for themselves. Other family members and the caregiver can assist the person in creating their life story book without influencing and directing the person (Haight, 2003).

In a systematic literature review of 51 papers McKeown, Clarke, Repper (2006) reported that evidence on the use of the life story is immature and they recommended more research, stating that there are some potentially far-reaching benefits of life story work in health and social care practice. Moos and Bjorn (2006) conducted a more specific review of the benefits of the life story as an intervention for people in institutional care with dementia and demanded more qualitative research to understand the potential of life story work. Therefore, this thesis addresses the psychosocial benefits of life story books for the older adult with mild to moderate dementia.

A conventional life story book is, of course, not the only potential tangible outcome of a life review, or indeed the only way of telling a life story. Memory boxes have been popular, containing a display of relevant items and materials, for example (Schweitzer, 2005). The potential for technology to assist people with dementia has been looked at increasingly in recent years, and one of several areas identified relates to life story books ([www.scie.org.uk](http://www.scie.org.uk)). Digital life story books are already commercially available (e.g. [www.memories-unlimited.co.uk](http://www.memories-unlimited.co.uk)) and so this is an area for potential development. Accordingly, a systematic review of the current literature on the use of technology to support reminiscence work was undertaken for this thesis (see Chapter 4).

### *Objective of the thesis*

The overall aim of the thesis is to make an original contribution to the literature and to practice on life review and life story books for people with mild to moderate dementia living in care homes.

Accordingly, two systematic reviews of the existing literature were undertaken. The first was concerned with individual reminiscence work with people with dementia, which in previous reviews has not been considered separately from group-based reminiscence work. The second followed on from this in identifying the increasing use of information and communication technology (ICT) in reminiscence work, and sought to establish the current state of knowledge.

Two empirical studies are reported, each based on the findings of a systematic review. The first study sought to distinguish the effects of a life review process, following Haight's Life Review model, leading to a life story book, from those of simply being presented with a

life story book. This study was also able to evaluate the effects of life review and life story books on quality of life, and of life story books on the quality of relationships with relatives and on staff knowledge and attitudes. The study design was a small-scale randomised controlled trial, with assessors blind to treatment allocation.

The second empirical study was more exploratory, and aimed to evaluate the usability and feasibility of implementing an ICT-based life-story movie with people with mild to moderate dementia residing in care homes. A multiple case study approach was employed, with participants who had a life story book completed in the first study.

The results of the empirical studies are presented in two separate papers in journal manuscript format.

## Justification for targeted domains

### *Quality of life*

Quality of life is a useful and meaningful concept in considering the experience of people with dementia (Thorgrimsen et al., 2003), and is viewed as a key outcome domain for people with dementia, especially in relation to psychosocial interventions (Kane, 2001; Woods, Thorgrimsen, Spector, Royan, & Orrell, 2006; Moniz-Cook et al., 2008). Although there are now a number of reliable and valid measures of quality of life for people with dementia (Hoe et al., 2009) not many studies have used it as an outcome variable to evaluate the effects of reminiscence work. One to two-year longitudinal research has highlighted that the quality of life of people with dementia is not necessarily reduced by the progress of dementia (Lyketsos et al., 2003; Missotten et al., 2007; Selwood, Thorgrimsen, & Orrell, 2005) and the level of quality of life may further improve with psychosocial intervention. Some non-reminiscence work, such as cognitive stimulation therapy, with people with dementia has shown improvement in quality of life (Woods et al. 2006). One study has also linked the impairment of autobiographical memory to a reduction in QoL (Jetten et al., 2010). A major research trial in group reminiscence work employed quality of life as a primary outcome variable (Woods et al., 2009). Older adults with mild to moderate dementia are argued to be able to rate their own quality of life rather than using a proxy (e.g. relatives or care staff) (Crespo, Bernaldo de Quiros, Gomez, Hornillos, 2011). Indeed, many older adults with significant cognitive deficits are able to describe their own quality of life (Mozley et al., 1999). There is very

limited research suggesting the effect of reminiscence as an intervention on the quality of life for people with dementia. In particular, no major studies evaluate the effects of the life review process/life-story book on quality of life for people with dementia. In this study, the QoL-AD (Logsdon et al., 2002) was used, as it has been shown to be appropriate for a wide range of people with dementia, and has shown sensitivity to change in relation to other interventions, and compares favourably with alternative measures (Moniz-Cook, et al., 2008).

### *Autobiographical memory*

The importance of autobiographical memory has been highlighted in previous sections, and it is clearly the single most relevant area of cognitive function in relation to reminiscence work, even though its contribution to sense of identity has not emerged as strongly as predicted from empirical studies. The Autobiographical Memory Interview (Kopelman et al., 1989, 1990) is the best established measure, and proved sensitive to change in the study reported by Morgan and Woods (2010), although it has required additional items for use with older people to cover the person's middle years (Jones and Woods, 2006). This extended version (AMI-E) has been used in the major trial of group reminiscence work (Woods et al., 2009) and is used in the current study. Additional data on its inter-rater reliability were collected as part of the work for this thesis and are presented in Appendix C.

### *Depression*

Numerous studies have reported that depression is a common symptom among older adults living in care homes (Seitz, Purandare, & Conn, 2010; Snowden, 2010; Snowden & Purandare, 2010) and frequently coexistent with dementia (Starkstein & Mizrahi, 2006). For example, the prevalence of depression in older adults living in institutions in England and Wales was 27.1%, compared with 9.3% in those living in a community setting (Seitz et al., 2010). Studies have also reported that depression in the dementia population is under-diagnosed (e.g. Cohen, Hyland, & Kimhy, 2003 & Gruber-Baldini et al., 2005) and undertreated (Brown, Lapane, & Luisi, 2002). One of the major effects of depression on older adults with dementia is a reduction in quality of life. Studies have attested that non-pharmacological treatment is effective in treating depression in older adults with dementia

(e.g. Teri, Logsdon, Uomoto, & McCurry, 1997). In work which is relevant to this study, Butler (1974) argued that depression is a common condition because a person has difficulty re-integrating his/her life events. Butler recommends life review as a tool to resolve the stagnation – that is, to resolve negative life experiences and move forward. Later Butler's idea was tested using LREF with older adults without dementia, and this work found a reduction in depression levels (Haight & Dias, 1992).

There is limited empirical evidence available regarding the effects of life review on depression in older adults with dementia. What evidence there is on the effects of life review on depression and mood among people with dementia indicates encouraging results (Haight, 2006; Morgan & Woods, 2010). A short-form of the Geriatric Depression Scale was selected for this study, as it is a self-report scale that people with mild to moderate dementia can complete and is recommended by Moniz-Cook et al. (2008). A short-form particularly appropriate for residents in care homes was selected (GDS-12R; Sutcliffe, et al, 2000).

### *Care-Giving Relationship*

There is an increased interest in exploring the quality of care giving and care-recipient relationships (Spruytte, Van-Audenhove, Lammertyn, & Storms, 2002). A recent systematic review provides evidence to support the importance of quality of relationship between relative (caregiver) and person with dementia (care-recipient) on both carer and person with dementia (Quinn, Clare, & Woods, 2009). Studies have demonstrated that closer caregiver relationships may be associated with dementia progressing more slowly in relation to cognition and functional ability (Norton et al. 2009). A positive care-giving relationship also delayed care home placement (Wright, 1994) and helps in the adjustment process to a care home for people with dementia (Whitlatch, Schur, Noelker, Ejaz, & Looman, 2001). Therefore the care-giving relationship is also a useful variable to explore, especially as it was planned to involve relatives to a large extent in preparing some life story books. The current study used the Quality of the Care-giving relationship questionnaire (QCPR) (Spruytte et al. 2002), as used in the large trial of group reminiscence work (Woods et al. 2009). This scale can be completed separately by the person with dementia and the relative, each giving their own perspective on the relationship. There are two sub-scales: warmth and absence of conflict.

### *Staff attitudes and knowledge*

The effects of reminiscence work on care home staff has rarely been studied. Only one study reported changes in staff knowledge after being involved in group reminiscence activity with the person with dementia (Baines, Saxby, & Ehlert, 1987). However, if the aim is to use the life story book as a means towards person-centred care it is important to evaluate whether staff do in fact get to know the person better, and whether there is a change in their attitudes to people with dementia. A questionnaire assessing staff knowledge of the person with dementia was designed specifically for the study. The measure of attitudes adopted was the Approaches to Dementia Questionnaire (Lintern, Woods & Phair, 2000). This scale has two sub-scales, one evaluating person-centred attitudes, the other assessing the person's sense of hopefulness about working with the person with dementia. More positive attitudes have been shown to be related to higher quality of life in care home staff (Zimmerman et al, 2005; Spector & Orrell, 2006).

### *Summary of thesis*

The current chapter has provided an overview of reminiscence work and its relation to people with dementia. It is clear that the idea of reminiscence work as a psychosocial intervention has been frequently tested with people with dementia; however, its usage is highly varied and it is difficult to draw a conclusion. Specifically, the application of a life review/life-story book as a therapeutic tool is very limited in terms of quality research and lacking in empirical evidence. Subsequently, the need to test the efficacy of the life review/life-story book for people with dementia is raised. In addition, the application of ICT-based reminiscence work also needed validation.

Chapter 2 is a systematic literature review that examines the potential psychosocial benefits of individual reminiscence work for people with dementia. Five published randomised controlled trials on individual reminiscence work (Lai et al., 2004; Politis et al., 2004; Haight et al., 2006; Haslam et al., 2010 & Morgan et al., 2010) were identified and included in this review. The review highlights the immediate and longer-term psychosocial benefits of individual reminiscence work; in particular, integrative reminiscence work (life review process and specific reminiscence approach), implemented in a one-to-one manner, produced more positive effects compared to general reminiscence material. The review also

highlights limitations of past research and makes some recommendations for future research into the application of individual reminiscence work with people with dementia.

Chapter 3 presents the first empirical study of this thesis. This compares the effect of producing a life story book through a life review process with simply presenting the person with a life story book prepared by a relative. This study also indicates the effects of a life review process on quality of life, compared with usual treatment, and the effects of life story books on the quality of relationship between the person with dementia and his/her relative and on care staff knowledge and attitudes.

Chapter 4 is a systematic review which explores the application of reminiscence work for people with dementia using information and communication technology (ICT). Most of the ICT-based reminiscence work for people with dementia studies included in this review was developed and tested either at preliminary or pilot work stage. Interestingly, most of the reminiscence system prototypes developed consists of personalised biographical material, which is similar to the life-story book for people with dementia, and this suggests the possibility of developing an ICT-based life-story book. This review highlights that the feasibility of using information and communication technology in reminiscence work for people with dementia is beginning to be established. Some important key issues are also discussed.

Chapter 5 addresses the questions raised by experiment 2, which relate to evaluating the usability and feasibility of implementation of an ICT-based life-story book with people with mild to moderate dementia residing in care homes. A total of six participants' life-story books developed in experiment 1 were 'transferred' to an ICT-based life-story movie and presented to them to watch over a four-week period. The same measures used in experiment 1 were repeated to ascertain the quantitative effect of the life-story movie. At the same time, qualitative approaches were applied by gathering information based on feedback from participants, relatives and care home staff feedback.

Chapter 6 concludes the thesis. This chapter summarises the previous work and integrates discussion of the findings and their implications. This chapter also highlights limitations and recommendations for future research.



Chapter 2: The impact of individual reminiscence therapy for people with dementia: systematic review

## Summary

This systematic review aims to review the potential psychosocial benefits of individual reminiscence therapy for people with dementia. Five randomized controlled trials were identified. All were carried out in nursing or care homes, and several different approaches were represented. The studies reported some immediate and longer-term psychosocial benefits to people with dementia of individual reminiscence work, where this involved a life review process or personalized, specific reminiscence work. These benefits included mood, well-being and aspects of cognitive function. There was no evidence that the use of general reminiscence materials was associated with psychosocial benefits. The use of life story books and multimedia alternatives, with or without an associated life review process, does appear to be worth pursuing from both clinical and research perspectives.

Subramaniam, P., & Woods, B. (2012). The impact of individual reminiscence therapy for people with dementia: systematic review. *Expert Review of Neurotherapeutics*, 12(5), 545 – 555

## Introduction

The dementias are a group of progressive neurodegenerative disorders affecting 36.6 million people worldwide (Alzheimer Disease International, 2009). In the UK alone, the prevalence of dementia is estimated at 820,000, with this number predicted to double in the next 20 years (Alzheimer's Research Trust, 2010). The total costs to the UK economy are currently estimated as GB£23 billion – higher than the costs for cancer and heart disease combined (Alzheimer's Research Trust, 2010). The typical impact of dementia on a person's life includes impairment in memory and other cognitive functions, as well as impairment of daily living activity and behavioral symptoms. Apart from the individuals with dementia, family carers are at increased risk of distress and strain related to care giving. People with dementia are at high risk of entering care homes and other institutional care.

Reminiscence work for people with dementia has attracted research and clinical attention for over 25 years (Norris, 1986). It has typically involved the discussion of past activities, events and experiences, aided by a range of memory triggers. These may include household and familiar items and artefacts from the past, such as photographs, music and archive sound recordings. Its roots may be traced back to 1963 and Butler's concept of 'life review', which proposed that reminiscing, in looking back at and reflecting on one's own life, is a healthy natural occurrence, rather than an indication of psychopathology (Butler, 1963). Later researchers incorporated reminiscence as a part of interventions with older adults, and there is now an extensive literature on the effectiveness of reminiscence work with depressed older people (Bohlmeijer, Smit, & Cuijpers, 2003). In dementia care, reminiscence work has been noted as the most popular psychosocial intervention (Woods et al., 2005), although many other psychosocial interventions have been developed over the years (Douglas et al., 2004), including a range of interventions with either a focus on cognition or emotions (Woods & Clare, 2008). Reminiscence work may be seen as falling at the interface of cognitive and emotion-focused approaches, with potential interacting effects on autobiographical memory and adjustment or well-being. However, rigorous evidence on the effectiveness of reminiscence work for people with dementia has been slow to emerge (Woods et al., 2005).

A number of different types and functions of reminiscence work have been described and numerous taxonomies have been proposed, ranging from two to eight varieties of reminiscence (Beaton, 1980; Kovach, 1991; Lo Gerfo, 1980-1981; Merriam, 1993; Romaniuk & Romaniuk, 1981; Webster & Cappeliez, 1993; Wong & Watt, 1991). In considering

reminiscence work with people with dementia, the key distinction is between reminiscence work that is based on sharing stories and memories from the past with others, which has a narrative and informative function, and reminiscence work that has a focus on the individual making sense of their own life story, which is described as having an integrative function (Subramaniam & Woods, 2010). This has implications for whether the work is carried out individually or in a group; integrative reminiscence is almost always individual, whereas narrative and informative functions can be sustained in one-to-one settings or in a group. Integrative work usually requires memory triggers specific to the person, whereas more general triggers may be sufficient to trigger a broad range of stories and memories in narrative and informative modes of reminiscence.

Wong and Watt suggested that the main function of integrative reminiscence is to achieve a sense of self-worth, coherence, and reconciliation with regard to one's past (Wong & Watt, 1991). This type of reminiscence should be associated with healthy and happy aging (Wong & Watt, 1991). Its primary function is intrapersonal, even though it may be carried out in an interpersonal context with one or more others. Life review, as a therapeutic approach, may be seen as a particularly structured form of integrative reminiscence (Haight, 1988; Haight, 1992a). Haight (1992a) has operationalized the life review process by developing the Life Review Experiencing Form (LREF), a set of guided questions and topics to assist the older adult in looking back at their life history in a chronological order, and evaluating their experiences. Haight argues that a structured approach that is guided, personalized and evaluative is needed to facilitate older adults in resolving conflicts in the final life stage, as suggested by Erikson's psychosocial development theory (Erikson, 1950). This final psychosocial development stage is characterized by the opposite poles of 'integrity versus despair' (Erikson, 1950). Integrity reflects acceptance, reconciliation and coherence; despair reflects unresolved regrets and hurt and a questioning of whether the life as lived had any value. As envisaged by Haight, the guided life review process for people with dementia results in the coproduction of a life story book, which sets out the person's life story as they wish to recount it, using the person's own words and relevant pictures, under the editorial control of the person with dementia. Increasingly, it is possible to offer the capacity for multimedia versions of 'life story books', so that music, film and sounds can be incorporated. In the UK, the Department of Health has funded the 'Your Story Matters' project, to train 500 people to carry out life story work with people with dementia and to train others to do so ([www.lifestorynetwork.org.uk](http://www.lifestorynetwork.org.uk)).

By contrast, simple or general reminiscence work involves discussing past events based on a number of selected topics or themes. For example, these might include 'school days' with tangible materials or prompts relating to school experiences, such as a school uniform, school bag and books. These prompts may be generic, such as reflecting in this example common experiences of school relevant broadly to the person's age cohort, or specific, relating specifically to the person's own experiences (Gibson, 2006). Specific triggers may be from the resources available to the person and his/her family or may be researched from relevant archive sources. Generic triggers are now widely available, in the form of reminiscence books, kits, music and video collections.

Given that there may be differences in approach between individual and group reminiscence work, it is important to consider them separately and to take account of the interaction between treatment modality and type of reminiscence approach. The current review is the first to focus on the psychosocial benefits of reminiscence activity specifically in individual settings for people with dementia. In the most recent Cochrane review, Woods et al (2005) included five randomized controlled trials (RCTs) carried out on reminiscence work with people with dementia, but only two of these trials studied individual reminiscence work (Woods et al., 2005). Therefore, the conclusions of that review are based on a mixed collection of studies, including group and individual reminiscence work of different types. In order to provide more specific evidence-based recommendations, it is timely to attempt to delineate the effects of the individual modality of reminiscence work. These effects could potentially be evident in benefits for family carers and for care staff, as well as for people with dementia.

## Method

A systematic search of original research papers reporting RCTs on reminiscence work for people with dementia was conducted in December 2011. The search engines used for relevant publications included PsychINFO, CINAHL, Medline, CENTRAL, EMBASE and Web of Knowledge. The search terms were the keywords 'reminiscence', 'life review', 'life story book', 'dementia' and derivatives. No limit was set on the date of publication, but papers were required to be in the English language. The search generated 82 references from a wide range of disciplines, including psychology, religious studies and medicine. Each abstract was reviewed by both authors to ascertain whether the journal article met the inclusion criteria of being an original research paper employing a randomized controlled design applying reminiscence as an individual intervention for people with dementia. Reasons for exclusion included: participants did not have dementia; the intervention did not primarily involve reminiscence activity, or a mixed approach was used (e.g., reality orientation or multisensory stimulation); the study was not a RCT; a group approach to reminiscence was used; the report was a review paper or a trial protocol; the report was a dissertation or book. Three relevant papers were identified from this electronic database search, with two further papers being identified from hand searches of relevant journals and from reference lists of papers and reviews. Overall, this resulted in five papers fulfilling the inclusion criteria and accordingly included in this systematic review.

## Results

The details of the five included studies on individual reminiscence work are presented in Tables 1 & 2. Table 1 summarizes information regarding the aims, outcomes and conclusions for each study. None of the five studies included outcome measures for family members and/or care staff. Table 2 contains the detailed characteristics of each study, in terms of research design, participants, diagnosis (and severity), setting, sample size and allocation to conditions, facilitators, reminiscence content/topic and activities, number of sessions (and frequency), duration of each session and outcome measures employed in each study.

Table 1. Summary of individual reminiscence studies

Characteristic	Study (year)				
	Lai et al. (2004)	Politis et al. (2004)	Haight et al. (2006)	Haslam et al. (2010)	Morgan & Woods (2010)
Aim of study	To investigate the psychosocial effect of specific reminiscence program, compared with a social contact control and treatment as usual	To evaluate the efficacy of a kit-based activity compared to one-on-one meetings (control group)	To test the effectiveness of a structured life review/life storybook process	To investigate the impact of group reminiscence and individual reminiscence activities on older adults living in care settings compared with a social activity group control	To investigate the impact of life review therapy on autobiographical memory, mood & life satisfaction
Outcome / Therapeutic effect	Improved well-being in intervention group	Improvement on NPI-apathy and total NPI scores in both groups. Significant quality of life improvement in control group. Also noted modest decrease in the need for cueing in the control group.	Significant change on depression, communication, positive mood and cognition	Group reminiscence enhanced memory performance. Social activity group enhanced well-being	Improved autobiographical memory & reduced depression
Conclusion	No significant differences between the three groups over time but significant improvement in psychosocial well-being for the intervention group	No clear advantage to kit based reminiscence activity over the time and attention (one to one) control intervention	Suggests a potentially promising technique to assist people with dementia	Group setting plays role in maintaining and promoting health and well-being, whether reminiscence or social activity. No benefits from individual work	Indicative of a possible psychological therapy for depressed mood in dementia
Recommendation	Reminiscence using a life story approach showed some promising effects on the well-being of people with dementia. More research is needed	Very simple 'one-to-one' intervention may have powerful effect on the outcomes of interest-more research needed to address the stated research objective	Recommend additional research with people who have dementia, possibly mapping the process with MRI to fully understand the effects	More work needs to be done to understand more fully the social and cognitive processes that contribute to the positive effects of group reminiscence interventions	Further research needed, for example, the effect of life story book alone, developed by relative
Therapeutic Benefits	Beneficial - well-being	No clear benefit of reminiscence-based intervention	Beneficial - life review as a low-cost, low-risk, brief intervention capable of producing substantial results	No positive outcomes from individual reminiscence work. Group reminiscence and social activity group more beneficial	Beneficial

NPI: Neuropsychiatric Inventory



Although all of the studies use RCT methodology (by selection), these studies may be best considered as exploratory in nature. Two studies made comparisons only with a ‘treatment-as-usual’ control condition (Haight et al., 2006; Morgan & Woods, 2010). The Lai et al. (2004) study additionally incorporated a comparison group receiving one-to-one social contact, and Haslam et al. (2010) made comparison with two types of intervention groups, one involving reminiscence and the other a social activity. Politis et al. (2004) compared a highly structured individual session making use of a reminiscence ‘kit’ with a more informal and personalized individual session with an activity therapist. Two studies report on missing data and include an intention-to-treat analysis (attrition was 15 and 33%, respectively) (Haslam et al., 2010; Lai et al., 2004). One study presented clinical observations and two case vignettes with some qualitative responses (Morgan & Woods, 2010).

The sample size included ranges from 17 (Morgan & Woods, 2010) to 101 (Lai et al., 2004) with all participants drawn from residential care or nursing homes, and no community-resident people with dementia included. All of the studies gave mini-mental state examination (MMSE) scores or the Dementia Rating Score as an indicator of level of cognitive impairment or dementia severity indicator. With the exception of two studies (Lai et al., 2004; Politis et al., 2004), details of diagnostic criteria were not provided. The 40 participants with dementia in Haslam’s study are reported as meeting the ‘general medical diagnosis of dementia’ and were in units designated for people with dementia (Haslam et al., 2010). Residents in other included units may well have also had dementia.

The duration of intervention sessions varied from 30 min (Haslam et al., 2010; Lai et al., 2004; Politis et al., 2004) to 1 h (Haight et al., 2006), with Morgan reporting a flexible duration between these figures. With one exception (Politis et al., 2004), where three sessions per week were offered, all sessions were once a week, with the total number of sessions varying between six (Lai et al., 2004; Haslam et al., 2010), eight (Haight et al., 2006) and 12 sessions (Morgan & Woods, 2010; Politis et al., 2004).

The individual reminiscence work described in the five studies ranged from a highly structured life review approach (Haight et al., 2006; Morgan & Woods, 2010) to a highly structured general approach (Politis et al., 2004) to a much less structured general approach (Haslam et al., 2010). The studies will be discussed in three categories: the first is the life review/life story book approach based on Haight’s protocol (Haight, 1992a), which was employed in two studies (Haight et al., 2006; Morgan & Woods, 2010) the second category involves elements of this approach, but is less clearly focused on a chronological and

evaluative approach to the life story (Lai et al., 2004); the third category, exemplified in two studies (Haslam et al., 2010; Politis et al., 2004), is based on general reminiscence work principles, ‘discussing past memories with relevant matching materials’ (Haslam et al., 2010).

#### *Life review/life story book approach*

Two small RCTs used a life review/life story book approach. In the report by Haight et al. (2006), the intervention was delivered to people with dementia residing in care homes by 15 familiar care assistants, who received weekly supervision. Thirty-one residents participated in this trial, with the control condition being ‘treatment as usual’. Intervention sessions were held once weekly for 8 weeks and each session lasted for 1 h. The intervention focused on the production of a life story book based on one-to-one life review sessions using Haight’s LREF. Participants all had a diagnosis of dementia with an initial mean score on the MMSE in the mild-to-moderate range (17.84). No information was provided about medication usage. Outcome measures included measures of cognition (MMSE), depression (Cornell Scale for Depression), mood (Alzheimer’s Mood Scale), daily activities (Functional Independence Scale) and problem behavior (Memory and Behavior Problems Check List). The findings highlighted significant improvements in depression, communication, positive mood and cognition among the residents with dementia who took part in the life review intervention.

Morgan and Woods (2010) used a similar approach, following Haight’s LREF protocol with people with dementia living in care homes, in a small RCT involving 17 people with dementia. The life review sessions (an average of 12 per resident) were carried out by a trainee clinical psychologist. Improvements in autobiographical memory and mood were identified following individual life review sessions. Notably, autobiographical memory had improved significantly relative to the ‘treatment-as-usual’ comparison group at the post-treatment assessment, whereas the improvement in depression became significant at a follow-up assessment 6 weeks later. These two studies provide evidence supporting the proposition that undertaking a life review and producing a life story book may produce significant psychosocial improvements for a person with dementia.

### *Specific reminiscence approach*

The details of the intervention approach utilized by Lai et al. (2004) are not fully documented in the published report, and it has been described elsewhere as a group intervention (e.g., Haslam et al., 2010). However, we have confirmed with the author that this was a study of individual reminiscence. A ‘life story book’ similar to a photograph album was produced for each person, but “the term ‘life story’ was used in a generic and global sense, referring to glimpses of an individual’s life, rather than to a biography or an entire life story” (see page 35 of Lai et al., 2004). The approach is described as ‘specific reminiscence’, in that the triggers were personalized according to the person’s life history, as far as possible (Gibson, 2006). The reminiscence sessions (and the life story book) then covered a range of relevant themes, operationalized in six 30-min sessions. Comparisons were made with a ‘treatment-as-usual’ control group and also a ‘social contact’ control group, who received the same number of sessions, but focusing on other topics such as ‘diet and health’ or ‘social security’, with the therapist steering the conversation away from reminiscing when necessary.

The study included 101 participants from two institutional nursing home settings with 36 participants being randomly assigned to receive specific reminiscence as an intervention (Lai et al., 2004).

In the primary analyses no significant differences between groups were noted. However, the intervention group, unlike either of the control groups, showed a significant improvement in measures of well-being and social engagement. No significant differences were noted in cognition as assessed by the MMSE.

### *General individual reminiscence approach*

Haslam et al. (2010) included 73 residents from care homes, with 24 participating in individual reminiscence sessions, of whom 13 participants were identified as having dementia. However, it is likely that the majority of participants had a degree of cognitive impairment, as the average MMSE score for those receiving individual reminiscence was 17.36 (standard deviation:  $\pm 7.08$ ), which falls in the mild-to-moderate range of dementia. The comparison conditions were group reminiscence and a social group that focused on a game of skittles (a rustic version of ten-pin bowling). The individual sessions were held once weekly for 6 weeks and lasted 30 min, using a general reminiscence approach identical for individual

and group sessions. This involved focusing on a particular life phase in each session and introducing objects for discussion relevant to that period. The six phases were: childhood; schooldays; domestic life; weddings; family life and holidays. Three members of the research team who had received introductory reminiscence training acted as facilitators; accordingly they were not blind to treatment allocation in carrying out the outcome measures. A wide range of outcome measures were used, evaluating cognition (Addenbrooke's Cognitive Examination – Revised); well-being (Hospital Anxiety and Depression Scale and Quality of Life in Alzheimer's Disease Scale); and identity (Personal Identity Strength and Social Group Homogeneity scales). Assessments were carried out immediately before and after the intervention. The results indicated that improvements in cognition were related to participation in group reminiscence sessions, but not individual reminiscence or the social activity groups. However, those participating in the social activity showed an improvement in well-being compared with both group and individual reminiscence. Finally, those taking part in the individual reminiscence sessions were more likely to agree with the statement 'I am very different from others here' than those taking part in either of the group interventions. This can be interpreted as reflecting less social identification with fellow residents; it did not appear to reflect a greater strength of personal identity, as no differences were seen on items evaluating this construct.

The individual reminiscence approach evaluated by Politis et al. (2004) involved the use of a 'kit' containing a variety of visual and auditory activities that might stimulate reminiscence. These were grouped into five themes: geography, fun foods, farm animals, vegetables and musical instruments. Questions and conversation starters are scripted on cards for the staff member, and so the sessions are to some extent standardized. The comparison group here involved an activity therapist spending the same time with the person with dementia, talking about their interests and engaging in activities as well as discussion. The topics could include the person's past, and so this 'control' condition also incorporated elements of reminiscence, albeit of a less standardized and more personalized nature. The average MMSE score of the 36 residents participating was 9.5, falling in the moderate-to-severe dementia range. Both interventions were associated with a reduction in apathy after the 4-week intervention period, but, although there were no differences between the groups, the control group showed an improved level of quality of life (rated by staff). Whilst the lack of an untreated control group makes it difficult to interpret the results fully, it is clear that the use of the 'reminiscence kit' did not provide any clear advantage over a more informal, personalized approach. If anything, the advantage was with the sessions where the staff

members took the trouble to listen to the person with dementia, discover their interests and engage in relevant and preferred activities.

Table 2 Summary characteristics of Individual reminiscence therapy studies

Characteristic	Study (year)				
	Lai et al. (2004)	Politis et al. (2004)	Haight et al. (2006)	Haslam et al. (2010)	Morgan & Woods (2010)
Design	'Pre and post' design (6-week follow-up) Randomized Controlled Trial	'Pre and post' design Randomized, controlled trial CRAI scale administered before, during and after intervention	'Pre and post' design Randomized controlled trial	'Pre and post' design Randomized controlled trial	'Pre and post' design (6-week follow-up) Preliminary randomized controlled trial
Measurements	Pre, post at 6 weeks after immediate intervention and follow-up at 6 weeks after intervention	Pre and post at 4 weeks after immediate intervention	Pre and post at 8 weeks after immediate intervention	Pre and post at 6 weeks after immediate intervention	Pre and post (on average 12 weeks after) immediate intervention and follow-up at 6 weeks after intervention
Total Participants (n)	101	36	31	73 (40 definitely with dementia)	17
Participants in individual reminiscence condition (n)	36	18	15	24 (13 definitely with dementia)	8
Mean Age(SD) or age range if mean not provided (years)	85.7 (7)	83.95 (4.7)	Range: 60 – 99	Range: nondementia/standard care: 58-95; dementia/special care: 62 – 93	82.47(6.78)
Diagnosis	Dementia	Dementia	Dementia	Nondementia & dementia	Dementia

<sup>†</sup>No outcome was reported for family or care staff for any of the studies included in the table.

CDR: Clinical Dementia Rating; CRAI: Copper Ridge Activity Index; MMSE: Mini-mental state examination; NPI: Neuropsychiatric inventory; QoL-AD: Quality of Life in Alzheimer 's disease; SD: Standard deviation.

Characteristic	Study (year)				
	Lai et al. (2004)	Politis et al. (2004)	Haight et al. (2006)	Haslam et al. (2010)	Morgan & Woods (2010)
Baseline MMSE (SD)/ CDR score	MMSE: 9 (5.43)	MMSE: 9.5 (5.6)	MMSE: 17.8 (5.66)	MMSE: 16.61(6.75)	CDR score, 1 (mild) to 2 (Moderate)
Setting	Nursing home	Nursing home	Care home	Care home	Care home
Individual/group conditions (n)	36 intervention group, 35 social comparison group and 30 no intervention group	18 intervention and 18 control	15 intervention and 16 treatment-as-usual control	24 individual reminiscence, 29 group reminiscence and 20 social activity control	8 intervention / 9 treatment-as-usual control
Individual reminiscence type	Specific Reminiscence (with life story book)	The geriatrics network kit	Life Review/life story book	General reminiscence	Life review/life story book
Individual/group facilitator(s)	Research assistant, three social workers and one occupational therapist	Trained activity therapist	15 care staff who received 2 hours preliminary training and weekly supervision with researcher for 10 hours of ongoing training	Three members from research team, who received introductory training from experienced facilitator	Clinical psychologist Trainee
Reminiscence activity	Stimulate recall during conversation	Asking questions from the kit and engaging in conversations based on participants' responses.	Life review/life story book session	Discussion, conversation	8 – 12 sessions ; Life review/life story book session
Session time/frequency	30 minutes/1 x per week	30 minutes/3 x per week	1 hour/1 x per week	30 minutes/1 per week	30 minutes – 1 hour/1 x per week
Length of intervention	6 weeks=6 meetings	4 weeks=12 sessions	8 weeks = 8 sessions	6 weeks = 6 meetings	8-12 weeks= 8-12 meetings

<sup>†</sup>No outcome was reported for family or care staff for any of the studies included in the table.

CDR: Clinical Dementia Rating; CRAI: Copper Ridge Activity Index; MMSE: Mini-mental state examination; NPI: Neuropsychiatric inventory; QoL-AD: Quality of Life in Alzheimer 's disease; SD: Standard deviation.

Characteristic	Study (year)				
	Lai et al. (2004)	Politis et al. (2004)	Haight et al. (2006)	Haslam et al. (2010)	Morgan & Woods (2010)
Major Outcome measure <sup>†</sup>	Social Engagement Scale; well-being / Ill-being scale.	NPI-apathy, NPI; Alzheimer's disease-related quality-of-life scale; Copper Ridge activities index.	MMSE; Cornell scale for depression in dementia; Alzheimer's mood scale; functional independence scale; communication observation scale; memory & behaviour problems checklist.	Addenbrooke's cognitive examination-revised; hospital anxiety & depression scale; QoL-AD.	Geriatric depression scale; autobiographical memory interview.
Assessor or rater blind to allocation	Single blinded (assessor)	Partially masked (rater)	Not blinded	Not blinded	Half of the assessments single blinded (assessor)
Type of randomization	Fixed allocation (computer generated random numbers)	A table of random numbers, in blocks of four.	No information available but mentioned participants were randomly assigned.	Stratified randomization	Randomization by minimization
Respondent drop out	Six in intervention group / six in social comparison group / three in no-intervention group (total: 15)	One participant dropped out before randomization	Out of 31 randomized participants, only 24 completed information on all tested measures but no drop outs	Ten in individual reminiscence / 12 in group reminiscence / 20 in social activity control (total: 42)	No drop outs
Report on missing data or missing values	Yes	All randomized participants completed the trial successfully and no report on missing values	All participants completed the trial but seven participants with incomplete data (missing values) on measures	Partly indicated (mentioned)	All randomized participants completed the trial and no report on missing values

<sup>†</sup>No outcome was reported for family or care staff for any of the studies included in the table.

CDR: Clinical Dementia Rating; CRAI: Copper Ridge Activity Index; MMSE: Mini-mental state examination; NPI: Neuropsychiatric inventory; QoL-AD: Quality of Life in Alzheimer's disease; SD: Standard deviation.



Characteristic	Study (year)				
	Lai et al. (2004)	Politis et al. (2004)	Haight et al. (2006)	Haslam et al. (2010)	Morgan & Woods (2010)
Intention-to-treat analysis (to overcome potential bias)	Yes	Not required	Not reported	Yes	Not required

<sup>†</sup>No outcome was reported for family or care staff for any of the studies included in the table.

CDR: Clinical Dementia Rating; CRAI: Copper Ridge Activity Index; MMSE: Mini-mental state examination; NPI: Neuropsychiatric inventory; QoL-AD: Quality of Life in Alzheimer 's disease; SD: Standard deviation.

## Discussion

This systematic review has investigated the impact of individual reminiscence work with people with dementia. Although only a small number of RCTs were identified, there is a consistent pattern that emerges, suggesting that it may be necessary to specify clearly the nature of reminiscence work undertaken. Individual reminiscence work that includes a life review process, uses specific memory triggers and results in the production of a life story book has been associated in three trials with outcomes suggesting psychosocial benefits for people with dementia (Haight et al., 2006; Lai et al., 2004; Morgan & Woods, 2010). The effects appeared stronger in the two (smaller) trials that made use of a structured life review protocol (Haight et al., 2006; Morgan & Woods, 2010). On the other hand, the two trials where a more general form of individual reminiscence was used did not provide evidence for the efficacy of this approach (Haslam et al., 2010; Politis et al., 2004). In one of these (Haslam et al., 2010), the results suggested that a group approach might have advantages in terms of cognitive function, with a social activity group having a more positive effect on well-being and quality of life than either individual or group general reminiscence work, whereas the findings of the other (Politis et al., 2004) lend support to a more personalized form of individual work, including reminiscence.

These findings are consistent with the person-centered care approach (Kitwood, 1997). This involves recognizing a person with dementia as a unique individual. It requires individualization or personalization in caring for and working with a person with dementia. It promotes values including freedom of choice, sharing and working together, effective communication, building good relationships, focusing on a person's strengths and recognizing the importance of the person's biography, which shapes and influences their current presentation.

An individualized or personalized reminiscence approach that caters for specific needs, preferences and interests, is more likely to support personhood and promote well-being.

The three studies included in this review that offered a reminiscence activity specific to the person (Haight et al., 2006; Lai et al., 2004; Morgan & Woods, 2010) fit well with a person-centered approach. A distinct objective of individual reminiscence work is to promote

personhood and person-centered care (Haight et al., 2006). A scripted, standardized, mechanical approach may well miss the mark in terms of quality-of-life benefits (Politis et al., 2004).

### *Life review process*

There has been a growing research interest in life review as a therapy with older people with dementia and memory difficulties. Kasl-Godley & Gatz (2000) reviewed reports indicating that reminiscence and life review provide those with mild-to-moderate stage dementia with interpersonal connections. Kunz (2002) noted that reminiscence and life review approaches have been successfully incorporated into treating older adults with dementia and a wide variety of methods have been developed and applied. Haight et al. (2003) report a study of life review involving family caregivers. People with dementia who actively participated in the life review process showed a slight decrease in their cognitive function, although a significant improvement in caregiver ratings of their mood was noted. Decreased burden and behavior problems were reported by the family caregivers, irrespective of whether the person with dementia had been an active participant in the life review process. In a further study of people with moderate Alzheimer's-type dementia living in institutional facilities, participation in life review therapeutic activities was associated with reductions in disorientation, fear and anxiety, and improvements in memory, social interaction and perceived self-worth (Tabourne, 1995).

Doubts have been expressed, however, as to whether cognitive impairment may make it difficult for a person with dementia to undertake a life review process owing to the demands on cognitive capacity and emotional engagement (Woods, 1996). Although Haight et al. (2006) recommend life review as a low-cost, low-risk, brief intervention capable of producing substantial results, on the other hand, Morgan and Woods (2010) observed and highlighted some important issues in using life review as a therapeutic tool. They reported that not all participants progressed at the same speed on the LREF as intended, with some participants needing to spend more time at certain stages. Also, there were difficulties in continuity between life review sessions due to participants' inability to recall material from the previous session. This is where the printed life story book proved invaluable in 'bridging' from the previous session. Accordingly, life review needs to be flexible according to the 'person's cognitive abilities, emotional needs, preferences and coping strategies'.

### *Life story books*

The idea of life story books or 'This Is Your Life' type scrapbooks was developed in childcare work (Gibson, 2006) and it has been argued that the creation of life story books could also be beneficial for people with dementia (Parker, 1995). Parker (1995) argues that in order for the person to maintain a sense of continuity he/she needs to be able to recall what has come before. For the person with deteriorating memory, the life story book may provide a tangible reminder of their life experiences and personal history. Haight et al. (2003) suggests that the story book should be based on the life review, as a tangible outcome of the life review process. The story book itself is created by the person with dementia, using their own choice of pictures, props and words. It is a recognizable piece of life that belongs to the person for at least a little while longer, a reflection of their own identity.

The life story book is then the person's own personal, illustrated record of their life story, compiled in the way they wish to narrate it. The person alone holds full control over selecting items to be included in the book. The role of family members and other carers is to provide assistance in completing the life story book by suggesting pictures or events to be included. Even a very close relative cannot tell the person's own story. Although books created by relatives may prove to have value in themselves, they should be seen as distinct from books emerging from a life review process.

In a systematic literature review of life story work in health and social care, including 51 papers, McKeown et al. (2006) reported that evidence on the use of life story work is immature and recommended far more research. However, it was evident that there are some potential far-reaching benefits of life story work in health and social care practice. Moos and Bjorn (2006) conducted a review on the benefits of life story as an intervention for people with dementia in institutional care, and called for more qualitative research to understand the potential of life story work. In the current review, two studies described the creation of a life story book along with a structured life review process (Haight et al., 2006; Morgan & Woods, 2010). Although both studies report the combined effect of the life review and the life story book, Morgan noted anecdotally that residents appeared to be uplifted by having the life story book at the end of the life review, and by the reaction received from family, friends and care staff (Morgan & Woods, 2010). This might help explain why in this study mood continued to improve in the follow-up period after the life story book had been completed and given to the resident. This raises the possibility that it is the life story book that is the major therapeutic vehicle, in relation to mood and potentially quality of life, rather than the life review process

*per se*. The life story book might also assist in maintaining autobiographical memory. Further research is needed to explore the usefulness of life story books for people with dementia, and the effects they may have on relatives and care staff.

### *Multimedia presentation*

An increasing amount of research has focused on applying reminiscence work/therapy using multimedia computer systems with people with dementia and caregivers. According to Gowans et al. (2004), the current traditional methods of conducting reminiscence therapy are time consuming, requiring planning and organization, and elicit varying degrees of success [35]. It can be repetitive and stressful for those involved. In the Computer Interactive Reminiscence and Conversation Aid (CIRCA) project reminiscence materials were presented on a touch-screen interface, which was used in care facilities to stimulate conversation among participants from the local city (Gowan et al., 2004). Materials in this interactive storytelling device were not personalized and contained several decades of public materials of the local city. The results were interpreted as showing that a multimedia conversation aid can contribute significantly to ‘quality of life’ in dementia care environments.

Lately, the majority of information and communication technology (ICT)-based reminiscence systems focus on a personalized approach that parallels specific reminiscence (Subramaniam & Woods, 2010). For example, Massimi et al. (2008) developed a highly personalized ‘biography theater’ for an 84-year-old person with Alzheimer’s disease. Improvements were demonstrated on apathy and positive self-identity, but not on tests of autobiographical memory, anxiety, depression and general cognition. The research team suggested that interdisciplinary work involving “off the desktop” computing technologies may be a fruitful way of providing rehabilitative benefits for individuals with Alzheimer’s disease. Another personalized multimedia biography using DVDs was tested with individuals with mild cognitive impairment and Alzheimer’s disease and their families. The intervention stimulated enjoyable memories for the participant, and family members expressed satisfaction that it promoted conversation regarding past events (Cohene et al., 2006). Sarne-Fleischmann and Tractinsky (2008) reported that a personalized multimedia system for reminiscence therapy in Alzheimer’s patients promoted conversations and evoked personal memories, with a preference being shown for personal over general material when both were available from the multimedia system. Yasuda et al. (2009) highlighted the effectiveness of

personalized reminiscence photograph videos for individuals with dementia. Now, the feasibility of using ICT in reminiscence work for people with dementia is beginning to be established (Subramaniam & Woods, 2010) and ICT-based individual reminiscence work is another option for the implementation of individual reminiscence work with people with dementia.

This review highlights the need for rigorous research to keep pace with clinical developments in the dementia care field. The evidence base for such a popular approach remains remarkably limited. There is a need for careful analysis of the components of any intervention program that is evaluated. We have seen that it cannot be assumed that all forms of reminiscence work are identical or will have similar effects. There is also a need to evaluate the effects, not only on people with dementia, but also on family carers (Haight et al., 2003) and on care staff (Gudex, Horsted, & Jensen, 2010)

#### *Recommendations for future research*

There are some key points from the current review that should be addressed in future research. First, ensuring the quality of the implementation of reminiscence work is vital in studying its effectiveness with people with dementia. Training from reminiscence experts (e.g. Haight et al., 2006; Morgan & Woods, 2010) with weekly supervision and ongoing training may help in implementing reminiscence work of high quality. Procedures for evaluating the quality of work undertaken need to be built into future projects and research undertaken on the best forms of training, supervision and support.

Second, the selection of appropriate outcome variables and measures is also important. These need to reflect the aims of the intervention, be appropriate for people with cognitive impairment and sensitive to change (Moniz-Cook et al., 2008). Mood has been a popular outcome, and self-report measures may be especially appropriate for people in mild-to-moderate dementia. For cognition, although the MMSE is widely used, the rationale for this is not clear. Measures of autobiographical memory may be more appropriate for this intervention (e.g., the Autobiographical Memory Interview, Morgan & Woods, 2010). Well-being and quality of life are also highly relevant variables and a number of self-report measures are now available (Moniz-Cook et al., 2008).

Third, none of the studies included in this review made use of measures to assess the impact of reminiscence work on family members and care staff. In a study of group reminiscence work, Baines *et al.* studied the effects of reminiscence work on care staff by asking the staff questions regarding their background knowledge of the residents involved, on the basis that reminiscence work should serve to increase staff knowledge of each person as an individual, and so contribute to a culture of person-centred care (Baines *et al.*, 1987). Future research studies should look at a range of effects, and not simply focus on changes in the person with dementia.

Fourth, the current review included three studies (Haight *et al.*, 2006; Haslam *et al.*, 2010; Politis *et al.*, 2004) that employed pre- and post-intervention measurements, without a follow-up assessment. Two studies (Lai *et al.*, 2004; Morgan & Woods, 2010) included 6-week follow-up measurements. Lai *et al.* (2004) reports no significant effect at the follow-up stage, including on a well-being measure that showed significant effects at the immediate post intervention assessment. Conversely, Morgan and Woods report significant results at the 6 weeks follow up on measures of depression and autobiographical memory (Morgan & Woods, 2010). They suggest that tangible outcomes of reminiscence work, such as life story books and memory boxes, may prolong the effects of reminiscence and act as a maintenance tool for people with dementia. Future studies should carefully consider the time scale of improvements, both in the immediate and longer term.

#### *Expert commentary*

Reminiscence work is a popular psychosocial intervention for people with dementia, but research has not kept pace with developments in practice. Individual approaches, such as life review and life story work are being widely used, but little is known about their effects. There is now a small body of evidence suggesting that carrying out a life review with a person with dementia, culminating in the production of a life story book, is associated with improvements in cognition and well-being. It appears that less personalized reminiscence work on a one-to-one basis, which does not use memory triggers (such as photographs and artifacts) that are of specific relevance to the person, has relatively little benefit. More studies are required to evaluate the different components of the life review/life story book approach, and to examine the role of relatives and paid carers in this process. There may be potential positive outcomes for them, as well as for the person with dementia.

### *Five-year view*

In 5 years' time it will be commonplace for people with dementia to have a digital life story, including favorite music, photographs and video clips. There will be a touch-screen interface for the tool. The problem will be how to organize the wealth of available material in such a way that the person can use the tool to stimulate their own memories and to share something of their life with others. If this can be addressed, this tool will enable care workers to quickly get to know the person with dementia, and to develop programs of activity and stimulation that reflect the person's interests and passions. This has the potential to take forward person-centered care to a higher level, with care workers being able to have more effective means of adopting an approach that takes into account the person's biography.

### *Key issues*

- Reminiscence work is a popular psychosocial intervention in dementia care, which uses a variety of memory triggers to stimulate past memories.
- Numerous types of reminiscence work have been identified, with a variety of functions and goals. Reminiscence groups are commonly described but more individual approaches are emerging.
- Individual reminiscence work lends itself to both integrative reminiscence, making sense of life through a life review, for example, and narrative/informative reminiscence, sharing stories and events, and knowledge from the person's experience.
- Five randomized controlled trials of individual reminiscence work were identified with people with dementia – all were nursing or care home residents.
- Studies where a life review was undertaken, working chronologically and evaluatively through the person's life, creating together a life story book, reported positive benefits in cognition and well-being.
- Where reminiscence work was less personalized, and memory triggers less specifically relevant to the person, there were fewer indications of benefit.
- Life story books are now being developed in multimedia formats.
- The results support the importance of person-centered care, where interventions are individualized and the importance of the person's biography is recognized.



Chapter 3: Life review and life story books for people with mild to moderate dementia: A randomised controlled trial

## Summary

Reminiscence work is a popular psychosocial intervention for people with dementia. The primary purpose of the present study was to evaluate the effect of different pathways for developing a life story book for people with dementia. Secondary aims included an evaluation of the effects of a life review process, and of the effects of life story books on the quality of relationship between people with dementia and their relatives and on staff knowledge and attitudes towards the person with dementia. In this preliminary randomised control trial, 23 older adults with dementia living in care homes (mean age 86) were randomly assigned into two groups. The first group received 12 sessions comprising an individual life review process, co-creating a life story book. The second group received, as a 'gift', a personal life story book created by their relatives. Outcome measures included the Quality of Life (QOL-AD) scale and Autobiographical Memory Interview – Extended version (AMI-E). Participants were assessed at baseline, after 12 weeks (when the life review was completed for those in this condition) (follow-up 1) and 6 weeks later, during which time both groups had had their own life story books (follow-up 2). Analysis using ANCOVA, with baseline scores as a covariate, showed no difference in quality of life between the two groups at the follow-up 2 assessment ( $F(1,20)=0.08, p=0.77$ ). Quality of life had improved for both groups at follow-up 2, but there was a significant difference in quality of life between participants in the life review group and the gift group at the follow-up 1 assessment ( $F(1, 20) = 5.11, P<0.05$ ), in favour of life review. The gift group then showed a significant improvement in quality of life subsequent to receiving the book as a gift immediately after follow-up 1. A similar pattern was observed on the AMI-E and its subscales, with the life review group improving significantly more than the gift group between baseline and follow-up 1, but the balance being redressed between follow-up 1 and follow-up 2. After the life story books were produced – by either pathway – there were significant improvements at follow-up 2 in the quality of relationship as rated by relatives ( $F(2, 39)=19.37, p<0.001$ ) and in care staff knowledge regarding the person with dementia and in care staff attitudes to dementia. These findings suggest that whilst life review leading to a life story book does result in improved quality of life and autobiographical memory, a book created for the person by relatives also has beneficial effects, and that life story books can have a positive impact on relatives and staff. The creation of life story books – through either pathway - appears to be a valuable therapeutic approach to assist people living with dementia in care homes. Three case vignettes provide supportive qualitative evidence.

*Keywords:* Reminiscence, Dementia, Life Review, Life Story Book, Staff and Relatives

## Introduction

A recent systematic review suggests that individual reminiscence work, using a life review or life story process, shows potential psychosocial benefits for people with dementia (Subramaniam & Woods, 2012). Benefits reported include enhanced well-being (Lai, Chi & Kayser-Jones, 2004); improvements in mood and some components of cognitive function (Haight, Gibson, & Michel 2006; Morgan and Woods 2010); and reductions in disorientation and anxiety and improvements in self-esteem, memory and social interaction (Tabourne, 1995). The use of a life review process to develop a life story book appeared to be associated with the most positive results with people with dementia (Haight et al 2006; Morgan and Woods, 2010) and the review concluded that this approach merits further exploration.

Garland & Garland (2001) describe life review as a highly structured form of reminiscence, which allows the participant to ascribe meaning and value to his/her life, and to come to terms with uncomfortable issues. A definition is provided by Woods, Spector, Jones, Orrell & Davies (2005): “Life review typically involves individual sessions, in which the person is guided chronologically through life experiences, encouraged to evaluate them, and may produce a life story book”. A life review process then helps a person with dementia to recount and evaluate his or her life history in chronological order. The process can be represented in tangible form as a life story book, photo album, scrap book, memory box or memory book.

Initially life story books or scrapbooks were created for work with children in care before the concept was adapted for older adults (Gibson, 1994). Life story books are now very popular in the dementia care field, and in 2011 in England the Department of Health provided the funding to train 500 people to carry out life story work with people with dementia (see [www.lifestorynetwork.org.uk](http://www.lifestorynetwork.org.uk)). Life story books have the potential to act as a tangible self-reminder and help to maintain a sense of continuity for people with memory difficulties.

A key area of uncertainty in this field relates to whether a life story book can be created for a person with dementia without the person’s engagement in a life review process. Family members may often create a ‘This is your life’ book for their relative, combining photographs and words, and various templates are available to assist with this. For example, Dementia UK provides a life story template with associated guidance (see [www.Dementiauk.org](http://www.Dementiauk.org)). Such a book may be presented as a gift to the person, a tangible reminder

of memories across the life-span. Where the person has a severe cognitive impairment, involvement in life review may not be feasible, and this may be the only option. Given that the life review process can be time-consuming, and require input from trained, skilled and supervised practitioners, the question must be posed as to whether the combined life review / life story book approach has added value compared with the simpler process of producing a life story book with family members that may be given to the person as a gift.

Haight et al (2003) has emphasised the important role of the person with dementia in having editorial control and decision making power throughout the process of developing the book, with the life review and creation of the book proceeding hand in hand. However, Morgan and Woods (2010) noted that it appeared that improvements in mood were associated with the period after the completion of the book, with reports from participants emphasising the value they placed on the book per se. The principal aim of the current study is to seek to address this gap in our knowledge regarding life review and life story books, and, for the first time, examine whether a life story book produced without a life review process has equivalent benefits to the combined approach that has previously been shown to have therapeutic benefits.

The two previous studies on the combined life review / life story book intervention (Haight et al, 2006; Morgan & Woods, 2010) reported positive outcomes in comparison with treatment as usual controls, in relation to mood and aspects of cognition, but did not evaluate self-reported quality of life directly. The current study additionally aims, in its first phase, to evaluate the effects of the combined approach on quality of life in people with dementia, in comparison with people with dementia receiving usual care.

Woods et al (2005) recommend that outcomes for family members and other caregivers also be evaluated in studies of reminiscence work. We hypothesise that the close involvement of relatives in the 'gift' group in the production of the life story book will lead to an improvement in the quality of relationship between the relative and the person with dementia after the book has been presented. A previous study (Baines et al, 1987) has shown improvements in care staff knowledge regarding residents' personal details following group reminiscence work. We hypothesise that having access to residents' life story books will improve care staff knowledge and also be associated with improved attitudes to people with dementia, reflecting person-centred care, irrespective of whether the book was produced by the person with dementia or their relative.

The research questions addressed by this study may accordingly be summarised as follows:

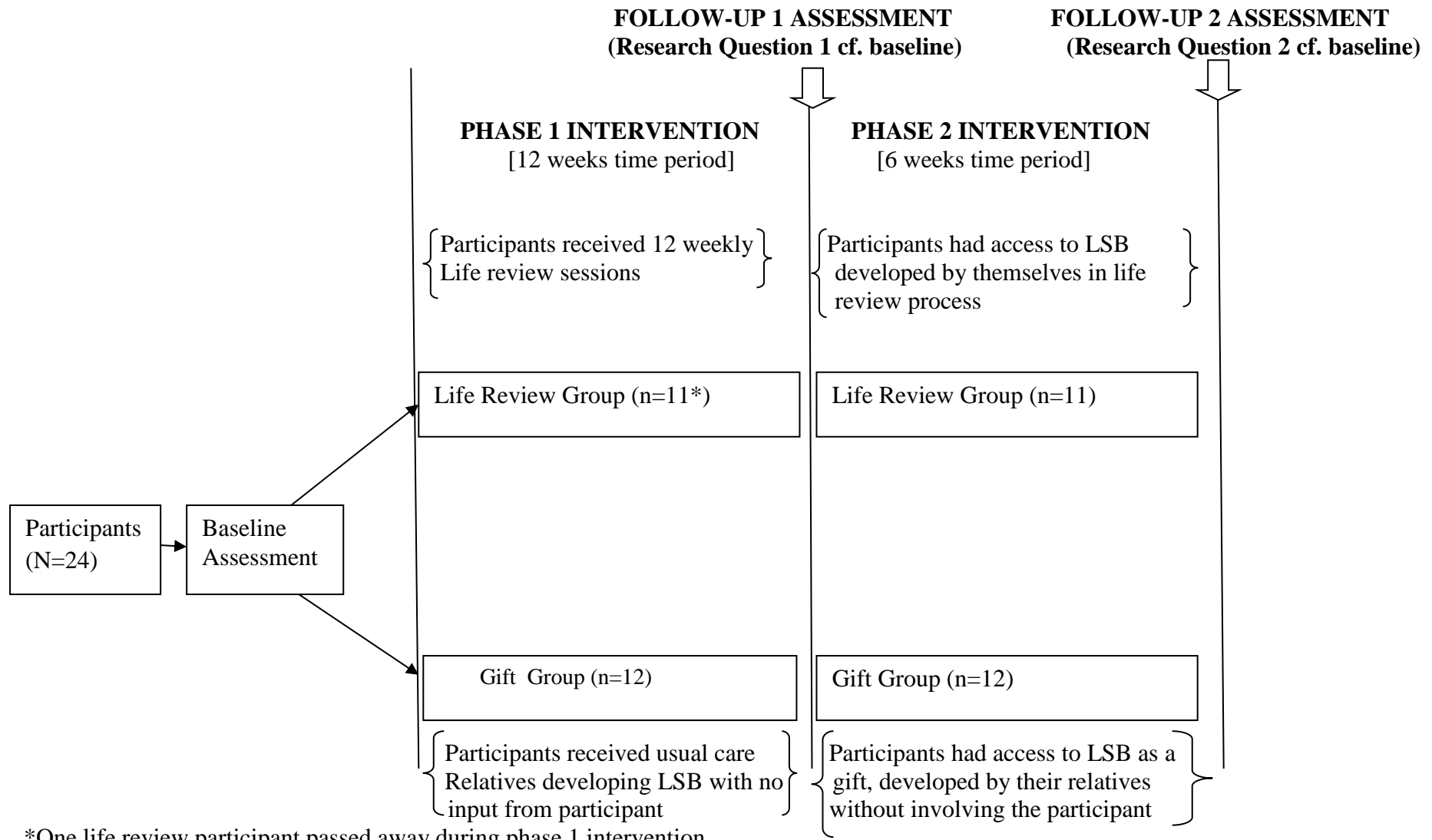
1. Does a life review intervention, resulting in a life storybook, have a positive effect on quality of life (primary outcome), mood, and autobiographical memory among older adults with dementia living in care homes compared with care as usual?
2. Does a life story book produced through a life review process improve quality of life (primary outcome), mood and autobiographical memory among older adults with dementia living in care homes, when compared with a life story book produced for the participant without their involvement?
3. Does involving a relative in the production of a life story book for a resident with dementia lead to improvement in the quality of their relationship as perceived by relative and resident?
4. Does providing a life story book for a resident with dementia lead to changes in staff knowledge and attitudes?

## Method

### *Design*

This was a preliminary randomized, single blind controlled trial, with two parallel arms, assessed at 12 weeks ('Follow-up 1' - primary time-point for research question (1) and 18 weeks after baseline ('Follow-up 2' - primary time-point for research question (2) (see Figure 1). The life story book was developed over a period of 12 weeks either involving the person with dementia (Life review group) or without involving the person with dementia (Gift group). A six week follow-up period was chosen pragmatically to give enough time for the life story book to be used and shared with family and staff, whilst minimizing the risk of attrition. This is a parallel time-scale to that used in Morgan & Woods (2010) study.

**FIGURE 1: Diagram of Research Design**



### *Sample size calculation*

Very few empirical studies have been conducted regarding the effects of life review / life story books on the primary outcome variable used in this research (quality of life). We estimated that the effect size would be large, given that Morgan & Woods (2010) reported an effect size for depression of 1.29 in a very similar context. To detect an effect size of this magnitude with 80% power at a significance level of 0.05 would require 11 participants per group (Cohen, 1988). The original target was set at 34, to allow for up to 33% attrition, as this was a care home sample of advanced age. In the event, attrition was very low (see Figure 2), and so the achieved sample of 24 gave adequate power to detect a large effect size in terms of quality of life.

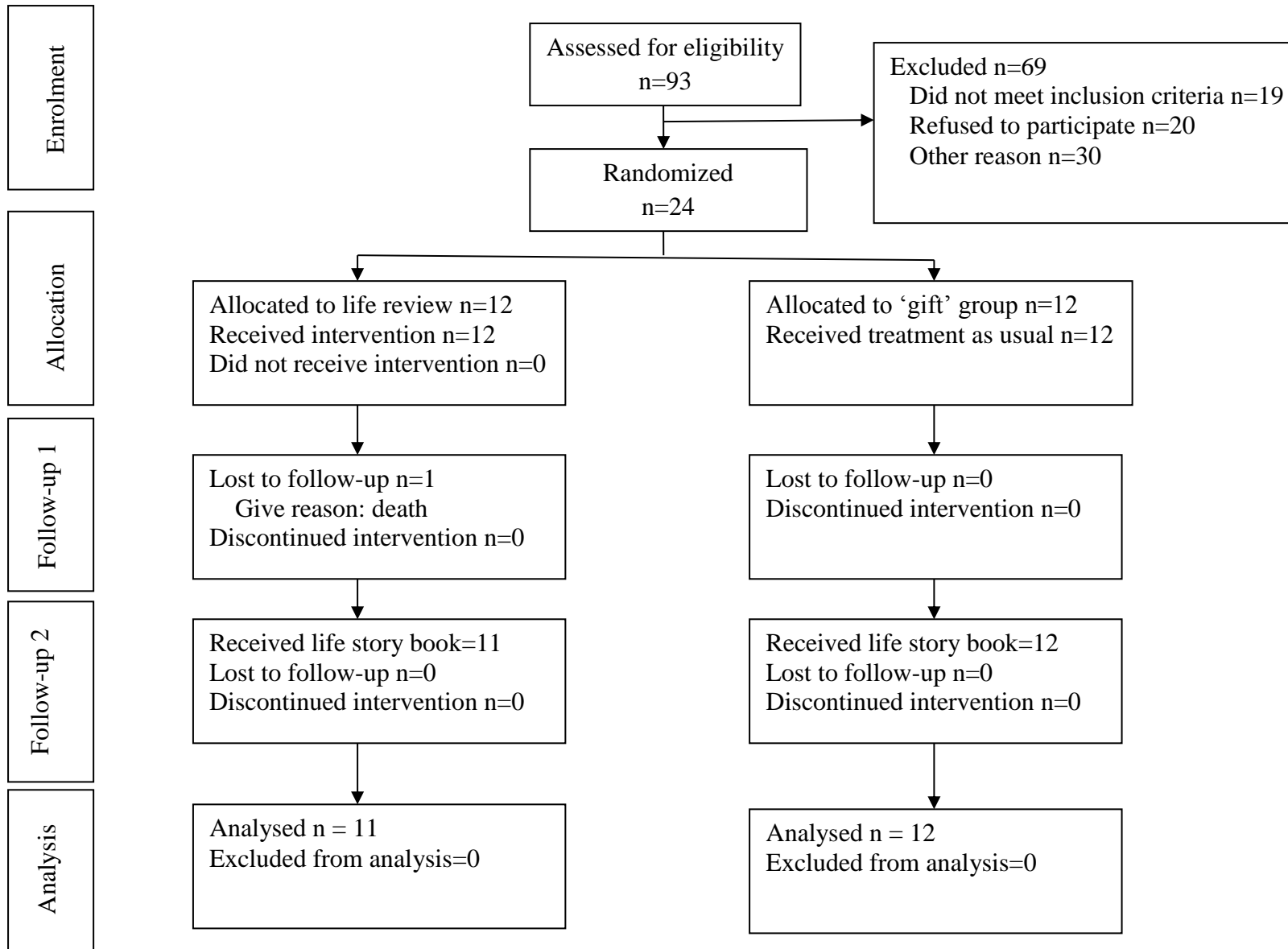
### *Participants*

The participants were all residents of care homes in North Wales (all but one privately owned). In total, 19 care homes were contacted and 14, with a total of 515 residents, agreed to an initial briefing meeting. Following this, the home manager or deputy manager together with the researcher scrutinized the list of residents at the care home to identify potential participants. The inclusion criteria for the study required the person to be a care home resident with a formal diagnosis of dementia, using the criteria from the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR) (APA, 2000), in the mild to moderate range. Degree of dementia was operationalized with the Clinical Dementia Rating (CDR) (Hughes, Berg, Danziger, Coben, & Martin, 1982). Participants were only included if judged to have mental capacity to give consent and had a relative willing and able to participate. Exclusion criteria included severe uncorrected impairment in vision or hearing, current or previous major psychiatric disorder and insufficient verbal ability in English to complete assessments. A total of 93 potential participants with a dementia diagnosis were shortlisted for further screening. Three care homes which had shortlisted 30 potential participants subsequently withdrew from the research. Ten potential participants' relatives did not agree to participate, being too busy or living too distant from the care home. Seven potential participants refused to take part in the research (e.g. 'not interested', 'tired', 'no time'), and three declined because they preferred to communicate through the medium of Welsh. Five potential participants were excluded as their dementia was rated as being severe, 4 in view of



psychiatric disorders (schizophrenia, bipolar disorder) and 4 due to speech impairment. Five potential participants became ill or died before baseline assessment and one did not have an available relative. Thus 24 participants from 9 care homes were eligible and entered the study (see Figure 2). The number of participants recruited from each of the 9 care homes ranged from 1 to 5.

Figure 2. Consort flowchart of study



### *Randomization*

Participants were allocated, following baseline assessment, to the two intervention conditions using a sequential individual based randomization, which randomizes participants into parallel groups using a dynamic stratification algorithm (Schulz, Altman & Moher, 2010). Each allocation aims to reduce any imbalance in the stratifying variables – in this case gender. Even when the sample size is small as in this case the method ensures approximately equal balanced groups. The entire randomisation process was carried out by the North Wales Organisation for Randomised Trials in Health & Social Care (NORTH), an accredited clinical trials unit.

### *Procedure*

This project obtained ethical approval from the School of Psychology, Bangor University and the North Wales NHS Research Ethics Committee before commencing with other research procedures. Data were collected from April 2010 until November 2011.

Participants were identified through a number of care homes around north Wales. Potential eligible participants were approached by the care home managers with an information sheet describing the project in order to ascertain whether they would be interested to discuss the project further with the researcher. The home manager also approached relatives to ascertain their opinion. Where both parties were in agreement, the researcher would proceed to screen the eligibility of potential participants in order to establish inclusion criteria and securing written informed consent from participants and their relatives.

After baseline assessments were completed, participants were randomly allocated to either the 'life review' group or the 'gift' group. Participants in the life review group received 12 individual sessions undertaking the life review process leading to the development of their own life story book. Meanwhile, participants' relatives in the gift group worked over the 12 week period, without involving the person with dementia, developing with the researcher a life story book for their relative. After the follow-up 1 assessment at the 12th week after baseline, each participant received their own completed life story book, with the gift group receiving this as a surprise gift. Each life story book recounted the life story of the participant in chronological order, illustrated with pictures from their childhood until the current time at

the care home. Each page, story and picture was labelled clearly e.g. where, when, what occasion and so on. The life story books developed through life review sessions also contained quotations from the person with dementia matched with appropriate pictures. Some information and pictures e.g. school, church, car, and place of work were obtained from internet resources. On average each book consisted of 50 – 70 pages and three copies of the life story book were printed; 1 copy with professional binding was given to the participant, and copies with comb binding were given to the participant's relative and to the care home's staff. A further assessment (follow-up 2) was carried out 6 weeks after the participant had received the life story book.

### *Intervention*

The therapist (PS) was a qualified clinical psychologist from Malaysia undertaking doctoral studies in the UK. Clinical supervision was provided weekly with a consultant clinical psychologist (BW) with many years' experience of reminiscence work. Prior to implementing the life review work, the therapist undertook supervised training in group reminiscence work for 3 months and became familiar with the assessment tools to be used working with older adults with dementia living in the community as part of the REMCARE project (Woods et al, 2009).

### *Life review/life story book intervention*

The life review intervention was based on Haight's Life Review model and Life Review Experiencing Form (LREF; Haight, 1992a). The purpose of the LREF is to achieve consistency of the life review process between participants (Haight, 1988). As explained by Haight (1988), therapists do not have to ask all the questions on the LREF, but can follow the lead of the reviewer. The initial focus is on childhood and adolescence, and then family, home, and adulthood; the final phase addresses the summary portion of the life review. In this study an average of 12 sessions (range, 11 to 16 sessions) of life review over a 12 week period were needed to complete the process. Participants typically received an hour of life review work on a weekly basis. Some participants' sessions were briefer (e.g. 30 minutes) due to the person having difficulty in continuously engaging in the life review process. However, this was compensated for by having two sessions in a week. The summarising

aspect is considered important as it assists the person in evaluating and integrating life's events (Haight, 1988). The life story book was developed according to the progress of the life review process. Participants played an active and decisive role in creating their own life story book. After each life review session, the therapist would draft sections and edit the book to integrate previous information with new information to be checked and endorsed by participant. The therapist reviewed the contents of the book with the participant during the following session to finalize the contents according to the previous life review section. The therapist liaised with the person's family to obtain suitable photographs and memorabilia. The pictures and the draft life story book from the previous session were important tools in helping participants engage in the life review sessions. Basically the therapist's role in developing the life story book is primarily as 'secretary'.

#### *Life story book as gift intervention*

Participants in the gift group were not involved in developing their own life story book. The researcher worked closely with the participant's relative, meeting with them 5 or 6 times over the period of 12 weeks to develop a life story book, illustrated with photographs and pictures to be given as a gift for their relative.

#### *Measures*

The administration of all tests at baseline was carried out by the researcher (PS) face to face with each participant. The follow-up 1 and follow-up 2 assessments were carried out by two assessors who were blind to treatment allocation, and had no other involvement in the process of the research.

#### *Clinical Dementia Rating Scale, (CDR); (Hughes et al, 1982)*

The CDR was used to assess the severity of the person's dementia. The CDR scale is a clinician-rated dementia staging systems that tracks the progression of cognitive and functional deterioration, from 0 (healthy) through 0.5 (questionable dementia), 1 (mild dementia), 2 (moderate dementia) to 3 (severe dementia). The CDR scale stages are

determined on the basis of the presumed order in which specific cognitive and functional abilities are lost during the usual natural course of Alzheimer's disease (Rush, First & Blacker, 2008), combining information about changes in memory, orientation, judgement / problem solving and day to day function. The CDR has been reported to have good concurrent validity with other measures, good test-retest reliability and inter-rater reliability ( $r=0.89$ ) (Hughes et al, 1982). For this study, the CDR was rated after consulting the clinical records, feedback from staff, family members and from one-to-one interview with the participant.

*Quality of Life-Alzheimer's Disease (QOL-AD; Logsdon, Gibbons, McCurry & Teri, 2002)*

The QOL-AD is a 13-item questionnaire designed to provide both a self-report and a caregiver (proxy) report of the quality of life (QOL) of the person with dementia. To facilitate its use with cognitively impaired individuals, the QOL-AD uses simple and straightforward language, responses are structured in a four-choice format that is consistent across all questions, and all items are rated according to the person's current QOL. The QOL-AD takes an average of 10 minutes to administer in an interview format. Overall scores were computed for the self-reports by summing the 13 items, for a total possible score ranging from 13 to 52, with higher scores indicating higher quality of life (Logsdon et al, 2002). This tool has been reported to be valid and reliable when used with people with mild to moderate dementia in structured format (Hoe, Hancock, Livingston & Orrell, 2006; Thorgrimsen et al, 2003). Only the participant version was used in this study, as all participants were able to provide an account of their own quality of life.

*The Autobiographical Memory Interview, Extended version (AMI; Kopelman, Wilson & Baddeley, 1990; AMI-E, Woods et al., 2009).*

The AMI was developed by Kopelman et al (1990) as a semi-structured interview schedule with two subscales, the Personal Semantic Schedule (PSS) and the Autobiographical Incident Schedule (AIS). It was constructed to assess the recall of autobiographical incidents and of 'personal semantic' facts about the person's life across three broad phases of the life-span: 'childhood', 'early adult life', and 'recent' events or facts. Personal semantic memory refers to factual knowledge about a person's own past (e.g. addresses where lived, names of teacher

or friends or colleagues at work, etc.), and ‘autobiographical incidents’ to events recounted with descriptive richness and specificity in time and place (Kopelman, 1992). Kopelman et al (1990) reported inter-rater reliability correlations of 0.83 – 0.86 between testers. The extended version, AMI-E (Woods et al., 2009) has additional sections relating to the middle years of the person’s life to increase its relevance with older adults. Inter-rater reliability of the extended form was assessed alongside the current study with 25 people with dementia taking part in the REMCARE trial (Woods et al., 2009). Agreement (Pearson’s correlation) between raters ranged from 0.70 - 0.98 for the different sections. For the middle to late adulthood Personal Semantic Schedule the correlation between scores was 0.92 and for the middle to late adulthood Autobiographical Incident Schedule 0.90. Overall the inter-rater reliability was 0.97 for the AMI (extended) Personal Semantic Schedule and 0.91 for the AMI (extended) Autobiographical Incident Schedule. These results indicate that the AMI-E has good inter-rater reliability values consistent with Kopelman’s report (1990) for the original instrument.

*The Geriatric Depression Scale (Residential) (GDS-12R; Sutcliffe, et al, 2000)*

The Geriatric Depression Scale (Residential) was developed from the 15 item version of the Geriatric Depression Scale (Sheikh & Yesavage, 1986) to measure depression levels in older adults in residential settings. The GDS-12R has greater internal reliability than the 15-item version. According to Sutcliffe et al (2000), the GDS-12R provides researchers with a brief, easy-to-administer depression scale that is relevant to residential and nursing home populations.

*Quality of the Care-giving relationship questionnaire (QCPR) (Spruytte, Van-Audenhove, Lammertyn, Storms, 2002)*

This questionnaire seeks the view of the person with dementia of their relationship with their relative. The quality of care-giving relationship questionnaire consists of 14 items with 2 subscales, ‘warmth’ and ‘absence of conflict or criticism’ with internal consistency reported as 0.82 (Spruytte et al., 2002). The participant is required to respond on a 5 point likert scale from ‘totally disagree’ to ‘totally agree’ with higher scores on both sub-scales indicating

better relationship quality. The same questionnaire was also completed by the participant's relative evaluating their perspective of their relationship with the person with dementia.

*Approaches to Dementia Questionnaire, (ADQ); (Lintern, Woods & Phair, 2000)*

Staff attitudes were evaluated with the Approaches to Dementia Questionnaire (ADQ), which contains 19 likert style statements; each scored from 1 (strongly disagree) to 5 (strongly agree). This measure has been widely used to assess staff attitudes to people with dementia (e.g. Zimmerman et al, 2005). It comprises two sub-scales, derived from factor analysis, 'hope' and 'person-centred', and can be summed to form a total score. The hopefulness subscale consists of 8 items, reflecting a hopeful attitude to dementia, while the person-centred subscale consists of 11 items indicating recognition of personhood in dementia. Items are scored so that higher scores indicate more positive attitudes. Lintern (2001) reported Cronbach's internal consistency of .76 for Hopefulness, .85 for Person-centred care and .83 for total ADQ scores.

*Staff Knowledge of Care-Recipient Questionnaire*

This questionnaire was developed specifically for this study to measure the knowledge of care staff about residents. It comprises 14 questions assessing the extent to which the staff member knows details regarding the participant such as his/her hobbies, favourite food, birth-place and school etc. Lower numbers of incorrect or 'don't know' answers indicated better knowledge.

The same set of measures was used at baseline, follow-up 1 and follow-up 2 assessments (see Table 1). The measures administered to residents to examine the intervention effects were QOL-AD, AMI-E, GDS-12R and QCPR. Relatives were also asked to complete the QCPR from their own perspective. Staff were asked to complete the ADQ and the Staff knowledge of Care-Recipient Questionnaire.



Table 1: Measures used according to time period and research questions

Measures	Time Period		
	Baseline	Follow-up 1	Follow up 2
<b><u>Research Question 1* &amp; 2**</u></b>			
Participant			
• QOL-AD	√	√	√
• GDS-12R	√	√	√
• AMI-E	√	√	√
• QCPR	√	√	√
Relative			
• QCPR	√	√	√
<b><u>Research Question 3</u></b>			
Relative			
• QCPR	√	√	√
Participant			
• QCPR	√	√	√
<b><u>Research Question 4</u></b>			
Staff			
• ADQ	√	√	√
• Knowledge	√	√	√

\*Comparing follow-up 1 scores with baseline scores entered as the covariate

\*\*Comparing follow-up 2 scores with baseline scores entered as the covariate

### *Statistical Analysis*

Baseline differences between the two groups on demographic variables were assessed with the Fisher's Exact test for categorical variables and independent samples t-test for continuous variables. One-way between groups analyses of covariance (ANCOVA) were used for the main analyses, with the baseline score on the corresponding outcome measure entered as a covariate (Vickers & Altman, 2001). Three variables, GDS-12R, AMI-E AIS subscale and QCPR's Conflict subscale rated by the resident did not meet the assumption of residuals being normally distributed and were transformed before entry into the analysis (Pallant, 2010). Square root transformation was used for GDS-12R, AIS-E AIS. The QCPR's Conflict subscale data were subject to a reflect and inverse transformation. Given the findings of the primary ANCOVA analyses (refer to results section) a secondary exploratory repeated measures analysis was conducted to examine changes over time in both groups. Repeated measures ANOVAs also were used to examine changes over time, with post-hoc comparisons using the Bonferroni correction, with relatives' data on the QCPR and the staff data on the ADQ and Knowledge Questionnaire. For staff data, between group comparisons were not carried out, as staff may have had contact with residents in both groups, and the hypothesis was not specific to the method of production of the life story book.

Research question 1 was evaluated by comparing scores between the groups at follow-up 1, using ANCOVA, with baseline as covariate, at the conclusion of the life review sessions. Research question 2, the effect of different approaches to the development of life story books, was evaluated by analysis of follow-up 2 scores, of the two groups using ANCOVA, with baseline as covariate. Research question 3 was evaluated by comparing scores at follow-up 1 and at follow-up 2, with baseline as covariate, on the quality of relationship scale rated by participants and relatives. Research question 4 was evaluated by comparing scores of care staff before the life story book was developed with those after residents with dementia had received their life story book.

## Results

### i. Demographic and descriptive results

Table 2. Summary of Participants' demographic information

Randomised Participants N = 23			
CHARACTERISTICS	Life Review Group (n=11)	Gift Group (n=12)	Fisher's Exact Test
	n (%) or Mean (SD)	n (%) or Mean (SD)	Statistics Sig.
Age	84.5 (6.7)	88.3 (6.0)	p=0.176 <sup>a</sup>
Gender			
• Male	n=3 (27.3)	n=4 (33.3)	p=1.000
• Female	n=8 (72.7)	n=8 (66.7)	
Marital Status			
• Married	n=3 (27.3)	n=2 (16.7)	p=0.640
• Widowed	n=8 (72.7)	n=10 (83.3)	
Length of Stay (Months)	26.5(9.0)	24.5 (10.2)	p=0.562 <sup>a</sup>
CDR			
• Mild	n=5(45.5)	n=6 (50.0)	p=1.000
• Moderate	n=6(54.5)	n=6 (50.0)	
Medication			
i. Antidepressants			
• Yes	n=3(27.3)	n=3(25.0)	p=1.000
• No	n=8(72.7)	n=9(75.0)	
ii Antipsychotics			
• Yes	n=2(18.2)	n=1(8.3)	p=0.590
• No	n=9(81.8)	n=11(91.7)	
iii Anxiolytics			
• Yes	n=1(9.1)	2=(16.7)	p=1.000
• No	n=10(90.9)	10(83.3)	

<sup>a</sup>Independent samples T-Test

A total of 24 participants were randomly allocated to the life review group or to the 'gift' group. However, one participant from the life review group died in week 7, having participated in 7 life review sessions. As no post-treatment data were available from this participant, data are presented for the remaining 23 who completed the study. Thus there were 11 participants in the life review/life story book group and 12 participants in the life story as gift group.

Table 2 summarises the demographic information on these participants. There were no statistical differences between groups in age, gender, marital status, length of stay, diagnosis and CDR tested by Fisher's exact test (categorical variables) and independent samples t-test (continuous variables). The mean age was 86.48 (standard deviation 6.48; range 73-99), 69.6% were female, 78.26% widowed and the mean duration of living in a care home was 25.30 months (SD 9.52; range 25-51). On the CDR, 47.8% were assessed as having a mild degree of dementia, with the remainder being in the moderate range. Psychotropic medication was being received by 30.4% of the participants, most commonly anti-depressants, with 13% receiving anti-psychotic medication.

The mean age of the 23 relatives who participated in the study was 64.65 (SD 10.74; range 44 -83); 15 relatives (65%) were female. On the relationship with person with dementia, 9 (39%) were daughter, 4 (17%) were son and the rest (43%) were made up of a variety of other relationships: nephew, brother, niece, son in law, wife, husband, daughter in law, sister and cousin.

The 68 care staff who participated in the study were predominantly female (91.2%) with a mean age of 39.04 (SD 12.20; range 20 – 64). Their mean length of experience working in care homes was 8.31 years (SD 8.79; range 1 to 40). In terms of qualifications, 9 (13%) staff had no qualifications 22 (32%) had achieved NVQ at level 1 or 2, 20 (29%) had NVQ at level 3 or 4 and 17 (25%) were educated to degree level. Only 3 (4%) were employed as registered nurses,

Research question 1: The effect of life review process compared with usual care (Table 3)

Table 3 Intervention outcomes: The effect of life review and life story book

	Baseline	Follow-up 1	n	ANCOVA	Follow-up 2	ANCOVA
	Mean (SD)	Mean (SD)		F (1, 20), p-value	Mean (SD)	F (1, 20), p-value
<b>QOL-AD</b>						
Life Review	30.1(8.5)	36.9(6.9)	11	5.11, p=0.04*	36.1(7.8)	0.08, p=0.77
Gift	35.7(2.5)	35.5(4.7)	12			
<b>+GDS-12R</b>						
Life Review	4.7(3.1)	4.3(3.7)	11	0.93, p=0.34	3.5 (2.7)	0.14, p=0.71
Gift	2.6(1.4)	2.5(1.8)	12			
<b>AMI-E</b>						
• PSS						
Life Review	31.0(19.7)	36.3(21.6)	11	14.01, p=0.001*	35.4(19.4)	3.98, p=0.06
Gift	36.7(15.5)	28.9(18.3)	12			
• +AIS						
Life Review	3.4(2.8)	8.2(8.2)	11	10.12, p=0.005*	6.6(5.4)	0.50 p=0.49
Gift	6.5(4.4)	5.8(4.1)	12			
• AMI Total						
Life Review	34.4(22.0)	44.5(28.5)	11	19.92, p<0.001*	42.0(23.5)	2.92, p=0.10
Gift	43.2(19.1)	34.7(21.3)	12			
<b>QCPR (participant)</b>						
• Warmth						
Life Review	32.4(1.0)	32.3(2.3)	11	2.56, p=0.13	33.5(2.3)	4.51, p=0.05*
Gift	32.2(1.0)	31.2(1.7)	12			
• +Conflict						
Life Review	23.5(0.8)	21.5(2.1)	11	0.43, p=0.52	22.0(2.1)	1.40, p=0.25
Gift	22.8(1.7)	22.3(1.2)	12			
<b>QCPR (Relative)</b>						
• Warmth						
Life Review	34.3(3.9)	35.2(3.7)	11	0.21, p=0.65	37.5(3.0)	0.08, p=0.78
Gift	34.8(4.6)	34.5(4.6)	12			
• Conflict						
Life Review	21.1(4.7)	22.3(4.1)	11	0.120, p=0.73	26.8(4.1)	0.03, p=0.87
Gift	23.3(3.3)	24.3(5.2)	12			

+Where assumption has been violated, variables were transformed to repeat ANCOVA analysis. However untransformed mean/SD reported.

\*Significant results

Table 3 shows the means and standard deviations for the QOL-AD, GDS-12R and AMI-E at each of the three time points. The results of the ANCOVAs at the end of the life review intervention and 6 weeks later are presented, in each case with the baseline score as covariate.

At follow-up 1, the primary outcome variable, QOL-AD showed a significant improvement in scores for the life review group, in comparison with the 'gift' group who were receiving usual care during this period ( $F=5.11$ ;  $df 1,20$ ;  $p=0.04$ ).

In relation to secondary outcomes, no significant difference was apparent on the measure of depression, the GDS-12R. However, there was a significant intervention effect on the memory test used, the AMI-E. This was evident on total scores ( $F=19.92$ ;  $df 1,20$ ;  $p<0.001$ ) and on the two sub-scales, the PSS and AIS, reflecting memory for facts and for events respectively. In each case, the scores of the life review group increased, whilst those of the usual care 'gift' group declined.

Research question 2: The effect of life story books produced by a life review process compared with life story books presented as a gift (Table 3)

To address this question, ANCOVAs were carried out comparing the effect of intervention group at the follow-up 2 assessment 6 weeks following the person having a life story book, with baseline scores entered as the covariate. There was now no difference between the groups on the primary outcome variable, QoL-AD. Therefore, an exploratory repeated measures analysis was carried out to examine the trajectory of change over time for the two groups. This indicated that there was a significant group x time interaction ( $F=4.19$ ,  $df 1.54,32.5$ ,  $p=0.033$ ). During the six week period following the gift group participants receiving their life story book, their quality of life mean scores increased 3.1 points ( $p=0.024$ ) compared with a reduction of 0.8 points ( $p=0.63$ ) for those whose books had resulted from a life review process. The receipt of a life story book produced either through a life review process or by the participant's relative is associated with increased quality of life among participants relative to the initial baseline assessment ( $p=0.007$ ).

Amongst the secondary outcome measures, there was no between group difference evident on the GDS-12R depression scale 6 weeks after receipt of the life story books. On the

AMI-E, the between group difference at the 6 week follow-up assessment was also not significant for total scores ( $F=2.92$ ;  $df 1,20$ ;  $p=0.10$ ) or either sub-scale. However, the exploratory repeated measures analysis again showed a significant group x time interaction (for total score,  $F=8.36$ ,  $df 2, 42$ ,  $p=0.001$ ). In each case the 'gift' group showed an improvement in score following the receipt of the book, whereas the life review group showed a small decrease. For total scores, the mean increase for the 'gift' group was 7.3 points ( $p=0.047$ ), compared with a reduction of 2.5 points for the life review group ( $p=0.46$ ).

Research question 3: The effect of life story books on quality of relationship as rated by participants and relatives (Table 3 & 4)

There was no between group difference on the relationship scales, rated by the participant or the carer at follow-up 1. At the follow-up 2 assessment, contrary to the hypothesis, relationship warmth, rated by the person with dementia, was significantly improved for those who had completed a life review process ( $F=4.51$ ;  $df 1, 20$ ;  $p=0.05$ ). No difference was apparent on the ratings of conflict in the relationship, or on the relative's ratings. Although there was no group x time interaction, the repeated measures analyses for the relatives' ratings of the relationship (Table 4) indicated that there was a significant effect of time ( $F=19.4$ ,  $df 2, 39$ ,  $p<0.001$ ), with relationship scores improving significantly at the follow-up 2 assessment compared with the baseline and follow-up 1.

Table 4: Quality of care-giving relationship (relative)

Measures	n	Time Period			ANOVA	Post hoc tests using the Bonferroni correction		
		Baseline (BL) (Mean/SD)	Follow-up 1 (FU1) (Mean/SD)	Follow-up 2 (FU2) (Mean/SD)		(BL vs.FU1)	(BL vs.FU2)	(FU1 vs.FU2)
QCPR: Total	23	56.83 (5.49)	58.17 (7.44)	65.13 (5.40)	F (2, 39) = 19.37, p<0.001	p=1.000	p<0.001	p<0.001
QCPR: Warmth	23	34.57 (4.18)	34.87(4.07)	37.74 (2.73)	F (2, 39) = 7.16, p=0.003	p=1.000	p=0.013	p=0.003
QCPR: Conflict	23	22.26 (4.11)	23.30 (4.74)	27.39 (3.23)	F (2, 35) = 16.21, p<0.001	p=0.764	p<0.001	p=0.005



Research question 4: The effect of Life Story Books on care staff attitudes and knowledge (Table 5).

A total of 68 staff directly involved as a carer for the resident with dementia took part. Of these, 65(96%) at time 1, 58 (85%) at time 2 and 52 (76%) at time 3 had completed the attitudes towards dementia questionnaire (ADQ). However, only 46 (68%) staff completed ADQ at all three point assessments. All 68 participants had completed the knowledge about resident with dementia questionnaires.

A one-way repeated measures ANOVA was conducted to compare scores on the ADQ scale and sub-scales and on the knowledge test across the three time points (Table 5).

Table 5: Care home staff attitudes and knowledge

Measures	n	Time Period			ANOVA	Post hoc tests using the Bonferroni correction p value		
		Baseline (BL) (Mean/SD)	Follow-up 1 (FU1) (Mean/SD)	Follow-up 2 (FU2) (Mean/SD)		(BL vs.FU1)	(BL vs.FU2)	(FU1 vs.FU2)
ADQ: Total	46	73.54 (10.50)	73.74 (9.23)	80.07 (8.65)	F (2, 74) = 14.31, p<0.001	p=1.000	p<0.001	p<0.001
ADQ: Hopefulness	46	26.72 (5.16)	27.00(4.88)	31.09 (5.55)	F (2, 84) = 19.38, p<0.001	p=1.000	p<0.001	p<0.001
ADQ: Person-Centred	46	46.83 (6.82)	46.74 (6.06)	48.99 (4.65)	F (2, 74) = 3.92, p=0.035	p=1.000	p=0.111	p=0.001
Knowledge: Correct	68	5.93 (3.77)	6.28 (4.14)	8.79 (5.31)	F (2, 120) =14.31, p<0.001	p=1.000	p<0.001	p<0.001
Knowledge: Don't know*	68	5.41 (3.68)	4.12 (3.33)	1.78 (2.25)	F (2, 115) = 31.65, p<0.001	p=0.025	p<0.001	p<0.001
Knowledge: Incorrect*	68	2.01 (2.37)	1.54 (1.83)	0.32 (0.68)	F (2, 119) = 24.88, p<0.001	p=0.273	p<0.001	p<0.001

\*As the score getting lower indicating improvement.

The ANOVA results indicated that the mean of each of the measures showed statistically significant differences between time points (see table 5). Post hoc tests (using the Bonferroni correction) showed that staff attitudes (ADQ total and subscales) towards the person with dementia did not change significantly before the life story book was completed (Baseline v follow-up 1). However, after the life story book had been available for 6 weeks staff attitudes had improved. Total scores and hopeful attitudes were significantly higher at follow-up 2 compared with initial baseline scores ( $p < 0.001$ ), and these scores as well as person-centred attitudes improved significantly between follow-up 1 and follow up 2 ( $p \leq 0.001$ ). Staff knowledge (in terms of number of correct and incorrect answers) similarly did not show significant change until the follow-up 2 assessment, where scores were improved compared with both the baseline and follow-up 1 assessments, although there were significantly less 'don't know' responses at the follow-up 1 time point ( $p = 0.025$ ). It appears that both staff knowledge and staff attitudes show significant improvement in the period when the life story book is available.

### *Case-study Vignettes*

In this section, three participants' experiences in taking part in the study are described, two of whom had developed a life story book through a life review process, with the other receiving it as a gift. All names used are pseudonyms.

#### Mary

Mary was an 80-year old widow with moderate dementia living at the care home for the past 30 months. Initially her sister, Jean, was reluctant to take part. However she agreed after Mary had shown interest in the life story book idea and Jean provided pictures and other tangible documents to illustrate Mary's life history. Mary was very engaged in most of the life review sessions. Her scores on the key measures are shown in Table 6.

Table 6: Mary's Scores on measures at three time points

Measures	Baseline	Follow-up 1	Follow-up 2
QOL-AD	31	38	43
GDS-12R	3	2	1
AMI			
• PSS	39	49.5	52
• AIS	4	9	11
QCPR (Mary)			
• Warmth	32	30	32
• Conflict	24	18	22
QCPR (Relative)			
• Warmth	29	32	32
• Conflict	15	23	16

During the life review process Mary expressed very rich information about her childhood life. Once she recounted her childhood difficulties;

“although I passed and qualified for the county school, I never got there because everything is too expensive...my father needed to look after my sister and brothers too...the County school needs special uniforms for different seasons...we couldn't afford that!”

Mary started to work at a young age to support her family. When asked about her first job as reported by her sister Jean, Mary corrected the information;

“I was a telephone operator with the post office for some years...many people don't know about that!”

One sad part of Mary's life was her husband's death after a few years of their marriage. Sometimes during the life review session she felt sadness about her husband's death. The life review process triggered many happy memories about her husband, greatly assisted by her wedding album, wedding invitation card and telegrams from relatives and friends which brought back many happy memories. Mary said;

“We had a very happy life...he died too soon...I wish he lived longer...little longer!”

Mary did not re-marry. She moved to live together with her parents and focused on her career.

“I'm always happy with my job...very nice job! Sometimes I replaced other telephonists if they had other things to do”

At the final session when the therapist asked about her overall life experiences and invited her to evaluate them, she replied;

“When I look back at my life (long pause)...I have no regret...all looks fine...I’m happy...no need to change anything...only one thing...my husband...he died...what can I do? Can we do anything? Overall I’m happy with my life”

At the assessment following the completion of the life review, carried out by an independent assessor, Mary’s scores on the QoL-AD had increased by 7 points, with a 10.5 point increase on the in PSS, and 5 points on the AIS. Mary’s GDS-12R score was below the clinical range (4 and over)at baseline and declined 1 point after the life review process.

After this assessment, Mary’s completed life story book was left with her and another copy presented to her sister. Jean’s reaction was;

“She (Mary) told all this to you (referring to quotations from life review sessions). Hard for me to believe...I thought she can’t remember all this. This is something great”

Mary expressed great pleasure with her life story book and she said she would keep the book in a very safe place as the book is very important to her. Six weeks later, she gained 5 more points on the QOL-AD, 2.5 more points on the PSS and 2 more points on the AIS. Her GDS-12R final score remained very low. Mary and Jean had a good relationship, which Jean rated slightly more positively at the follow-up assessments. Mary rated the relationship as being worse at follow-up 1, but this improved again at the final assessment. Overall, in Mary’s case, the book appeared to play a role as a maintenance tool after the completion of the life review process.

## Gwen

Gwen (aged 73) had been living alone after her husband passed away and then moved to residential care for the previous 27 months due to memory difficulties. She had a mild degree of dementia. She had no children but was regularly visited by her two sisters, who were very happy to assist Gwen in this project. They provided Gwen’s life history with many pictures covering Gwen’s entire life. When approached regarding participation one of her first reactions was;

“I worked in a pub for many years, I met many people...we always talk...I love to talk...sometimes too much (laughing)...I missed that...Now not many people to talk...at least I can talk to you”

Gwen liked to talk and positively engaged in the life review process. Most of the time, she would give responses at length for each question which triggered lots of her life experiences and important life events. Sometime it was quite difficult for the therapist to end each session as she always had something else to tell. When the therapist arranged for the following appointment, she would make sure that the therapist wrote the date in his diary so as to not forget! All her pictures together with the structured LREF helped Gwen to engage in the life review process in chronological sequence.

She spent a great deal of time talking about her childhood, her parents and sisters.

“My father was a wonderful man...lovely man...but with very little money...sometimes he gave money for me to buy sweets...“I love prawns and crabs....my father used to go fishing with his friends and he brought fish and crabs for us and sometimes prawns if lucky”

One of Gwen’s main life-time interests was poetry. She enjoyed reading some of her poems with the therapist and chose one of her favourite poems to be included in her life story book.

Whilst Gwen enjoyed her childhood and teenage years, she perceived her first marriage as a major setback in her life.

“When I look back at my life...I’m happy about my life. However my first marriage was horrible. The first 2 years of my 1<sup>st</sup> marriage were nice but after that things changed from bad to worse”

However she quickly substituted the memories of the failure of her first marriage with very pleasant memories of meeting her second husband.

“The best thing that ever happened to me in the world is meeting my husband (name)”

When asked ‘What do you think about life review?’ Gwen replied

“Oh wonderful! You bring back all my memories...nice to see them again!

Gwen’s scores on the key measures over time are shown in Table 7.

Table 7: Gwen's Scores on measures at three time points

Measures	Baseline	Follow-up 1	Follow-up 2
QOL-AD	37	43	40
GDS-12R	3	0	1
AMI			
• PSS	76.5	79	71.50
• AIS	8	27	10
QCPR (Gwen)			
• Warmth	32	34	33
• Conflict	24	23	24
QCPR (Relative)			
• Warmth	39	28	33
• Conflict	12	18	23

Gwen showed improvements in quality of life, depression and autobiographical memory following the life-review intervention, with a tremendous improvement on the AIS subscale of 19 points after actively taking part in the life review process. However, at follow-up 1, quality of life and depression scores had worsened slightly, although still better than at baseline. AMI-E scores had also fallen, with PSS lower than baseline, and much of the AIS improvement lost. The relative's ratings on the relationship scale show an interesting pattern with a reduction in warmth but also a reduction in conflict at the end of the life review. Six weeks later, at follow-up 2, warmth had improved again and the conflict scale showed further improvement. Overall, the book did not appear to maintain the initial improvements in this instance, perhaps because Gwen was physically less well during the follow up 2 assessment. However, she was pleased with her life story book and would become excited if someone sat and talked with her about her life story book.

## Nell

Nell was a 90 year old widow living in the care home for 2 and a half years. Her CDR rating was indicative of mild dementia. She loved to read, and enjoyed solving puzzles and crosswords. Nell agreed to be part of the project saying that she had nothing to lose by taking part. Her son was supportive in providing Nell's life story and pictures. In addition, a number of pictures were gathered from online resources. Nell was randomized into the 'gift' group.

Therefore, the researcher worked closely with her son and her daughter-in-law developing a life story book without any direct contact with Nell over a period of 3 months. However, her son did check the accuracy of some information, facts or/incidents with Nell without showing her the progressing drafted book. After the 12 week intervention period, one copy of the book was given to Nell as a gift, and one copy was provided for her son with another for the care home. The first reaction from Nell was,

“I was very pleased with my book...all about me!”

She was surprised with the gift and asked many questions, such as where the researcher had obtained her information and pictures. The researcher together with her son spent some time going through the book for the first time with her. Looking at each page, she read loudly, confirming the information in the book and also providing additional information that surprised her son. Her son and the home manager promised that they would spend time with Nell every time they had the chance.

In further feedback, Nell mentioned the book helped her to look back on her life.

“Now, I can see my life again...lots of good memories...the book triggers and stimulates my memory...nice to have one (the book)”

Nell’s son also said that he really enjoyed all the process of developing the life story book for his mother as a gift. The process helped him to reminisce, especially regarding his memories of his mother.

“I had a chance to revisit my life with my mother again...thank you so much!”

He agreed that the book helped his mother in recalling many life events in her life. He further added;

“The book helps me to spend quality time with my mother...Now we engage in meaningful conversation. Every visit she would tell me new information from the book”

All the feedback about Nell’s book is reflected in the key measures in Table 8.



Table 8: Nell's Scores on measures at three time points

Measures	Baseline	Follow-up 1	Follow-up 2
QOL-AD	38	37	41
GDS-12R	4	3	2
AMI			
• PSS	57	60	66
• AIS	14	14	24
QCPR (Nell)			
• Warmth	33	32	33
• Conflict	23	22	24
QCPR (Relative)			
• Warmth	33	32	37
• Conflict	25	25	28

Nell's life story book as a gift was associated with some positive effects. Her quality of life score improved 4 points after she received the book, and her depression and autobiographical memory scores also improved in the final time period. Nell's son reported an improvement in their relationship after he had presented his mother with the life story book as a gift.

## Discussion

This randomized controlled trial compared two different approaches to developing life story books with people with mild to moderate dementia living in care homes. The results are consistent with previous research (Morgan & Woods, 2010) in indicating that a life review process, resulting in a life story book, is associated with improved autobiographical memory, compared with usual care. Improvements were noted in both factual information and memory for events in the person's life. For the first time, improved quality of life has also been shown in this context. On the other hand, in contrast to previous work (Haight et al., 2006; Morgan & Woods, 2010), improvements in mood were not identified, This may be related to a 'floor' effect, with mean scores of participants being below the clinical range.

However, when the 'usual care' group were themselves presented with a life story book, prepared by a relative as a 'gift', differences between the groups in autobiographical memory and quality of life were no longer evident. The gift group's mean quality of life and autobiographical memory improved significantly following receipt of the book, whereas the mean scores of participants who had undertaken a life review did not appear to change.

Our hypothesis that the close involvement of the relative in the 'gift' group in producing the life story book would lead to an improvement in relationship specifically for relatives and residents in this group was not supported. There was a clear improvement in the relationship, as rated by the relative, irrespective of group, in the period when the life story book was available. Although relatives were not directly involved in producing the book for those in the life review group, they actively sought out photographs and memorabilia, and so relatives in both groups may have experienced increased engagement. However, the improvement only appeared to begin when the book was available, perhaps related to its role in increasing communication and enhancing interaction (Woods, Keady & Seddon, 2007).

Relationship ratings by the person with dementia showed less clear findings, being noted in the life review group in the period after the books were completed. This is paradoxical, in that this was the period when quality of life was not showing improvement for this group.

This research also demonstrated improvements in staff attitudes and knowledge after the life story book was available. This is an important finding because our earlier systematic review on individual reminiscence work (Subramaniam & Woods, 2012) indicated that, despite their key role in caring for the person with dementia, the impact on staff was rarely evaluated. For example, some individual reminiscence work (e.g. Haight et al, 2006; Lai et al, 2004) involved staff directly in the intervention process but the effects on them were not reported. Therefore, for the first time, improved staff knowledge and attitudes has been shown in this context. The current finding parallels the improvements in staff knowledge after engagement with group reminiscence work with older adults with dementia reported by Baines et al, (1987).

### *Limitations*

The major limitation of the present study was the small sample size, which reduces the generalizability of the findings, and leads to the risk of a Type II error, in that the study was powered for a large effect size, and so if there was a small to moderate difference between the groups this may not have been detected. Some of the variables have skewed distribution and non-homogeneity of data. This violated the assumptions to conduct ANCOVA and required transformations to be undertaken on the data before analysis could proceed.

The group was not equal at baseline on key variables, QoL-AD, AMI-E and GDS 12. At the beginning of the trial, all possible measures were taken to avoid bias in randomisation, using a randomisation method determined, set up and controlled by an independent accredited clinical trials unit. All the participants were strictly selected according to the inclusion criteria and data were only entered for analysis after all the participants completed the trial. Despite these measures, the intervention group had lower scores on these measures at baseline assessment despite there being no demographic differences between the groups. Of course, these differences were controlled for statistically, using analysis of covariance, but interpretation of the results would clearly be more straight-forward if the groups had been equivalent on key measures at baseline. It is worth highlighting that, stratifying the quality, or other features, of the care home was not possible with a sample drawn from 9 care homes with a range of 1 – 5 participants from each care home.

A further limit to generalizability was the use of a single therapist to provide all the interventions for both groups. The present study cannot indicate whether similar results would be obtained by different therapists. The current study also lacked an active control group. Improvements in the life review phase could be attributed to the social contact with and attention from the therapist.

Another notable limitation of the present research is a potential sample selection bias. Participants in the current research had depression scores, assessed using the GDS-12R, on average well below the clinical range from baseline to the end of the research trial. One possible explanation is that participants with a low level of depression were selectively referred to the project, perhaps being seen by the home manager as the best potential candidates from their home. This may have led to participants with less mood disturbance being included.

#### *Further research*

Further research is needed to replicate these findings with people with mild to moderate dementia, with larger sample sizes to overcome the limitations of the current trial. Multiple-sites and therapists following a common protocol would be needed. A longer follow-up period would also be of interest. The present study has suggested that the outcome measures used here are sensitive to change in this context, but economic evaluation would be required alongside a future trial.

The lack of an active control group in the current study means that it is not clear whether the life review sessions or social contact or both have contributed to the participant's improvement in QoL and AMI-E. Future research could clarify the mechanism of change. For example, Politis (2004) reported that participants in a control group who received one-to-one weekly social contact improved in quality of life compared with participants in a treatment group who received a standardized reminiscence activities kit. Conceivably, the present study results also may be influenced by social contact and may not be entirely due to the life review process per se. Therefore, it may be too early to draw conclusions about the absolute effects of the life review process. The future design could include a 'placebo' group to receive social contact, equal in terms of number of visits and time engaged in general

conversation as for the life review group. The need for having placebo for reminiscence work has been highlighted by Cotelli et al (2012).

The success of the life story books provides further encouragement for the development of alternative formats, including the use of digital media (Subramaniam & Woods, 2010). Further studies could consider comparing multi-media digital life story books with the conventional paper life story book.

### *Implications for practice*

The findings from this study add weight to the continued development and use of life story books. As well as any benefits for people with dementia, they have been shown in this study to improve staff attitudes and knowledge, underpinning person-centred care, and improve relatives' perception of their relationship with the person with dementia.

The structured life review process does appear to provide a clinical evidence-based therapeutic tool to promote psychosocial well-being with people with dementia living in residential setting. This research supports the benefits of this approach over 'treatment as usual' adding new empirical evidence to our existing knowledge of the usefulness of life review reminiscence work (Haight et al, 2006; Morgan & Woods, 2010). The developing life story book was found to be an essential component of the life review process with people with dementia, acting as a 'bridge' between sessions. The drafted life story book helped the participant to recall the previous session and continue to engage in progressing through the life review. In addition, the drafted life story book also appeared to help in building trust and a meaningful relationship with the therapist.

This study does not, however, indicate that life story books can only be developed through a life review process. Books prepared by relatives without the person's involvement were also associated with improved quality of life and autobiographical memory over the study period. Relatives can be encouraged to develop such books, especially where the person with dementia is less able to participate actively in the process. The findings support the hypothesis set out by Morgan & Woods (2010) that the life story book is an intervention in its own right.

Generally, dementia is seen as an irreversible progressive condition. Therefore psychosocial treatment may be seen as having very little benefit. However in this research, despite the progressive nature of dementia, persons with dementia showed they still had the ability to recall past memories and to experience improvements in their perceived quality of life. This provides an opportunity for care staff, activity officers and other professionals to use life review and life story book as a part of care activity to improve and maintain the quality of life, cognitive function and mood of individuals with dementia as long as possible. The clear difference that staff saw in people with dementia participating in the study could well have contributed to the improvements in hopeful attitudes regarding dementia, recognising that it was possible to make a difference. The emphasis on individual's life stories and experiences appeared to help staff to get to know residents better, and offers the potential for more individualised, person-centred care which recognises the importance of the person's biography (Kitwood, 1997).

The life story books appeared to have a significant impact on the participating care homes. Care home staff and relatives suggested that each resident should move in to the care home together with their own life story book. Even some of the senior management were surprised with the amount of new information they had gained from the life story books of the participating residents. Some of the care homes that took part in the present trial started to develop life story books for all their residents, integrating the life story book as part of the care programme.

Participants' relatives also experienced having accomplished something worthwhile and meaningful for the person with dementia. For example, some relatives reported that the book enabled them to spend quality time with the resident and reduced repetitive questions. Some relatives also made extra copies of the life story book for other significant family members. Some relatives started to develop a life story book for another older adult in their family. This approach provides a means for the relative to find constructive engagement with the person with dementia and the care home, which may be helpful in reducing some of the negative aspects experienced by many relatives in this position (Woods, Keady & Seddon, 2007). Encouragement to produce a book before the person enters a home would perhaps also be beneficial. The improvement in relationship noted in this study may reflect the life story book assisting the relative to re-establish contact and meaningful communication with the person with dementia. Relatives often describe a loss of relationship, and this approach may help redress this.

The life review process has the potential to evoke unpleasant memories as well as memories of happy times. In the present study, two broad categories of unpleasant or disturbing memories were observed. First, almost half of the participants shared sadness and grief over the loss of a loved one in their life, mainly the loss of a spouse or children. Secondly, a few participants shared memories of traumatic experiences including war experiences, physical violence, domestic violence and sexual harassment. This led to negative emotions during some life review sessions, including emotional upset, feelings of guilt, stress, sadness and anger. However in every case participants were able to cope and move forward in the life review process progress with continued support from the therapist. Participants chose, without exception, not to include any details of traumatic memories in their life story book, although many did comment on bereavements and losses in their books.

Based on this experience, we would suggest that working on a life review process should only be undertaken by a trained helper equipped with knowledge regarding the nature of dementia, Kitwood's person centred approach, cognitive processes, the life review model and, most importantly, person-centred counselling skills (Rogers, 1980). The trained staff needed supervision from a professional with expertise in the field as observed in Haight et al (2006) and Morgan & Woods (2010) studies. Where such training, supervision and expertise is not available, the current research suggests that the life story book can be developed satisfactorily by relatives for the person with dementia, although we would suggest that they present a draft version over which the person with dementia may exercise editorial control, rather than present the person with the 'finished article' as was the case in this study.

Overall, the present research provides some empirical evidence on the effects of the life review process and the creation of life story books with or without involving the person with dementia. Specifically, it has demonstrated that the creation of a life story book by a relative without involving the person with dementia may produce psychosocial benefit for people with dementia living in care homes. The life story books, however created, were viewed positively by participants, relatives and care staff. The creation of a life story book appears to be a valuable therapeutic approach to aid a person living with dementia.

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Chapter 4: Towards the therapeutic use of information and communication technology in reminiscence work for people with dementia: A systematic review.

## Summary

This article reviews key issues in relation to reminiscence work with people with dementia, and presents the findings of a systematic review of original studies on information and communication technology reminiscence systems and dementia published since 2000. Eleven studies were included in the review; most studies report preliminary or pilot work, with sample sizes ranging from one to 23. The feasibility of these systems is now well-established. Most systems comprise primarily personalised biographical materials, and these could be seen as a replacement for a life story book, which could be produced following a life review process. A few systems comprise more general material, and would lend themselves as memory triggers to enhancing conversation in small groups, or in pairs with care workers. Current reminiscence work with people with dementia is essentially interpersonal and social. The development of these systems offers some opportunity to explore the potential usefulness of private reminiscence work.

Subramaniam, P., & Woods, B. (2010). Towards the therapeutic use of information and communication technology in reminiscence work for people with dementia: A systematic review. *International Journal of Computers in Healthcare*, 1(2), 106 – 125.

## Introduction

The term dementia refers to a syndrome where a person develops global cognitive impairment, affecting day-to-day life functioning, in clear consciousness (Woods, 2005). The growing numbers of people with dementia have been well-documented (e.g., the UK dementia report – Alzheimer's Society, 2007), with a projected increase in the UK of over a third by the year 2021 and globally a doubling of the number affected every 20 years (Alzheimer's Disease International, 2009). These projections and their associated costs for governments, families and people who will develop dementia, provide a major incentive to test methods for maintaining and improving quality of life.

Although pharmacological treatments have received most attention, there is increasing evidence that psychological interventions may be equally effective. One of the psychological interventions widely used in practice and now receiving attention from researchers has been 'remembrance therapy' or 'remembrance work'. Although a large variety of therapeutic activities may be described as remembrance, typically, this involves the discussion of past activities, personally significant people, events and experiences, usually with the aid of tangible prompts (e.g., photographs, household and other familiar items from the past, music and archive sound recordings) (Woods et al., 2005). The Cochrane review on remembrance therapy for people with dementia (Woods et al., 2005) identified only four randomised controlled trials (RCTs) suitable for analysis. Each examined different types of remembrance work; all were small or of poor quality. The trials together identified significant improvements in cognition and mood four to six weeks after treatment, and stress in caregivers who participated with the person with dementia in a remembrance group. However, the review concluded that 'in view of the limitations of the studies reviewed, there is an urgent need for more quality research in the field'. Subsequent, larger, studies of remembrance groups in both institutional (Wang, 2007) and community settings (Tadaka and Kanagawa, 2004, 2007) report some positive findings in relation to cognition and mood. There does then appear to be potential for remembrance work to have positive outcomes with people with dementia.

### *Classification of reminiscence work*

It has been pointed out for many years that the term ‘reminiscence’ covers a variety of activities, with diverse modalities and objectives. A variety of taxonomies of reminiscence have been proposed over the last 30 years, delineating between two and eight types of reminiscence (e.g., Beaton, 1980; LoGerfo, 1980–1981; Romaniuk and Romaniuk, 1981; Kovach, 1991; Merriam, 1993; Watt and Wong, 1991; Webster, 1997). A fundamental distinction is between social and private reminiscence. Social reminiscence is more likely to be elicited by prompts and questions in conversation, by shared activities or a group setting (Cohen and Taylor, 1998). Private reminiscence may occur involuntarily, consisting of personal memories that become conscious with or without preceding intentional attempts at retrieval (Berntsen, 1996).

Coleman (1974) highlighted the differences between simple reminiscence, informative reminiscence and life review. He explained simple reminiscence as non-directed, relatively automatic, narrative recollection of past experiences as in day-dreaming. Puentes (2002) proposed a model of the phenomenon of simple reminiscence suggesting that it may in itself lead to positive outcomes but may also serve as an impetus for deeper self-evaluation of memories, in the form of life review. *Informative reminiscence* teaches and entertains others and may also be seen as storytelling which is reported to have a positive effect on adaptation because it provides a valuable social function in terms of oral history and enhanced self-esteem (McMahon and Rhudick, 1967). Transmissive reminiscence (Sellers and Stork, 1997) and narrative reminiscence (Pasupathi and Carstensen, 2003) similarly involve recalling past experiences and anecdotes for the purpose of sharing information or entertaining the listener.

Wong and Watt (1991) described *integrative reminiscence*, the function of which is to achieve a sense of self-worth, coherence, and reconciliation with regard to one’s past. Life review is a particularly structured form of integrative reminiscence, which draws on work by Butler (1963) and Haight (1988). According to Butler (1964) life review is a naturally occurring, universal mental process characterised by the progressive return to consciousness of past experience, and particularly, the resurgence of unresolved conflicts. The aim of life review may be conceptualised as helping the reviewer deal with Erikson’s (1950) final developmental stage of ‘integrity v. despair’. Life reviews are seen as a mechanism for older adults to resolve old conflicts in this final stage (Haight, 1988).

Integrative reminiscence is seen as contributing to the person's sense of identity and as involved in preparation for death (Webster, 1997). Integrative and related types of reminiscence are concerned with issues of life's meaning, coherence and continuity (Cappeliez et al., 2005). Integrative types of reminiscence have a greater intrapersonal focus, relating more to the inner self rather than having an interpersonal function and are said to be associated with healthy and happy aging (Wong and Watt, 1991).

*Escapist reminiscence* is characterised by a tendency to glorify the past and deprecate the present. It is also referred to as defensive reminiscence (LoGerfo, 1980–1981). Characteristic statements are those that boast of past achievement, exaggerate past enjoyments (with or without favourable comparisons with the present), or reveal a desire to return to the 'good old days' (Wong, 1995). Wong and Watt (1991) suggest that, like any form of fantasy, escapist reminiscence may provide instant relief from a painful present, but it may become maladaptive if prolonged and excessive to the point of engulfing one's waking hours.

*Obsessive reminiscence* was labelled by LoGerfo (1980–1981) and is evidenced by statements of guilt, bitterness, and despair over one's past failures. Wong and Watt (1991) viewed obsessive reminiscence as indicative of one's failure to integrate problematic past experiences, resulting in ruminations about these disturbing past events. McKee et al. (2005) showed that a high frequency of reminiscence characterised by regrets was associated with negative psychological health.

The reminiscence function scale (RFS) (Webster, 1997) focuses attention on the function served by the reminiscence undertaken. The functions identified include 'identity', which maps onto integrative reminiscence, and 'teach/inform', which parallels informative reminiscence. 'Reminiscence for conversation' refers to communicating personal memories in an interactional context with no evaluative or instructive intent, 'boredom reduction' refers to memories used to fill a void of stimulation or interest, whilst 'intimacy maintenance' involves keeping alive the memory of a significant other who is separated from the reminiscer, most typically on account of death. 'Reminiscence for problem solving' refers to bringing past experiences to mind in tackling present problems. 'Death preparation' refers to using memories to come to terms with one's finitude and finally, 'bitterness revival' pertains to ruminating on memories of difficult life circumstances.

Gibson (1994) distinguishes two approaches to the selection of memory triggers for reminiscence work: general and specific reminiscence. 'General' reminiscence work refers to well-prepared work that uses a variety of multisensory triggers to stimulate shared conversation on an agreed topic or theme which relates loosely to the known background and interests of the participants. 'Specific' reminiscence work refers to carefully selected triggers known to closely approximate the detailed life-history of the participant. Both approaches may be used in small groups or with individuals but 'specific' work is more easily managed with individuals.

From this discussion, a number of dimensions that will help describe the modality and function of any approach to reminiscence work emerge. These may be summarised as:

- Is the reminiscence private or social?
- Is the reminiscence work carried out with an individual or with a group?
- What is the function of the reminiscence work? The key distinction here is between integrative reminiscence work (life review) and informative/narrative/transmissive reminiscence work (story telling), but a number of other functions have also been identified.
- How specific to the individual are the memory triggers used?

### *Integrative reminiscence work and life story books*

Much reminiscence work in dementia care has been in group settings, and has had primarily a narrative, conversational function, enhancing communication and enjoyment in a social context. However, a strand of life review work can be identified. In the context of dementia care, Woods et al. (2005) stated that "Life review typically involves individual sessions, in which the person is guided chronologically through life experiences, encouraged to evaluate them, and may produce a life story book". The evaluation of experiences is key to the approach allowing the participant to ascribe meaning and value to his/her life, and to come to terms with uncomfortable issues (Garland and Garland, 2001), involving emotional processing of events in the individual's past (Hirsch and Mouratoglou, 1999).

Haight et al. (2003) reported that the mood of the person with dementia (as rated by the caregiver) was significantly improved for those people with dementia participating actively in the life review, although their cognitive function decreased slightly. Caregivers participating in the life review, alone or with the person with dementia, reported significantly reduced burden and fewer behaviour problems in the person with dementia. A study by Tabourne (1995) indicated that a life review therapeutic-activities intervention promoted memory, perceived social values of self, decreased disorientation, reduced fear and anxiety and improved self-esteem and social interaction among older adults institutionalised for moderate dementia of the Alzheimer's type. Haight et al. (2006) and Morgan and Woods (2010) have reported small scale controlled trials of individual life review work with residents of care homes. In both studies, improvements in mood and some aspects of cognitive function were noted, in comparison with residents receiving 'treatment as usual'. In both studies, for each resident undertaking a life review, a life story book was produced, under the editorial control of the resident, consisting of pictures and text setting out important aspects of the person's life in a broadly chronological sequence.

The notion of 'This is your Life' type scrapbooks has been adapted from child care work (Gibson, 1994) and is becoming popular among residential and nursing homes, although so far there is no standard protocol or guideline for the preparation of such a life story book. It has been argued that if life review can facilitate the older person's adaptation to the ageing process and to transitions in older adulthood, then the creation of life story books could be beneficial for people with dementia (Parker, 1995). Parker (1995) argues that in order for the person to maintain a sense of continuity the person needs to be able to recall what has come before and a life story book for the person with deteriorating memory may provide them with a tangible reminder of their lives and personal history. Haight et al. (2003) proposed a clear definition suggesting that the story book is based on the life review and is a tangible outcome of the life review process. The story book is created by the person, using the person's choice of pictures, props and words. It is a recognisable piece of life that belongs to the person for at least a little while longer and may serve as a legacy for the family after the person has died. The life story book is a pictorial reminder of an individual's life as directed by the individual. It is seen as essential that the book include the items the individual chooses as important to him/herself. Even a lifetime caregiver cannot direct the book because then it is not the story of the self, although the caregiver can usefully contribute by providing pictures and memorabilia from which the individual can select. Without the person's own

input, the book may be seen more as a memory aid, along the lines of those successfully developed and evaluated by Bourgeois (1990, 1992, 1993, 1996), McPherson et al. (2001) and Andrews-Salvia et al. (2003). Two reviews of life story work are available: McKeown et al. (2006) in a systematic literature review, across health and social care practice, including 28 papers, reported that evidence on the use of life story work is immature and recommended far more research but stated there are some potential far reaching benefits of life story work. Moos and Bjorn (2006) conducted a more specific review on the benefits of life story as an intervention for people with dementia in institutional care and called for more qualitative research to understand the potential of life story work.

### *New modalities of reminiscence work*

Low technology developments that are worthy of mention include ‘memory boxes’ (Schweitzer and Bruce, 2008), where a small display box is created with the person with dementia, capturing key aspects of their life in the form of images and objects. These boxes may be exhibited in or adjacent to the person’s room in a care home, or have pride of place in their own home in the community. However, most developments have related to the use of information and communication technology (ICT) to support reminiscence work with people with dementia, and there have been numerous conference presentations highlighting the potential of this approach (e.g., Kuwabara et al., 2004). It has been known for some time that people with dementia respond well to material presented via a computer, especially where response is through a touch-screen (Carr et al., 1986) and this has been utilised in cognitive training programmes (e.g., Hofmann, Hock, Kuhler, & Muller-Spahn, 1996).

The flexibility of ICT or computerised reminiscence work could result in improvements to traditional practice, being less demanding on staff or carer resources, and providing a more user-friendly interface than e.g., the traditional photograph album (Yasuda et al., 2009), with its small photographs and bulky nature. Mulvenna, Zheng, & Wright (2009) define reminiscence systems (RS) as the application of technology to facilitate reminiscence work. These range from basic multimedia reminiscence work incorporating video-tapes or DVDs to computerised reminiscence work including internet networking technologies. Systems have now been described with a variety of aims including: assisting reminiscence (Alm & O’Mara, 2001); facilitating the person with dementia and caregiver to conduct reminiscence therapy sessions (Sarnecki-Fleischmann and Tractinsky, 2008); as a



support system for reminiscence and maintaining episodic memories (Hallberg, Kikhia, Bengtsson, Savenstedt, & Synnes, 2009); helping to engage in meaningful conversation (Alm et al., 2003); prompting conversation (Yasuda, Kuwabara, Kuwahara, Abe, & Tetsutani, 2006); recollecting and reinforcing memory via multimedia family histories (Cohene, Baecker, & Marziali, 2004); and increasing engagement compared to traditional reminiscence (Gowans et al., 2004). The beginnings of multimedia based reminiscence work appear to be closely related to extensions of traditional reminiscence work such as scrapbooks or memory books (Mulvenna et al., 2009). Usually, this traditional tangible work is exported into multimedia systems to offer added value with better quality of vision and sound.

The present review aims to identify what has been achieved to date in terms of this innovative approach to reminiscence work with people with dementia. This work will be placed in the context of the broader literature on reminiscence work with people with dementia, seeking to identify the modalities and functions of the reminiscence undertaken.

## Method

Relevant studies were identified through searches of computerised literature databases (PsycINFO and MEDLINE), using combinations of the key words 'reminiscence', and 'dementia', 'life review', 'computer' and 'multimedia'. Hand-searches of the *International Journal of Social and Humanistic Computing (IJSHC)*, *Gerontologist*, *Neuropsychological Rehabilitation*, and *Journal of Robotics and Mechatronics* were also undertaken for the relevant period. The search was limited to journals published in English since the year 2000. The database searches generated 57 references with a total of 38 papers remaining after removal of duplicates. The abstracts were then read to ascertain whether they met our inclusion criteria i.e., original studies (not reviews) conducted with people with dementia on technological based reminiscence work. Reasons for exclusion were: reviews of a range of interventions (16); focus on cognitive testing or cognitive processes (6); use of technology with people with dementia, but not reminiscence (4); interventions other than reminiscence (4); use of music with non-dementia population (2); use of reminiscence with other client groups (2). This resulted in four papers identified from the computerised literature databases with a further five papers identified from hand searches, giving nine suitable studies published during 2000–2009 for inclusion in the current review. In addition, a Google search

was undertaken for conference proceedings papers and this resulted in two further papers being included, both from research groups whose work was already represented, but which reflected distinct lines of work in progress, not represented in the published articles.

## Results

Details of the 11 studies are provided in Table 1 and Table 2. Table 1 reports the objectives of each study and the reported outcomes. Table 2 describes the details of each study, in terms of number and type of participants, research design, measures used, technology system and reminiscence content. In addition, whether or not the person with dementia is involved in the design of the system and its content, and the type of reminiscence work employed is indicated.

In terms of methodological approach, most of the research is still at a preliminary or pilot study level, although some within subject experimental designs have been employed to evaluate certain aspects of the person's response, using comparison conditions such as TV shows or conventional photographs. No comparison or control groups have so far been used. Some studies (e.g., Sarne-Fleischmann and Tractinsky, 2008) have used appropriate qualitative methodology (e.g., content analysis) to collate and analyse responses of system-users. Detailed observational work has been undertaken, often involving video-recording the interaction of the person with dementia with the system (e.g., Yasuda et al., 2009).

The main achievement to date has been to demonstrate the feasibility of prototypes of ICT based RS, by showing their acceptability with participants with dementia, family members and staff. A variety of descriptors of these systems have been used: individual picture gramophone; biography theatre; therapeutic/restorative biographies (TR-Bios); personalised reminiscence video; personalised multimedia biographies; multimedia biography; personal TV photo album; digital life histories; and interactive life story multimedia. Seven of the 11 studies developed individualised RS essentially consisting of personalised multimedia systems built around the person's biography; one study used localised material (i.e., all or most of the material from one geographical area e.g., town, village or city) in the multimedia system and one study used preferred music, in some cases in a group context. The remaining two studies demonstrated respectively that reminiscence

work could be undertaken remotely, using a video-phone; and that generic pictures presented on a computer screen were just as effective as tangible photographs.

As expected in a developmental phase of research, sample sizes have been small. Three were single-case studies; other studies varied in size from five to 23 participants. Although, comparisons are difficult to make, it appears that a range of dementia severity has been included. For example, Damianakis et al. (2010) included participants covering the range from mild cognitive impairment (MCI) to advanced stage dementia. The duration of studies has varied from one session to follow-up over a six month period (Damianakis et al., 2010); there is a need for follow-up over a period of months, so that the continuing benefits and feasibility of the system, rather than simply its novelty value, can be evaluated.

Table 1. Studies' objectives and benefits

Author(s)	Objective of study	Outcome /feedback
Cohen, G.D. (2000)	Introduce long-term care interventions for AD patients and their families to increase quality of life.	<i>Participants:</i> Increased attention, reduced agitation and improved mood. <i>Relatives:</i> Increased family member's interest in the project. <i>Staff:</i> Increased staff interest in the project.
Alm, A., Astell.,A, Ellis, M. (2004)	To develop a reminiscence system as a cognitive and communication aid. (1) Pilot study to test acceptability and accessibility of the prototype (2) Pilot study to make close evaluation of the system in practice.	<i>Pilot study 1:</i> <i>Participants:</i> enjoyed, entertaining and easy to use the touch screen. <i>Relatives:</i> found the system easy to use and liked the video clips. <i>Staff:</i> The system effectively prompted the client to speak more than usual; pleased with choice of material available. Also, easy to use the touch screen. <i>Pilot study 2:</i> <i>Participants:</i> enjoyed and will reuse the system and indicated desire for more personally relevant contents. <i>Staff:</i> enjoyed the session together with participants and reported the session worthwhile and success for both. One staff suggested personal items be included.
Topo. P., Maki. O., Saarikalle et al (2004)	Describes results of an assessment study of a music based multimedia program called 'Picture Gramophone' (PG) with people with dementia and carers in day care units.	<i>Participant:</i> Facilitated reminisce; mostly able to use the PG, find PG very interesting and enjoyable. <i>Staff:</i> -Generally high motivation about PG use. -Reported, overall positive impact on mood and social interaction among participants.
Tamura, T., Ohsumi, M., Oikawa, D. et al (2007)	To compare conventional reminiscence therapy and PC-based reminiscence therapy.	<i>Participant:</i> steadily made positive responses about both reminiscence types and statistically no differences. Pictures can be presented on a PC with same effect as photograph.
Massimi. M., Berry., E., Browne., G. (2008)	To describe the development of a 'biography theatre' and its impact on participant with dementia and family members.	<i>Participant:</i> improved on standardised tests of apathy and positive self identity and some positive behavioural changes. <i>Relatives:</i> helped to cope better, helped to reminiscing together with participant.

Author(s)	Objective of Study	Outcome/feedback
Sarne-Fleischmann, F & Tractinsky, N (2008)	To evaluate the effectiveness of a personalised multimedia system for conducting reminiscence therapy sessions for people with dementia and their caregivers.	<i>Participants:</i> satisfied with the system e.g. enjoyed and wanted to continue using it; stimulated memories for reminiscing, indicates system easy to use, prefer personal content, enhance conversations. <i>Staff:</i> reported the system helped to initiate and prompt conversation with participants, enhance relationship between them and easy to use the system.
Waller, P. A., Östlund, B., & Jönsson, B. (2008)	To evaluate the prototype of a TV photo album.	<i>Participant:</i> enjoyable activity, facilitated in recollection of memory, more verbal reflection and detail compared to traditional photo album, easier to recognized photos compare to traditional album. <i>Relative:</i> family members can more easily watch photos with the participant compared to a traditional album.
Yasuda, K., Kuwabara, K., Kuwahara, N. et al. (2009)	To examine the effectiveness of personalised reminiscence photo videos compared with two types of TV shows.	<i>Participants:</i> 80% showed increased attention towards personalised reminiscence photo videos compared to other 2 TV shows.
Damianakis, T., Crete-Nishihata, M., Smith, K.L. et al (2010)	To evaluate AD and MCI patients responses to personalized multimedia biographies (MBs) and assess the psychosocial benefits of MBs.	<i>Participants:</i> evoked remote memories, stimulating reminiscing and enjoyment. <i>Relative:</i> helped recall past memories of their loved ones and enhance social interaction between family members and participant.
Kuwahara, N., Abe, S., Yasuda, K., Kuwabara, K (2006)	<i>Trial 1</i> To test whether participant has ability to communicate with therapist by videophone as well as face to face. <i>Trial 2</i> Conducted field trial to test networked reminiscence therapy in care homes.	<i>Trial 1</i> <i>Participants:</i> capable of communicating by videophone as well as face to face. <i>Trial 2</i> <i>Participants:</i> the reminiscence networked system, generally successful for conducting reminiscence sessions with participant equally as good as face to face reminiscence sessions.
Cohene, T., Baecker, R., Marziali, E (2005)	To test interactive multimedia with personalized life stories prototype with individuals with Alzheimer's.	<i>Participant:</i> delighted and engaged and interacted well with the system. <i>Family:</i> report personal growth from involvement in preparing life story.

\*Relative=Family members or significant others

Table 2. Detailed description of Studies

Author(s)	Target Population	Research Design	Data Collection	Reminiscence content and media type	Name of Reminiscence system	User	Technology	Participation in selecting content (primary user) (Y/N)	Participation in Using system (primary user) (Y/N)	Type of reminiscence
Cohen, G.D. (2000)	10 people with dementia	Pilot: Treatment v. control conditions	Global Deterioration Scale (GDS) Observed Emotion Rating Scale	Individualised; Family photos; old videos; Interview with relative; favourite stories	Therapeutic / Restorative Biographies (TR-Bios)	People with Alzheimer's ; Family members; Significant others; volunteers	Video	N (by family members)	N	Specific Reminiscence; Private & social reminiscence ; Narrative / informative Reminiscence; Boredom Reduction reminiscence
Alm, A., Astell.,A, Ellis, M. et al (2004)	<i>Pilot 1:</i> community (n=3) and day care centre (n=3) <i>Pilot 2:</i> at day care centres (n=9)	Action Research (Qualitative ) Pilot 1; 1 session Pilot 2; 20 minute sessions	<i>Pilot 1:</i> MMSE; Structured Interview; self report questionnaire <i>Pilot 2:</i> MMSE; Evaluative questionnaires for staff and participants	Localised & generic; categories: Entertainment; Recreation; local Dundee life	Multimedia reminiscence package(photographs, video clips, songs and music)	Person with dementia; family members; care staff	Computer-LCD touch-panel display (touch screen menu)	N	Y	Social Reminiscence; General reminiscence ; Reminiscence for conversation

Author(s)	Target Population	Research Design	Data Collection	Reminiscence content and media type	Name of reminiscence system	User	Technology	Participation in selecting content (Primary User) (Y/N)	Participation in using system (Primary User) (Y/N)	Type of reminiscence
Topo. P., Maki. O., Saarikalle et al (2004)	5 Day care centres - 28 participants, 5 dropped out	Action Research (mixed-methods): 5 assessment points over 6 month period (data here on first 3 weeks)	Health related quality of life (15 D); MMSE; description of participant by staff; List of 14 open-ended questions	Individualised (but also used in groups); ( personal preferences) Music Songs – words on screen photographs	Ready made individual Picture Gramophone (PG) multimedia program	Person with dementia; care staff Individual, group and pairs	Touch screen PC with CD-ROM to play CD -same concept with karaoke	Y	Y	Private & social reminiscence ; Specific reminiscence ; Boredom Reduction reminiscence
Tamura, T., Ohsumi, M., Oikawa, D. et al (2007)	6 people with dementia (nursing home and day care centre)	Experimental: Two 5 minute therapy sessions with 1 week interval	Snap reading method from observation and videotape recording	Generic: 2 Photographs of old-style Japanese fireplace and washboard -no other multimedia features	PC-based reminiscence	Person with dementia	17-inch display PC -Power-point file with JPEG images	N	N	General reminiscence Transmissive /narrative reminiscence

Author(s)	Target Population	Research Design	Data Collection	Reminiscence content and media type	Name of reminiscence system	User	Technology	Participation selecting content (primary user) (Y/N)	Participation in using system (primary user)(Y/N)	Type of reminiscence
Massimi. M., Berry., E., Browne., G. (2008)	84 year old man with Alzheimer's - living at home	Exploratory Study (Quantitative & Qualitative) Single case study; 3 phase data collection	Psychometric tests; custom questionnaire; interview; observation	Individualised: Personal: Music; Photographs; movies; narratives	Biography Theatre: digital life histories (DLHs) in ambient display	Person with dementia; Family members	PC (Sahara slate PC positioned on a stand); touch-screen interface; Special feature-continuous play - has pause, skip, and return buttons.	Y	Y	Specific reminiscence ; private & social reminiscence ; reminiscence for identity
Sarne-Fleischmann, F & Tractinsky, N (2008)	5 participants with Alzheimer's and their caregivers at day care centre	Action Research (Qualitative) Two sessions of interaction with system	Observation - videotaped; interviews; MMSE	Individualised; Media type; photos, music and video clips; Personal (personal old photos and favourite songs) vs. generic/general (e.g. photos of familiar places, familiar songs)	Personalised multimedia system	People with dementia; Staff; family members	PC-17"LCD with Web-based system and touch screen	N (personal items chosen by family – could involve person with dementia in this)	Y	Specific reminiscence ; social reminiscence ; Reminiscence for Conversation



Author(s)	Target Population	Research Design	Data Collection	Reminiscence content and media type	Name of reminiscence system	User	Technology	Participation selecting content (primary user) (Y/N)	Participation in using system (primary user) (Y/N)	Type of reminiscence
Waller, P. A., Östlund, B., & Jönsson, B. (2008)	1 person with Alzheimer's in a care home	Action research – single case study	Mutual feedback; direct observation; semi-structured interview	Individualised; Television -photos -singing clip	Personal TV photo album	Person with dementia; family members; care staff	32" LCD screen TV	Y	Y	Specific reminiscence; Private & social reminiscence; reminiscence for conversation
Yasuda, K., Kuwabara, K., Kuwahara, N. et al. (2009)	15 people with dementia from community	Experimental Research (40 minutes) (quantitative) ABCA design: A – photo video B – TV variety show C – TV news	Observation; digital video recording	Individualised; Personalised (Personal photos in chronological order with narration, background music and visual effect)	Personalised reminiscence photo video	People with dementia; Family members	Video (photo video); special feature: pan/zoom effect.	N (the photos were selected by family members not participants)	N	Specific reminiscence; Private reminiscence
Damianakis, T., Crete-Nishihata, M., Smith, K.L. et al (2010)	People with Alzheimer's (n=6) and MCI (n=6) from community	Qualitative feasibility pilot study 3 time; points: baseline, 3 and 6 month	In depth interview - observation note records -video recording Content analysis	Individualised: Digitized pictures, videos with voice-over narration and music. Workbook used to develop the biography.	Personalised multimedia biographies (MBs)	Alzheimer's and MCI participants; family members	DVD based digital video technology (DVD player)	Y (family members more involved with people with Alzheimer's)	N	Specific reminiscence; Private & social reminiscence; Intimacy Maintenance; informative reminiscence; Reminiscence for identity.

Author(s)	Target Population	Research Design	Data Collection	Reminiscence content and media type	Name of reminiscence system	User	Technology	Participation selecting content (primary user) (Y/N)	Participation in using system (primary user) (Y/N)	Type of reminiscence
Kuwahara, N., Abe, S., Yasuda, K., Kuwabara, K (2006)	9 people with dementia from hospital for 1 <sup>st</sup> trial; 5 people with dementia (and 2 normal participants) from care homes	Experimental design: 1 <sup>st</sup> trial: AB or BA design was used; 2 <sup>nd</sup> trial: 15 face to face sessions and 17 networked sessions (each session 30 minutes)	Observation; digital video recording; questionnaire (SD method); interview	Individualised; Reminiscence video, contains personal photos by slideshow with audio and visual effects. and narration	Networked Reminiscence Therapy	Person with dementia	Combine s IP videophones with a photos and video sharing mechanism based on Web technology. - broadband network	N	N	Specific Reminiscence; social reminiscence ; reminiscence for conversation
Cohene, T., Baecker, R., Marziali, E (2005)	A person with dementia and her family member	Ethnographic approach: case study	Contextual exploration ; interview	Individualised; Personalised life story (workbook)	Interactive Life Story Multimedia	Person with dementia Family members	DVD format	N (family involved)	Y	Specific reminiscence ; social reminiscence ; reminiscence for conversation

Four studies have emphasised the involvement of the person with dementia in selecting materials, and it is clear that this can be a time-consuming process. Massimi et al. (2008) reported having around eight unstructured reminiscence sessions with their participant to generate materials for their system. Where dementia is more advanced, family members have been more prominent in selecting personalised materials (Damianakis, Crete-Nishihata, Smith, Baecker, & Marziali, 2010), and in some cases it has been left to the family to involve the person with dementia (e.g., Sarne-Fleischmann and Tractinsky, 2008). Cohene et al. (2005) acknowledge the potential difficulty of relying on family members who were not alive or present throughout the participant's life-span, in leaving gaps in potentially important areas. The issue of editorial control of biographies may become an important one, especially where the person has had several partners or there has been a family breakdown. Family members may wish to protect the person with dementia from sad memories e.g., the loss of loved ones, but Damianakis et al. (2010) document that such pictures often produce a reaction that combines both sadness and happiness, and that, in their sample, negative reactions were relatively few in number. The potential effects on family members in being involved in producing the biography is described by Damianakis et al. (2010) and Cohene et al. (2005), for example, Effects on care staff are also reported, in terms of enhanced communication and better relationships with the person with dementia (e.g., Sarne-Fleischmann and Tractinsky, 2008), and the need to evaluate the effects of these interventions on the whole system around the person with dementia is evident.

The participation of the person with dementia in using the system also varied between studies. Some systems are clearly designed to be interactive, so that the person can select music or photographs or video clips from a menu, typically with a touch-screen (e.g., Alm et al., 2004; Topo et al., 2004). Other systems essentially play a DVD, rather like a movie or a TV show, perhaps with some opportunity for selecting chapters (e.g., Damianakis et al., 2010), but which otherwise is viewed more passively. The ambient system developed by Massimi et al. (2008) combines a continually playing sequence, with options for selection when the participant wishes to interact with the system.

In line with the personalised focus of the majority of systems, nine studies were categorised as prompting specific reminiscence work, and a similar number could be used for social reminiscence work, i.e., reminiscing with one or more other people. Six studies reported reminiscence work which could be undertaken by the person with dementia alone, prompting private reminiscence. At this stage of development, only three showed evidence of

prompting informative/narrative (i.e., story-telling) types of reminiscence work, and just two were clearly seen as promoting the sense of identity of the participant (Massimi et al, 2008; Damianakis et al., 2010), with the latter study showing clear indications of intimacy maintenance, in terms of maintaining a sense of closeness with loved ones who had been lost. About half the systems were seen as prompting conversation (without necessarily being informative or narrative) and two systems (Cohen, 2000; Topo et al., 2004) were described as potentially reducing boredom.

## Discussion

The objective of this review was to explore the current status of ICT based reminiscence work with people with dementia in terms of the broader literature on reminiscence with this population. A good deal of detailed developmental work has been undertaken, and the feasibility of these multimedia approaches has been established. The question now is how best can these systems (and their successors) be used therapeutically with people with dementia and their supporters?

In fact, this remains a key issue in reminiscence work generally, where there has been a lack of clarity regarding the aims of reminiscence work. Two distinct objectives may be considered, which will have implications for the system requirements:

- a *Maintaining the identity of the person with dementia:* This will be best served by the biography based systems such as those developed by Massimi et al. (2008) and Damianakis et al. (2010). Personalised materials are needed, and there needs to be a major resource commitment in terms of developing the biography with the person with dementia, with additional input from the family as needed. The biography would parallel the 'life story book' which is the usual outcome of a life review process (Haight et al., 2006; Morgan and Woods, 2010), but potentially it would be much more powerful in its on-going impact. Life review emphasises a structured, evaluative approach to the development of the biography [in contrast with the unstructured approach used by Massimi et al. (2008)], with the person with dementia having editorial control. Accepting that this process is more challenging with people with more severe impairment, there will be merits in encouraging people with dementia to develop their multimedia biographies early in their condition. The resulting biography

may be used for private reminiscence (when its ease of use is a prime consideration) or socially, with family members or care workers, and may have particular value if the person moves to a new environment such as a care home or if carers change.

- b *Encouraging communication with other people with dementia and care-staff:* This can be achieved with a variety of systems, and there is not the same requirement for materials to be personalised, although they do need to reflect participants' preferences and interests. For use in groups, projection systems or large screens will be required. Training for group leaders will be needed to facilitate discussion and allow space for participants to share stories and enjoy narrative reminiscence. In any reminiscence group there is the risk of the available memory triggers determining the direction of discussion, and with more powerful multimedia memory triggers this becomes an even greater danger. Those facilitating such work will need skills in following the direction of the participants, rather than being driven by a set programme of images and music. This will require the system to be highly interactive, although not necessarily requiring the person with dementia to navigate through it. Future systems might well have the ability to suggest related materials, pictures and music linked or associated with initial choices made by the users. There is a danger here that the person with dementia will become a passive viewer, rather than an engaged participant. The difficulty in incorporating taste, smell, touch and action, valuable memory triggers in conventional reminiscence groups, may add to the risk of passivity. Research will need to address whether ICT multimedia systems can adequately replace the multi-sensory memory triggers used in best practice reminiscence work.

Although both types of approach may have outcomes relating to mood and enhanced relationships, with benefits also for family members and care-workers, the focus and mode of operation are quite distinct. The challenge for future research will be to ascertain whether ICT systems are primarily a more powerful and engaging replacement for current aspects of reminiscence work (life story books, multi-sensory memory triggers) as envisaged in these two strands of work, or whether there is a whole new dimension of private reminiscence work that can be facilitated by these systems, as operationalised by Massimi et al. (2008) with their continuously running system on the person's kitchen table. The potential outcomes of reminiscence work with people with dementia outside of an inter-personal context have not previously been explored, and the development of these systems provides the impetus for a

new area of research and evaluation. Understanding the relative benefits of private and social reminiscence will be valuable in responding to the inevitable anxieties that these systems will be used to replace rather than augment interaction with family carers or care staff. The ideal scenario would perhaps be if these systems made it easier for carers to converse and develop and maintain relationships with the person with dementia, rather than simply keeping the person entertained.

Chapter 5: Digital life story books for people with dementia living in care  
homes: An evaluation

## Summary

There is increasing interest in using information and communication technology to help older adults with dementia to engage in reminiscence work. Now, the feasibility of such approaches is beginning to be established. The purpose of this study was to establish an evidence-base for the acceptability and efficacy of using multimedia digital life story books with people with dementia in care homes, in comparison with conventional life story books, taking into account the perspectives of people with dementia, their relatives and care staff. Participatory design was used to create a life story movie based on a previously completed conventional life story book with six older adults with dementia (four female; mean age 82). Relatives were involved in helping the participant to provide additional information and materials for the digital life story book. In this multiple case study design, both quantitative and qualitative approaches were used. For quantitative purposes, set of questionnaires that had been completed three times before and after the conventional life story book was developed were repeated 4 weeks after the life story movie was completed. Semi-structured interview questions were designed to collect feedback from participants, relatives and care staff. The result indicated that five of the six participants showed additional improvement in measures of quality of life and autobiographical memory. All participants showed improvement or stability in depression scores. Thematic analysis showed that, participants, relatives and care home staff viewed life story movies as a very useful tool triggering memories and (largely) positive emotions. Participants' case vignettes were presented to document the impact of digital life story book.

Keywords: Reminiscence, Dementia, ICT, Life Story Book, Life Story Movie, Case Studies



## Introduction

The concept of using information and communication technology (ICT) to assist people with dementia in everyday life is increasingly popular (see [www. scie.org.uk](http://www.scie.org.uk)). One application has been to support and facilitate reminiscence work (Subramaniam and Woods, 2010). This has taken a variety of forms, such as an interactive multimedia storytelling device (Gowans et al, 2004, Astell et al, 2010), multimedia biographies (Cohene et al, 2006; Smith et al., 2009), networked reminiscence systems (Kuwahara et al, 2006), media ‘memory lane’ (Olsen, Hutchings, & Ehrenkrantz, 2000), YouTube and internet based reminiscence work (O’Rourke, Tobin, O’Callaghan, Sowman, & Collin, 2011), personalized reminiscence photograph videos (Yasuda et al, 2009), networked videophones (Kuwahara et al, 2006), personalized multimedia systems (Sarne-Fleischmann & Tractinsky, 2008) and digital life stories using life-logging entities (Kikhia, Hallberg, Bengtsson, Savenstedt, & Synnes, 2010). The contents of the reminiscence materials used range from general (e.g. Gowans et al, 2004) to highly personalized (e.g. Massimi et al, 2008).

Our review of this field indicates the feasibility of using information and communication technology in reminiscence work for people with dementia (Subramaniam & Woods, 2010). Specifically, the development of multimedia biographies with people with dementia appears to have great potential (Smith, Crete-Nishihata, Damianakis, Baecker, Marziali, 2009). The aim of this study is to establish an evidence-base for the acceptability and efficacy of using multimedia digital life story books with people with dementia in care homes, in comparison with conventional life story books, taking into account the perspectives of people with dementia, their relatives and care staff.

## Method

This is a mixed method study using a multiple single-case approach (Yin, 2009) with six participants recruited having completed a previous life story book project. Each participant acted as their own control and were not blinded to the intervention they received. This project obtained ethical approval from the School of Psychology, Bangor University and the North Wales NHS Research Ethics Committee.

## *Participants*

Six participants (4 female) with mild to moderate dementia living in care homes were recruited for this study (Table 1). Five participants were rated on the Clinical Dementia Rating (CDR) with a score of 1 (mild dementia) and 1 participant had a CDR score of 2 (moderate dementia). The mean age of the participants was 82.2 (range: 73 – 89). Each participant had their own television in their room and was able to operate it. Written informed consent was obtained from all participants and from one of their relatives. All of the participants had recently completed participation in a randomised controlled trial where two approaches to developing a life story book were compared (Subramaniam and Woods, submitted). The book was either prepared with the full participation of the person with dementia, through a life review process, or was prepared with a relative independently of the person with dementia, and presented to them as a ‘gift’. Assessments were carried out at baseline, 12 weeks later, (timed to fit with the end of the life review process for those in this condition) and at 18 weeks. Three of the participants in the current study had produced a book through the life review process and three had received it as a gift. All had given positive feedback on their book. The average length of the life story books was 49 pages (range: 33 – 65).

Table 1: Participants Demographical Information

Participants	Gender	Age	CDR	Previous Group	Engage in self reminiscence <sup>+</sup>	Enjoy reminiscence <sup>++</sup>	Any Regret <sup>+++</sup>	Length of LSB (Pages)	Brief Feedback when Life story book presented to them
John	M	81	1	Life Review	Great deal	Yes	Never	33	Very nice...I can't believe this is for free
Sam	M	74	1	Gift	Great deal	Yes	Never	51	I can't believe this, my mother will be proud of me. I feel like I'm being appreciated.
Nia	F	89	2	Gift	Great deal	Yes	Never	49	I feel like I'm famous. I feel very excited
Betty	F	90	1	Gift	Great deal	Yes	Never	40	This is great. Book about me! Look like useful book to me.
Mary	F	73	1	Life Review	Great deal	Yes	Sometimes	54	One of the best thing happened to me after so long
Ann	F	86	1	Life Review	Very little	Yes	Sometimes	65	Excellent! Thank you very much...may be this is what I needed

<sup>+</sup>How often do you engage in self-reminiscence?

<sup>++</sup>Do you enjoy reminiscence?

<sup>+++</sup>By looking back at your life, do you have any regret?

### *Digital Life Story Book Description*

The digital life story books developed for the six participants were based on the photographs and other visual materials utilised in their conventional life story books, augmented with background music, participants' favourite songs and narration of the story. The 'Windows Movie Maker' programme was used to create a dynamic presentation, which was then burnt onto disc as a DVD. Other tools/devices used in making the life story movies included a voice recorder and a digital camera. Existing materials e.g. pictures, poems, creative works, hobbies and words from the participant's life story book were the main material used. Participants' favourite songs and music were used as in the soundtrack, matched with appropriate pictures where possible e.g. favourite dance music with a photograph of the participant dancing with his wife. Video clips were also included e.g. a participant's favourite ballet dance clips, or favourite football team's highlights clip with songs. The words used by participants during the life review process were also included as quotations. The 'movie', like the original life story book, followed a chronological order from childhood until the current time, divided into 6 segments e.g. childhood, teenage life, career, mid-life etc.

Narration was provided by participants and relatives. The spoken word was reinforced by the text appearing on the screen or scrolling across the screen, in a clear font, allowing the person sufficient time to read the words if they wished to do so. Three participants decided to record their own narration for their movie (Table 2). One participant recorded his voice together with his nephew. The remaining 2 participants' narration voice for their movie was provided by a relative.

Table 2 Production Descriptions

Participant	Family member Involved	Voice for narration	Prototype Screened for feedback	Number of weeks <sup>+</sup> to produce	Length (minutes)	Segments* (chronological)	Loop	Multimedia effects
John	Nephew	Both (GH & nephew)	3 times (1x with GH) (2x with GH & Nephew)	10 weeks	27.02	yes	no	audio, music, songs & words
Sam	Brother & Daughter	JR	4 times (2x with JR) (2x with JR & Brother)	9 weeks	18.06	yes	no	audio, music, songs, clips & words
Nia	Daughter & Granddaughter	G/daughter	3 times (2x with MS & daughter) (1x with All)	9 weeks	16.47	yes	no	audio, music**, songs**, clips & words
Betty	Son & Daughter in Law	JH	3 times (2x with JH) (1x with All)	8 weeks	14.18	yes	yes	audio, music, songs, clips & words
Mary	2 Sisters	MH	3 times (2x with MH) (1x MH & Sisters)	7 weeks	12.20	yes	yes	audio, music, songs, clips & words
Ann	Daughter	Daughter	3 times (1x with RB) (2x with RB & daughter)	7 weeks	16.00	yes	yes	audio, music, songs, clips & words

<sup>+</sup> The weeks count from converting life story book to movie based video and not included from beginning of life story book development.

\* The movie easy to select according to segments e.g. childhood, schooling, career, married life etc or also can be played us all movie

\*\*All the music and songs are in welsh e.g. Welsh national anthem etc

Participatory design was used, with the participant actively involved in the decision making process, designing and creating their own life story movie (Greenbaum & Kyng, 1991). Each resident played the role of director of their movie with the researcher acting as co-editor. The length of movies ranged from 12 to 27 minutes, with an average length of 18 minutes. Three movies were set up to loop and play continuously. On average 3 sessions were required to test the prototype movie with the participant and their relative before the movie was finalized. The movies took on average 8.3 weeks (7 weeks to 10 weeks) to produce.

### *Procedure*

Participants were approached after they had completed participation in the life story book project and informed consent obtained from the participant and their relative. A plan and design with timeline were then discussed. Whilst the participant's existing life story book became the main material resource for the movie, the participant together with their relative and researcher worked together in gathering additional information e.g. selecting and sourcing the participant's favourite music, songs, video clips or footage etc. Based on this input from the participant and his/her relative(s), in the following weeks, the researcher developed a first draft of the movie without any narration. The initial screening took place in the participant's room with their relative(s) for their feedback. The feedback was intended to check the speed of the movie including subtitles and other words, the content according to timeline, matched music and songs. The participant and relative were able to ask for any alterations and changes in the movie at this point. Once the drafted movie had been altered and adjusted according to the participant's wishes, the narration was recorded, using a voice recorder. The researcher incorporated the voice into the movie by best matching with the pictures and timelines. For those participants lacking in personal materials to support their life story movie chronologically, voice narration and pictures and video-clips from online resources were used.

Once the participant was entirely satisfied with their movie, the movie was burnt onto DVD discs. Three copies were made, 1 for the participant, 1 for their family members and one for the staff of the care home. The DVD cover was printed with a photo of the participant and titled "Life Story Movie of (participant's name)".

The digital life story book was played on the television in the participant's room with assistance from care staff and relatives. Participants without a DVD player were provided with one by the researcher. The researcher watched the final version of the movie together with the participant at least twice. After the participant had had access to the completed digital life story book for four weeks the questionnaires as used in the initial life story book project were repeated. Follow-up assessments in the initial project were completed by an assessor blind to the intervention received by the participant; in this open study, the researcher completed the assessments with the participant. The researcher also sought feedback from the participant, their relatives and care home staff about the digital life story book, including the frequency of its use and perceived enjoyment (see appendix 1).

## Measures

### *Quantitative Measures*

The Clinical Dementia Rating Scale (CDR) (Hughes et al, 1982) was used as a screening tool to determine the severity of dementia. It is a clinician-rated dementia staging system with 5 levels from no dementia through to severe dementia. Information for the CDR rating was obtained from the participant's medical record, an interview with the participant, relatives and care staff and by observation.

The following measures used in the initial life story book project were also used in the digital life story book project to monitor further changes over time:

1. The Quality of Life-Alzheimer's disease scale (QOL-AD) was developed by Logsdon (2002). It is a 13-item questionnaire used here in an interview with the participant to provide an indication of self-reported quality of life. To facilitate its use with cognitively impaired individuals, the QOL-AD uses simple and straightforward language. Higher scores indicate higher quality of life.
2. The Autobiographical Memory Interview (AMI) was developed by Kopelman et al (1990) and consists of two subscales, the Personal Semantic Schedule (PSS) and the Autobiographical Incident Schedule (AIS), seeking respectively factual information and memory for events across the person's life. The AMI extended version (AMI-E) was developed by Woods et al., (2009) with additional sections relating to the middle years of the person's life.

3. The Geriatric Depression Scale (Residential) (GDS-12R) was developed by Sutcliffe et al (2000). It is a brief, easy-to-administer depression scale that is relevant to residential and nursing home populations.

4. The Quality of the Care-giving relationship questionnaire (QCPR) (Spruytte et al., 2002) was used to measure the quality of care-giving relationship between the participant and their relative. It has two sub-scales, warmth and absence of conflict, and can be completed by both the person with dementia and the relative, providing two perspectives on the relationship.

### *Qualitative Measures*

In order to collect more in-depth information regarding the perceived value of the digital life story book, a set of open ended questions was developed. The same questions (appendix 1) were asked with the participant, the relative, the relative as a proxy (answering from the perspective of the person with dementia as they perceived it), staff and staff as a proxy. The questions were asked in verbal interviews with the participants and with some of their relatives. The staffs and some of the relatives chose to provide written responses to the questions. The questions covered feelings and thoughts about the movie, the benefits of the movie, repeat watching of the movie, anything they wanted to change and their preference between the conventional life story book and the digital life story book movie. The qualitative data were analyzed using thematic analysis (Braun and Clarke, 2006). The Thematic analysis involves ‘identifying, analyzing and reporting patterns (themes) within data’ (Braun and Clarke, 2006). The responses from the semi- structured interviews were transcribed (appendix D), and the coded data were read and re-read and grouped according to emerging themes and reviewed. Each theme was defined and the themes were named. This process was checked by another researcher.



## Results

### *Acceptability and utility of the digital life story book*

All the 6 participants successfully engaged in and completed their participation in the project. They all reported enjoying taking part in the project (Table 3). None wished to make any changes to their current life story movie. Four participants needed a little assistance from relatives and care staff to operate the DVD player. For the remaining two participants, one could sometimes operate it with a little assistance and sometimes needed someone else to start the movie (mainly due to an antiquated TV set). One participant needed complete assistance due to limited physical movement. However, all participants needed someone to remind them to play the movie. Only one participant had a reminder note near to the TV asking staff and visitors (relative) to turn on the movie - this participant viewed her movie twice as often as the other participants. Most of the participants watched their movie at least 3 to 4 times in a week with assistance from a relative, carer and researcher. All the participants' DVD players were found to be connected with the TV set with the DVD disc in the DVD player, in ready to play mode. If given a choice, most of the participants reported preferring to have their life story book in digital form.

Table 3: Usability, Usage and feedback of Life Story Movie

Participant	Ability to use TV/DVD player with assistant <sup>†</sup>	Need to remind to play <sup>++</sup>	Reminder notes <sup>+++</sup>	System in Ready Mode <sup>*</sup>	Average usage per week	Feedback about LSM project <sup>**</sup>	Wanted to make changes in movie <sup>***</sup>	Preference (book vs. Movie) <sup>****</sup>
John	Can use	yes	no	yes	3-4 times	Good Idea	no	The movie, more then everything.
Sam	Sometimes	yes	no	yes	3-4 times	Brilliant Idea	no	The movie, because it involve all other parts that I like, music, songs etc.
Nia	Can't	yes	no	yes	3-4 times	It is good	no	I like the book, I always can open & read. The movie, I like too but no one wants to show me.
Betty	Can use	yes	no	yes	3-4 times	Yes I liked	no	The movie, because I can see it & remind me more. Very relax compare to book.
Mary	Can use	yes	no	yes	4-5 times	Wonderful	no	The movie, because of the music and my voice.
Ann	Can use	yes	yes	yes	7-9 times	Good Idea	no	Both are the same! I like both. Sometimes I want to read & sometimes I want to watch.

<sup>†</sup>Participant ability to operate their own TV and DVD player with assistant from relatives and staff.

<sup>++</sup>Whether someone needs (e.g. relatives, care home staffs) to remind participant to watch their own movie.

<sup>+++</sup>Do participant provided reminder (e.g. notes next to TV) to play their movie which is in their DVD player.

<sup>\*</sup>Whether the TV and DVD player with participants movie in standby mode to be played easily by participant.

<sup>\*\*</sup>Very brief feedback from participant about what they about 'This is Your Life Story Movie' project.

<sup>\*\*\*</sup>Do participant wanted to make changes in their movie after the movie completed and gifted to them.

<sup>\*\*\*\*</sup>Which one, either the life story book or life story movie preferred by participant if both available.

### *Outcome measures*

Table 4 shows the quantitative results, contrasting the scores at the end of the initial conventional life story book project with those obtained after the person had had the digital life story book for four weeks. Five participants (John, Sam, Betty, Mary and Ann) had improved scores on the quality of life measure. However, Nia's QoL-AD score decreased by 5 points. The average QoL-AD score improved by 3.17 points after having the life story movie from 38.5 to 41.67 mean points. Five participants reported a lower score on the GDS-12R, and the sixth showed no change. The mean level at baseline was relatively low (2.17) but had declined by 1.84 points to a mean of 0.3, indicating an improvement in participants' overall self-reported mood since having their life story movie.

On the Autobiographical Memory Interview (Extended), five participants improved their performance and one maintained their level on the knowledge aspect of the test. The average improvement was 9 points. However on the 'autobiographical incidents' subscale, requiring rich recall of specific events there was an average decline of 1.5 points, with four participants having a lower score at follow-up. Taking a total score on this test, combining the sub-scales, five of the six participants showed an improvement.

The quality of relationship between participants and their relative, rated by the person with dementia, shows overall improvement on both subscales. On the Warmth subscale, all participants reported improved scores, with a mean improvement of 6.8 points. On the Conflict subscale, four participants showed improved scores with an overall average improvement of 3.2 points. The relatives' rating on quality of relationship also shows overall improvement on both subscales. On the Warmth subscale, three relatives (relative of John, Sam and Ann) scored maximum points at baseline and maintained this score after having the life story movie. Betty and Mary's relatives reported improved quality of relationship, whilst Nia's relative score did not change from baseline. The average improvement on the Warmth subscale rated by the relative of the person with dementia is 0.83 points. On the Conflict subscale, the average improvement was 1.17 points. Three participant's relatives (Sam, Mary and Ann) reported further improvement, two relatives (John and Sam) maintained the maximum score obtained at baseline and one relative (Betty) showed no changes in the score from baseline.

Table 4: Participant Raw Scores, Mean and Score changes

Measures	After Having Life Story Book							After Having Life Story Movie							Changes (-/+)						
	John	Sam	Nia	Betty	Mary	Ann	Mean (SD)	John	Sam	Nia	Betty	Mary	Ann	Mean (SD)	John	Sam	Nia	Betty	Mary	Ann	Mean(-/+)
QOL-AD	37	31	45	41	40	37	<b>38.50(4.72)</b>	38	39	40	43	43	47	<b>41.67(3.33)</b>	+1	+8	-5	+2	+3	+10	<b>+3.17</b>
GDS-12R	2	4	3	2	1	1	<b>2.17(1.17)</b>	0	1	0	0	1	0	<b>0.33(0.52)</b>	-2	-3	-3	-2	0	-1	<b>-1.84</b>
AMI																					
• AMI (PSS)	33	61	15	65	71	55	<b>50.17( 21.84)</b>	33	66	23	68	95	70	<b>59.17(26.24)</b>	0	+5	+8	+3	+24	+15	<b>+9</b>
• AMI (AIS)	1	10	5	24	10	18	<b>11.33(8.43)</b>	4	7	2	19	17	10	<b>9.83 (6.91)</b>	+3	-3	-3	-5	+7	-8	<b>-1.5</b>
QC (Participants)																					
• Warmth	32	32	31	33	33	32	<b>32.17 (0.75)</b>	39	40	40	39	36	40	<b>39.00(1.55)</b>	+7	+8	+9	+6	+3	+8	<b>+6.83</b>
• Conflict	24	18	27	24	24	24	<b>23.50 (2.95)</b>	24	29	18	30	29	30	<b>26.67(4.80)</b>	0	+11	-9	+6	+5	+6	<b>+3.17</b>
QC (Relatives)																					
• Warmth	40	40	39	37	33	40	<b>38.17 (2.79)</b>	40	40	39	39	36	40	<b>39.00(1.55)</b>	0	0	0	+2	+3	0	<b>+0.83</b>
• Conflict	30	30	23	28	23	28	<b>27.00 (3.22)</b>	30	30	27	28	25	29	<b>28.17 (1.94)</b>	0	0	+4	0	+2	+1	<b>+1.17</b>

*Feedback on digital life story books from people with dementia, relatives and staff*

Participants and their relatives viewed their experience of taking part in this project very positively. Participants, relatives and staff welcomed the idea of developing a life story movie. Table 5 presents some examples of feedback on the usefulness and benefits of the digital life story books. A number of key themes (Table 6) emerged from the thematic analysis.

Table 5: Highlights of Feedback on usefulness and benefit of Life Story Movie

	<b>John</b>	<b>Sam</b>	<b>Nia</b>	<b>Betty</b>	<b>Mary</b>	<b>Ann</b>
<b>Participant's feedback</b>	Yes! It bring back my memories...I remembered that I love to play golf. I can see all them again! I can see my wife ...nice to see her again & again...make me to feel nice. I like all the songs. The songs that I & my wife used to dance. Nice...very nice!	Yes! The movie brings back my memories. I remember all that in my mind. The movie brings back all that memories. The movie tells my wonderful life, the childhood was very great...church! Lots of enjoyment...It brought back the time again! The right type of music, that I liked...I enjoyed...My own voice is good. (Feel like 'sit in the moon', can't believe)	It is good...I like it! I feel like I'm famous. I don't know but; I like to watch again & again...I don't know! I feel happy to watch it. I can see them all again! Just by sitting! Nice memories ...I feel happy...very happy.	It reminds me many things, bring back my memories. Make me feel good. The movie makes me feel happy... Very triggering. Stimulating my memories. It makes me to look back my life 'I had good life'...I'm happy about my life. I'm happy about my life. Make me very happy, all my family can understand my life & see them over-over again	Wonderful! Best thing that ever happen to me after meeting my husband. I enjoyed. I have tears. Good memories. Stimulating & trigger memories (very good one). The movie bring back happy memories	I think it is good idea. I can see back my live stage by stage...Wonderful. I can see my life again...I remember many things that I never able to remember. The movie tells about me...songs and ballet make me happy.
<b>Relative's feedback as proxy</b>	Its bring back memories to him & encourage him to think. Its seem he is happy. Bring back memories & stimulating. Make him feel happy	Every time Sam will sit until the movie finish & he will thumb up. That seconds (when he watching the movie) it happy with smiles, trigger lots of discussion & stimulating memories (bring back memories). Make him feel good without doubt & he enjoyed very much.	She liked because all about herself and her family. Bring back her memories, stimulating with good expression from her. Happy, good mood & she feel famous.	Surprised she's been chosen. Yes, helped her to recall people and events from the past. Happy and reminiscent	Wonderful & very good. Yes 'memory comeback'. The movies bring back her memory & good to see 'them' back. Make her feel good.	She thinks it most interesting, dramatic music at beginning but likes it very much. I'm sure it stimulated her. She responded to the music & The ballet section. She really enjoyed. Stimulated, happy, nostalgic at times

	<b>John</b>	<b>Sam</b>	<b>Nia</b>	<b>Betty</b>	<b>Mary</b>	<b>Ann</b>
<b>Staff's feedback as proxy</b>	Encouraged John to ask questions about people he may not have recognized and asking about their whereabouts now. Happy – He enjoyed the photographs and was able to remember some members of his family	Will enjoy it while it's on, but does soon forget about it. Good while he is watching it.	It probably helps her remember things.	It seemed to put something back into her life. Very happy	Give them something to be proud of / discuss. Very happy	Encouraged and motivated Ann to remember parts of her history. Ann enjoys talking about her family
<b>Relative's feedback</b>	Help me to spend good ½ hour with John... very productive & not like before. Make me feel better because John happy by watching the movie	Feel good & happy. At least for ½ hour Sam happy. I was really great! Honestly I feel, I'm doing good for Sam. What else I want. Wonderful idea... Really, really good because it make Sam happy while watch it.	Fantastic idea! The movie makes my relative happy & I'm glad to see her (Nia) face full of happiness. Help me to go back to understand Nia's life better. The movie help me to match her story that she use to tell me. He make more sense to me now. I glad that I helped Nia to left her legacy & I did something very good for her. (Nia would ask different questions every time she watch together with me)	It was quite enjoyable. It made me feel good. It made me think about the past. It helped me to remember things... Reminiscent	Old pictures & songs bring back good memories. Trigger many-many memories. Very precious moment. The movie bring backs everything. The movie brings memories/ we feel good. Sometimes make us feel sad (e.g. mother & father pictures). Make sad but also make you happy about life... We miss our childhood life.	I felt excited and pleased on mum's behalf and the family and myself. Mum would really enjoy seeing it. Pleasure in seeing photos of mum's life; obviously it covers some of my life too. Enjoyment in showing my daughters and watching their reactions and particular pleasure seeing the ballet & listening to some of the music. Nostalgic, happy, moved by the ballet section & some of the music. Emotional at times.

	<b>John</b>	<b>Sam</b>	<b>Nia</b>	<b>Betty</b>	<b>Mary</b>	<b>Ann</b>
<b>Care staff's feedback</b>	<p>I felt it was a good idea. When residents come into a care home, we know very little about their history. Yes, I feel I know John much more than I did before. I gained more information about John. What music he liked etc. I know about his interests and his family.</p>	<p>They are very good. Help us know a lot more things about the person, also nice to see a background of the person pictures etc. Enjoy chatting about the past and it seems more real</p>	<p>I got to know more about Nia and her family even though I have cared for her ten years and know some family members, still learnt a lot from the movie. I will be able to relate more with Nia when she talks about her family.</p>	<p>Yes I was able to discuss it &amp; I learned from it. I learned even more about the client</p>	<p>Yes I was able to discuss it &amp; I learned from it. I learned even more about the client</p>	<p>This movie is very good, with a very high content of information. Yes, it helped me understand Ann more. Their past history makes them who they really are, and without information like this, we really don't know them. I found out things that I never knew about Ann and her life. People who suffer with dementia may go back to a certain point in their life, and knowing more about Ann's past life / history will benefit staff in assisting to Ann's needs.</p>



Firstly, relatives and people with dementia agreed that the digital life story book was stimulating and triggered past memories.

*The movie brings back my memories. I remember all that in my mind.* (Sam)

*Bring back memories & stimulating* (John's relative)

A second theme related to the feelings and emotions associated with watching the movie.

Feelings of enjoyment, pleasure and just 'feeling good' were commented upon, by people with dementia and relatives. The relatives reported positive emotions in themselves as well as for the person with dementia.

*Make me feel good. The movies make me feel happy* (Betty)

*Happy, good mood & she feel famous.* (Nia's relative)

Relatives commented on feeling 'excited' in watching the movie, perhaps a mix of seeing the person with dementia respond and their own response to the movie:

*I felt excited and pleased on mum's behalf..... Pleasure in seeing photos of mum's life; obviously it covers some of my life too.* (Ann's daughter)

Some memories were associated with mixed emotions:

*The movie brings memories/we feel good. Sometimes make us feel sad* (Mary's relative).

Generally, life was seen by the people with dementia positively overall:

*'I had good life' ...I'm happy about my life.* (Betty)

*The movie tells my wonderful life,* (Sam)

Some staff and relatives commented on how the movie encouraged communication and interaction:

*Encouraged Ann to talk about her history* (care staff)

*Help me to spend good half hour with John... very productive & not like before.*  
(John's relative)

For staff, a major theme related to the information and knowledge they gained about the person with dementia:

*Yes, it helped me understand Ann more. Their past/history makes them who they really are, and without information like this, we really don't know them.* (care staff)

Nia's relative felt she now understood her relative's story better and she thought the movie would serve as a living legacy for Nia:

*Help me to go back to understand Nia's life better* (Nia's relative)

However, staff also pointed out that the person would often not remember the movie until shown it:

*Does not remember seeing it but would like to see it* (care staff regarding Sam)

Table 6: Themes emerging from participants, relatives and staff feedbacks

Perspective	Main Themes
Person with dementia	-Stimulating, triggers memories, -Enjoyment and feeling good
Relatives (proxy)	-Stimulating, triggers memories -Enjoyment and feeling good
Staff (proxy)	-Enjoyment and feeling good -Encourage conversation
Relatives	-Enjoyment and feeling good
Staff	-Gained information and knowledge

## Case Vignettes

### Case no. 1: John

John was an 81 year old widower, diagnosed with dementia over five years ago, living in a care home for the last 3 years, His nephew, who had been closely involved in caring for John, agreed to participate with John. He visits the care home regularly.

John was randomly assigned into the life review group in the initial project and he enjoyed taking part in the life review process which stimulated many pleasant memories e.g. playing golf with his wife, holidays and dancing with his wife. The life review process also served to remind him of his wife's death, which he found difficult to accept, but comforted himself by the thought they would be re-united when he himself died.

John was very happy with his life story book and proudly showed it to other residents, staff and visitors at his care home, explaining about the pictures in his book and talking animatedly about his pictures with his wife.

Table 7: John's scores on primary outcome measures over time

	Baseline	follow-up 1/ before book presented	follow-up 2/ after book presented	1 month after movie presented
Measures				
QOL-AD	32	37	37	38
AMI-AIS	1	3	1	4
AMI-PSS	27	39.5	32.5	33
GDS-12R	0	2	2	0
QCPR (Participant)				
-Warmth	35	32	32	39
-Conflict	23	24	24	24
QCPR (Relative)				
-Warmth	31	38	40	40
-Conflict	24	24	30	30

About 4 months after the final follow-up assessment in the initial project, John was approached again to take part in the digital life story book project. Both, he and his nephew agreed to extend his life story book to become a life story movie. John's favourite music and songs were recorded and his nephew narrated John's life story. John also recorded a few words about his wife in his own voice. John proposed 2 main changes at the initial viewing:

first the movie was moving too fast for him and he wanted one of the songs matched with photos of him and his wife dancing. After the movie was revised and finalized, with assistance, John watched his movie at least 3 to 4 times a week. The movie triggered many conversations:

It encouraged John to ask questions (while watching the movie) about people he may not have recognized and asking about their whereabouts – Ms SE (Carer)

John preferred his story movie compared to his life story book. He was happy with his movie and said:

Very good! Make me feel good...It bring back my memories...I remembered I love to play golf...I love all the songs, the songs that I and my wife use to dance together...Nice...very nice.

However the care staff thought the life story book was more suitable for John;

John has easier access to the book. He can just pick it up when he wants. Operating a DVD would be difficult for him – Ms SE

His nephew's feedback was;

The book is a good idea; the staff will look at it more compared to a DVD. The movie is more useful for a person with dementia and relatives. John's sister thinks the movie project is a great idea and she going to make one for herself.

Both nephew and care staff agree that the movie helps John and themselves;

Makes him (John) happy, brings back memories to him, stimulating and encouraging him to think. I'm not sure about long term effect but for short term it is beneficial. - Nephew

The movie helped me to spend good half an hour with John. Very productive and not like last time – Nephew

I gained more information about John. What music he liked etc. I know about his interests and his family...I learned more about John. I think everyone (residents) should have a life story book or movie. – Ms SE

Although the changes in the outcome measures for John are small in this phase of the project, his QoL-AD score shows further improvement, remaining at a higher level than the original project baseline, and he scores zero on the depression scale. His autobiographical memory scores are also higher than at the initial baseline. For John, it appears that the major changes in quality of life and autobiographical memory occurred during the life review process, but that the digital life story book has helped to consolidate these changes.

## Case no. 2: Sam

Sam was a 74 year old man who joined the study initially at his brother's suggestion. He was divorced and living alone, and had entered residential care after memory difficulties had developed.

The researcher worked closely with Sam's brother to develop Sam's life story book, which was presented to him as a gift. Sam was very happy and excited with his life story book and was especially proud of his army life. Again, both were happy to join the digital life story book project 5 months after the completion of the life story book project. The first draft of the movie was presented to Sam and he agreed to record his voice for narration. Together with his brother, some of Sam's favourite songs were selected. Sam was also interested in his favourite football team's song and a relevant video clip. Sam was excited when the movie was screened for a second time together with his voice and background music and songs, and after some minor corrections were made to the narration, he approved the drafted movie. Sam watched his movie 3 to 4 times a week.

Sam's feedback about his life story movie included:

"The movie brings back my memories very much. I remembered all that in my mind. The movie brings back all that memories. The movie tells my wonderful life, the childhood was very great...my church!"

Although Sam prefers to have his life story book and his movie, his first choice would be the movie;

"The movie, because it involve all other parts that I like, music, songs etc."

Sam's brother also thinks Sam enjoyed the movie more;

"Wonderful idea...really, really good because it makes Sam happy while he watches it...at least for ½ hour Sam is happy... Every time Sam will sit until the movie finishes & he will give a thumbs up... Those seconds (when he watching the movie) he is happy with smiles, triggers lots of discussion & stimulating memories ...The movie helps him be calm, sit down & enjoy" – Sam's brother

Sam's brother also thinks the movie is better than the book;

Both are very good. Without doubt the movie much better, movie contains background music, Sam's voice...many things...-Sam's brother

Feedback from the care home staff indicated that they are also pleased with Sam's movie;

Helps us know a lot more things about the person, also nice to see a background of the person pictures etc. Enjoy chatting about the past (with Sam) and it seems more real with the movie now – Carer

Table 8: Sam’s scores on primary outcome measures over time

Measures	Baseline Before book presented	Follow-up 1 / Follow-up 2/ after book presented	Follow-up 2/ after book presented	1 month after movie presented
QOL-AD	34	30	31	39
AMI-AIS	06	06	10	07
AMI-PSS	61.5	58	61	66
GDS-12R	03	07	04	01
QCPR (Participant)				
-Warmth	33	32	32	40
-Conflict	24	22	18	29
QCPR (Relative)				
-Warmth	39	35	40	40
-Conflict	19	25	30	30

Sam’s quality of life scores having had the movie for 4 weeks had improved beyond the initial baseline level and his depression score was also at the lowest recorded during the project. Autobiographical memory was also better than at the initial baseline, with the knowledge based memory at its highest level. With the exception of memory for specific events, which is slightly less than after he had received the conventional book as a gift, Sam appears to have shown most positive changes during this final phase of the project.

### Case no. 3: Nia

Nia was an 89 years old widow, who had been resident in the care home for 5 years, receiving regular visits from her daughter in law and other relatives. She had a very active life until developing severe arthritis which has led to her being wheelchair-bound. With her daughter in law’s cooperation a life storybook was developed and presented as a gift to her. Quantitatively the book did not produce any dramatic effect on Nia as shown in Table 9. However she was very pleased with her book.

“Oh dear me! You see...this is all about me, I can remember many things now...Now I can name all of them (referring one of her childhood pictures)...This book brings back so much of my memories...I’m excited...thank you so much” – Nia’s initial reaction about her book.

After around 5 to 6 weeks, Nia was approached again to be part of the digital life story book project. She and her daughter in law happily agreed to convert Nia's life story book into the movie format. Nia was very much interested in Welsh music and managed to list out her favourite music and songs for her movie. Her daughter in law helped to collect some of the music and others were obtained from the internet. The initial screening with background music and songs elicited a positive response, as she sang along with great feeling and with some movement. She explained the meaning of the songs to the researcher (who was not able to understand the Welsh language).

“It is a good reminder; she can see her life in chronological order. I'm glad to see her face full of happiness. The music makes her sing together...she stopped singing for the past 20 years & now she is singing again, shaking her hand and leg. – Nia's daughter in law.

Initially Nia agreed to record her own voice for narration. However, after discussion with her family members she decided to record her granddaughter's voice. The movie was screened for a second time with Nia's granddaughter's voice and with other adjustments based on early feedback e.g. rearranging the opening music, the speed of the movie and so on. Nia was very satisfied with her movie but still suggested some further changes (together with her daughter in law). The movie was approved at the third screening and burned onto a DVD disc, and a DVD with cover was placed on the DVD player in Nia's room, so it was easy to notice by Nia and care staff. When the researcher visited Nia after a few weeks and watched the movie again with her, she said:

I don't know but, I like to watch it again & again...I don't know! I feel happy to watch it. I can see them all again! Just by sitting! Nice memories...I feel happy...very happy! – Nia after 2 weeks presented with DVD movie.

During the final feedback, when asked about the book and movie, Nia commented;

I like the book; I always can open & read. The movie...I like too but no one wants to show me! I feel nice if you show to me! Only you show me the movie.

Nia's daughter in law also feels that the movie helped her in different ways. For example;

“Helps me to go back to understand Nia's life better. The Movie helps me to match her story that she used to tell me before. Now, her story makes more sense to me”

When asked how she felt about taking part in this project, she replied;

“I'm glad that I helped Nia to leave her legacy & I did something very good for her. The songs are very good for Nia. The voice from my daughter is brilliant!. The movie helps Nia to ask different questions every time she watches together with me”

Nia’s daughter in law considered that both the book and the movie were useful.

“She likes both; the book makes her to look back (forward & backward). The movie makes her to enjoy more because of voice & music”.

The home manager arranged a session with most of the staff at the care home to watch Nia’s movie. They saw having the movie as a wonderful idea and felt every resident should have their own life story movie.

“I got to know more about Nia and her family even though I have cared for her ten years and know some family members, still learnt a lot from the movie” – Carer

“Thought it was very good and well put together. Nice for family to keep” – Carer

“I will be able to relate more with Nia when she talks about her family” - Carer

Table 9: Nia’s scores on primary outcome measures over time

Measures	Baseline Before book presented	Follow-up 1 / Follow-up 2/ after book presented	Follow-up 2/ after book presented	1 month after movie presented
QOL-AD	41	44	45	40
AMI-AIS	01	05	05	02
AMI-PSS	14	14	15	23.5
GDS-12R	1	0	3	0
QCPR (Participant)				
-Warmth	33	31	31	40
-Conflict	23	21	27	18
QCPR (Relative)				
-Warmth	32	32	39	39
-Conflict	24	24	23	27

There is a mixed picture comparing Nia’s scores on the outcome measures before and after she had the digital life story book. Whilst her QoL-AD score fell, her (already low) depression score reduced further; her autobiographical knowledge increased, whereas her memory for specific events reduced slightly. Compared with the overall project baseline, the main change has been in her improved autobiographical knowledge, and this does appear to be associated specifically with the movie phase of the project.



#### Case no. 4: Betty

Betty was a 90 year old widow who moved into residential care 3 years previously due to memory difficulties. She had a great interest in reading and crosswords and spent most of her time engaged in these two activities and less time in conversation with other residents, preferring to be alone. Her son worked closely with the researcher over a period of 3 months to produce Betty's life story book, which was presented to her as a gift.

Betty was surprised with her book. The book triggered very useful conversations between Betty, her relatives, other residents and care staff. Her life story book stimulated her to recall further information about her life story. She gained more points on all primary measures after having the book for 6 weeks. In particular, she improved greatly on AIS scores, reflecting her ability to recount memories of specific incidents in her life with rich content.

Table 10: Betty's scores on primary outcome measures over time

Measures	Baseline	Follow-up 1 / Before book presented	Follow-up 2/ after book presented	1 month after movie presented
QOL-AD	38	37	41	43
AMI-AIS	14	14	24	19
AMI-PSS	56.5	60.5	65.5	68
GDS-12R	4	3	2	0
QCPR (Participant)				
-Warmth	33	32	33	39
-Conflict	23	22	24	30
QCPR (Relative)				
-Warmth	33	32	37	39
-Conflict	25	25	28	28

Betty and her son were happy to convert the life story book into a movie. Betty actively recalled all her favourite music and songs with assistance from her son. She decided to also include segments of her favourite BBC radio programme and to record her own voice to narrate her movie. Betty made some recommendations and changes (mostly about matching the songs with pictures) to two drafts of the movie before approving the third version. .

Betty and her son were as happy with the movie as they were with the book. Again, Betty feels her movie is stimulating and triggers many memories in her life. Most importantly she reports feeling good every time she watches her movie.

It reminds me of many things, brings back my memories. Makes me feel good. The movie makes me feel happy... very triggering. The movie stimulates my memories and makes me look back on my life 'I had a good life' ...I'm happy about my life. I'm happy about my life. – Betty

Although Betty was excited and happy with her conventional life story book, she reported that the movie is more stimulating and makes her relax more compared with her life story book.

The movie, because I can see it & reminds me more and makes me very relaxed compare to book. – Betty

Betty's son perceived the movie as a Christmas gift for the whole family. Betty's movie was played on Christmas day in a family gathering together with Betty. Her sons and daughter felt that this was a very memorable event because they also shared important segments of Betty's life story.

The movie was quite enjoyable. It made me feel quite good. It made me think about the past. It helped me to remember things. – Betty's son

The care home staffs were helpful in showing the movie to Betty (usually at night). They thought the movie helped them to understand Betty better and at the same time Betty was proud of her life.

I was very excited. Yes I was able to discuss it & I learned from it. I learned even more about the client. – Betty's carer

I thought it gave her (Betty) something to be proud of – Betty's carer

Again the outcome measures show a mixed picture, with a reduction in autobiographical memory for events, but improved quality of life, reduced depression and improved autobiographical knowledge following the exposure to the digital life story book. All the measures show improvement compared with the initial project baseline assessment and the assessment prior to Betty receiving her conventional life story book.

### Case no. 5: Mary

Mary was a 73 year old widow diagnosed with mild Vascular Dementia, who had been resident in the care home for three years. Mary's main interests apart from talking to people were writing poetry, creative work and watching television. Mary was randomly allocated to produce a life story book through the life review process. She was very active in life review sessions, providing very rich information about her life story. All Mary's outcome measures improved during the life review process, with a particular improvement in her recall for specific events and incidents during her life. Her scores then fell during the period when she had the conventional book, perhaps because she prefers to be interactive with someone about her life story.

Table 11: Mary's scores on primary outcome measures over time

Measures	Baseline	Follow-up 1 / Before book presented	Follow-up 2/ after book presented	1 month after movie presented
QOL-AD	37	43	40	43
AMI-AIS	08	27	10	17
AMI-PSS	76.5	79	71.5	94.5
GDS-12R	03	0	01	01
QCPR (Participant)				
-Warmth	32	34	33	36
-Conflict	24	23	24	29
QCPR (Relative)				
-Warmth	39	28	33	36
-Conflict	12	18	23	25

Mary agreed to take part in the digital life story book project with her sisters, and they discussed a list of background music, songs and video clips to include in the movie. After a few weeks, the drafted movie was screened to Mary, who was visibly excited to watch it, singing along with the songs in the movie.

I stopped listening to music & songs for a very long time. All of these songs are full of memories and have a story behind it...nice! Very nice! – Mary, when screened drafted movie for first time.

Although Mary had some difficulties with speech she decided to record her own voice in her movie, and achieved this, recording small segments at a time. She was clearly proud and

highly excited when the movie was completed. And her sisters also were very pleased with the outcome. When asked how she felt about the movie, Mary replied:

I enjoyed it. I have tears. This is my life in a movie & not everybody gets this. Wonderful!  
Best thing that ever happened to me, after meeting my husband

As observed from Mary's reaction, she was more excited with her movie compared with her life story book

The movie, because of the music! Good memories. Stimulates & triggers memories! Very good one!

When the sisters and staff were asked 'Do you think this movie helped Mary in anyway?' They answered;

"Yes 'her memory comes back'. The movies bring back her memory - good to see 'them back' – Mary's elder sister

Gives her (Mary) something to be proud of & to engage in discussion – Mary's carer

Her sisters who had shared the same childhood and teenage life with Mary also felt their memories were triggered by the movie. Every time the movie was played to them, Mary and her sister were observed to engage in active conversation full of laughter and excitement. Each of them would recount stories responding to movie clips or the pictures in the movie.

Old pictures & songs bring back good memories. Trigger many-many memories, all very precious moments. The movie bring backs everything. The movie brings memories and we feel good. Sometimes it makes us feel sad (e.g. mother & father pictures). Makes us sad but also makes you happy about life... We miss our childhood life – Mary's sisters.

Staff reported improved knowledge about Mary after watching the movie. The staff thinks the movie would help in communicating with Mary.

I leaned even more about my client... Yes I was able to discuss it & yes I learned from it – care staff

Comparing scores on the outcome measures before and after receiving the movie, Mary improved on all measures, and all were improved compared with the initial baseline. However, whilst autobiographical memory for factual knowledge was at its highest at the

final assessment, memory for specific events was lower than had been the case immediately following the life review process. Quality of life scores were identical following the life review and following the availability of the movie.

Case no. 6: Ann

Ann was an 86 year old widow diagnosed with vascular dementia, resident in a care home for three years. She spent all her day in her room except for meal times, refusing to sit in the lounge and her main interest is reading and watching television. Ann was randomly assigned to the condition where a life story book was developed through a life review process.

Table 12: Ann’s scores on primary outcome measures over time

Measures	Baseline	Follow-up 1 / Before book presented	Follow-up 2/ after book presented	1 month after movie presented
QOL-AD	29	37	37	47
AMI-AIS	08	09	18	10
AMI-PSS	41	55	55.5	69.5
GDS-12R	07	02	01	0
QCPR (Participant)				
-Warmth	31	32	32	40
-Conflict	24	24	24	30
QCPR (Relative)				
-Warmth	40	39	40	40
-Conflict	23	25	28	29

Ann had a huge collection of pictures and other tangible items that covered her entire life. Before the life review process began, the researcher spent hours with Ann’s daughter to sort out some of these, according to the phases of Ann’s life history. Ann responded well in all the life review sessions. She enjoyed talking about her life story and her pictures really stimulated her memories.

“In whole, all the sessions (life review process) make me feel good. I’m happy to take part in this research” – Ann about her view on life review

The effect of the life review process on Ann is shown in Table 12. She improved on all measures, although memory for specific events showed relatively little change. Interestingly she was clinically depressed at baseline assessment and her score was well below the clinical range at the end of the life review sessions.

Ann was very happy and pleased with her book. She spent time reading her own life story book, sometimes engaging with 2 or 3 pages (with pictures) for 20 – 30 minutes. In Ann's case, her life story book seemed to act as a 'maintaining tool' for the effects of life review process as shown at 6 weeks after having the book, by which time there was also a more marked improvement in autobiographical memory for specific events.

Ann was very happy to agree to take part in the digital life story book project. Her daughter provided a collection of Ann's favourite music and songs. Ann chose her most favourite background music, songs and clips for her life story movie. The drafted movie was screened to Ann and she was pleased with the outcome. Due to breathing difficulties, Ann decided her daughter's voice would be better for the narration. The movie was finalised after 3 screenings and adjustments. Ann was happy with her movie but seldom watched the movie right through to the end. Instead she uses pause and rewind to focus on specific sections.

Apart from being happy and enjoying watching her life story movie, Ann also feels that the movie stimulates her memories.

I think so. I can see back my life stage by stage... Wonderful... I can see my life again... I remember many things that I was never able to remember. The movie tells about me... songs and ballet make me happy. Really good! I'm a happy person now. I can sit and watch it!

Although her daughter thinks the opening ballet music in her mother's movie is over dramatic, Ann wanted to retain the movie as it is.

Please don't change anything... please! I wish I can have this from a long time ago! – Ann

Ann prefers both the movie and the book equally. She thinks both are the same.

Both are the same! I like both. Sometimes I want to read & sometimes I want to watch

Ann's movie brings good feelings also to Ann's daughter:

I felt excited and pleased on mum's behalf and the family and myself. Mum would really enjoy seeing it. Nostalgic, happy, moved by the ballet section & some of the music. Emotional at times. - Ann's daughter

The care home staffs feel the movie helped them to understand their client better as a person and help them in caring process.

A very good idea, which will assist staff in caring for the individual. This movie is very good, with a very high content of information - Carer

Yes, it helped me understand Ann more. Their past/history makes them who they really are, and without information like this, we really don't know them. - Carer

I found out things that I never knew about Ann and her life. People who suffer with dementia may go back to a certain point in their life, and knowing more about Ann's past life / history will benefit staff in assisting to Ann's needs. - Carer

I was excited to be able to learn more about Ann and her history. We only know about the reason they are admitted to the care home, and their medical history. We have very little or no information about our client -Carer.

On the outcome measures, Ann's quality of life and factual autobiographical memory reached their highest levels, although the memory for specific events appeared to decline to around the level immediately after the life review process. She reported no symptoms of depression at all at the final assessment.

## Discussion

It is now well established that a person with dementia may enjoy taking part in many activities and be able to report a good quality of life (e.g. Woods, 2012). One of the activities highly valued by relatives and care staff is reminiscence work (Gibson, 2006). A tangible outcome of structured individual reminiscence work, life story books can be presented in various formats, including making use of information and communication technology (ICT). In the current study we provided further evidence for the feasibility of using information and communication technology based reminiscence work.

All the six people with dementia approached to take part agreed to do so, and we have provided qualitative and quantitative evidence regarding the effects on each individual, with the perspectives of relatives and care staff also represented. Half of the participants had previously undertaken a life review process, and all the participants had received a conventional life story book, broadly chronological and well-illustrated with photographs and pictures.

Qualitatively, the life story movie project produced similar effects to the life story book project. Participants reported the movie helped them in recalling their past memories. One of the key themes observed in participant's feedback was the movie stimulated and triggered their memories. All of them enjoyed watching their own movie. Relatives also agreed the movie helped their family member with dementia in stimulating memories and

engaging in meaningful conversations. Some relatives also highlighted the movie helped them to spend quality time with the person with dementia. The common theme emerging from care home staff about the movie is that it helped them to improve their knowledge of a person with dementia under their care.

Previous studies have highlighted the positive psychosocial impact of life story work on cognition and emotion for people with dementia. The creation of a life story book has been viewed positively by participants, relatives and care staff (Morgan & Woods, 2010; Haight et al, 2006 & Lai et al 2004). The life story book is a tangible aid that appears to be of therapeutic value to a person living with dementia.

In this pilot multiple single case study, the transformation of life story books into digital movie life story books has been validated. This format has been well received by all 6 participants and their relatives and care staff. All participants valued their own life story movie either more than their life story book or at least equally. This study has also established that the person with dementia can contribute to the development of his/her life story movie. This participatory design, with the person with dementia fully directing his/her own life story movie is a strength of this study, and parallels with the development of a life story book by engaging in a life review process.

Both traditional life story books and ICT based life story media aim to stimulate the recall of past memories to help a person with dementia to engage in therapeutic reminiscence activity. The psychosocial benefits of ICT based reminiscence work appear similar to those associated with a conventional life story book, according to the qualitative data collected in this study.

The enjoyment and pleasure from engaging in watching the life story movie emerged as a prominent theme. Both people with dementia and their relatives reported positive feelings from watching the movie, and relatives felt pleasure in seeing the enjoyment of the person with dementia. Feelings of sadness were expressed, and some tears shed, but these were seen as natural expressions of loss, mitigated by the overall narrative of the life story.

The development of the life story movie encouraged person-centred care in that it helped care staff to see their client as a person and to value their experience. The common theme emerging from care staff that took part in interview and discussion was that they feel they know more about that person their care for. Kitwood (1997) emphasises the importance



of understanding the person's life history to provide better care. The pride expressed by participants reflects a strengthening of the person's sense of identity.

Sarne-Fleischmann and Tractinsky (2008) reported that a personalized multimedia system for reminiscence therapy in Alzheimer's patients promoted conversations and evoked personal memories. Yasuda et al (2009) also highlighted the effectiveness of personalized reminiscence photograph videos in increasing attention of individuals with dementia. The same effects were observed in participants while watching their life story movie. Apart from having the concentration and attention to complete the movie, they also engaged in very rich conversation. Family members also reported they are having more meaningful conversations about the participant's past history and that the movie helped them to have more quality time together. Staff also reported that they could engage in more sensible conversations with the person with dementia.

The life story movies were highly stimulating and successfully triggered the past memories of the participants. Almost all the feedback from people with dementia and their relatives highlights the usefulness of the life story movie as a tool for stimulating past memories. People with dementia triggered their memories by watching the movie and it helped them in recalling past memories. This reinforces previous findings using ICT based approaches to reminiscence work (Cohene et al, 2006; Damianakis et al, 2010).

In relation to the quantitative measures, the six case-studies show that in all but one instance, the person's highest self-reported quality of life score came after the person had had access to their movie, Similarly, in all but one instance, the person's autobiographical memory for factual knowledge (the PSS score) was at its highest at this point. Depression scores (although generally low) show a similar picture. Memory for specific events and incidents (the AIS score) was only at its highest point at the final assessment for one participant, with this measure peaking after the life review process or after the conventional book had been received for different participants. It is possible to hypothesise that this aspect of autobiographical memory – which comes closest to story-telling – is aided more by the shared experience of a life review process, or of showing a book to another person, whereas the movie may lend itself less to story-telling. The movie moves on at its own pre-set pace (without the intervention of the pause button), and the moment for recounting an anecdote, a story around a particular event, may be lost. The movie may be better suited to reinforcing personal factual information, with its multiple presentation of the life story, hence the good results on the PSS scale. However, it is important to note that in each case, the final score

exceeds the initial score on both sub-scales of autobiographical memory, despite some months having elapsed between these two time points.

It is of course important not to give too much weight to changes of a few points on these scales, in a small series of cases. There are measurement errors on each, and performance on a given day may be influenced by a variety of extraneous factors, including the person's health and mood. For example, the QoL-AD has a Reliable Change Index of 6.8 – reflecting the points change required to be 95% certain the difference in scores for an individual person with dementia is not due to chance (taking a standard deviation of 5.8 and Cronbachs' alpha of 0.82 from Thorgrimsen et al., 2003). Different assessors carried out the assessments at different points in time, potentially introducing other sources of variability, although all were trained to carry out the assessments, and the researcher (PS) carried out the baseline and final assessments personally. The study was not designed as a group study, and the group changes noted are to be viewed simply as a source of hypotheses for more rigorous, larger-scale evaluations. It does seem reasonable, from the six cases presented here, to hypothesise that the effects of a life story movie can reinforce and augment the effects of life review and conventional life story books, and that quality of life and autobiographical memory are appropriate outcome measures to consider. The positive outcome for the two cases where the baseline depression score was in the clinical range (4 and above), also suggests the value of the approach for people with dementia and depression would be worth exploring further.

Another limitation noted was the ceiling effect on ratings of the quality of the relationship on the QCPR. This was apparent with a few people with dementia after having the life story movie. However the ceiling effect was most obvious on QCPR ratings by relatives whereby some had already achieved maximum scores when the conventional life story book was presented. Therefore, further effects of life story movie on the relatives' quality of relationship with the person with dementia could not be assessed.

In this multiple case study, we have established the feasibility of creating digital life story books. Life story movies have the advantage over life story books in terms of the multimedia effects. People with dementia were fully involved in directing their movie, recording their own voice or their relative in narrating their movie. The songs, clips and background music stimulate memories from earlier life. All the participants expressed pleasure in viewing their movies. The relatives and staff reported a positive effect of the life

story movie on them as well as on the person they cared for. Based on feedback, discussion and observation no side or negative effects were reported or observed. For those people with dementia unable to operate the DVD themselves, staff may need additional prompting to make use of the movie, and a conventional life story book may be a useful supplement, rather than being seen as an alternative. This study prepares the ground for a larger-scale evaluation, with an appropriate control group.

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## Appendix 1

### Questions for Participants, Relative and Staff

- a. How did you feel about taking part in 'This is Your Movie' project?
- b. What do you think about your movie?
- c. Do you think this movie helped you in any way?
- d. In your opinion, what 'benefit' did you gain from your movie?
- e. How did the movie make you feel?
- f. Anything that you would change about your movie?
- g. Do you think that you will watch it again?
- h. Would you like others to see it?
- i. Which one do you prefer, the book or the movie?

### Questions for Relative and Staff as a proxy

- a. How did you feel about your relative (name)/ client taking part in the 'This is Your Movie' project?
- b. What does your relative / client think about the movie?
- c. Do you think this movie helped your relative/client in anyway?
- d. In your opinion, what 'benefit' did your relative/client gain from this movie?
- e. How did the movie make your relative/client feel?
- f. Anything that you would change about your relative's / client's movie?
- g. Do you think that your relative / client will watch it again?
- h. Would your relative /client like others to see it?
- i. Which one does your relative /client prefer - the book or the movie?

## Chapter 6: Discussion

## Discussion

This thesis has examined the topic of different approaches related to individual reminiscence work with people with mild to moderate dementia living in care homes. Reminiscence is a popular psychosocial intervention mostly implemented in group settings. Only a small amount of research has been directed at individual work. Previous literature reviews primarily reported the combined effects of group and individual reminiscence work as if constituting a single approach.

The exploration of earlier work on types and taxonomies of reminiscence clearly indicated that integrative reminiscence work is related to healthy ageing. In particular, the life review process may be viewed as a type of integrative reminiscence work with potential therapeutic effects.

Therefore, a systematic review is reported in Chapter 2, which aimed to explore for the first time the possible psychosocial benefits of individual reminiscence work with people with dementia (Subramaniam & Woods, 2012). The review concluded that both a structured life review process (Haight & Dias, 1992) and a specific reminiscence approach are related to greater psychosocial benefits than general reminiscence work. The individual approach (e.g. Haight et al; 2006; Lai et al, 2004; Morgan & Woods, 2010) in a one to one setting appears to have both immediate and long term positive effects. The empirical studies in this thesis built on the promising findings of this review on individual reminiscence work. The first empirical paper (Chapter 3) is closely related to Morgan & Woods (2010) work, and is in fact, a partial replication, as well as an extension of their work. One of the suggestions for further research by Morgan & Woods (2010) was that it is the life story book itself which may have the potential to induce greater therapeutic benefit.

Recent developments, especially since the CIRCA (2004) project, have indicated the beginning of a new era in using information and communication technology (ICT) in reminiscence work. A review (Chapter 4) (see review, Subramaniam & Woods, 2010) of this new but growing field indicated that personalised ICT based reminiscence work, which has much in common with life story work, is becoming popular. Preliminary reports indicated that some psychosocial benefits ensue for people with dementia. Therefore a second empirical study (Chapter 5) was conducted to test the usefulness and feasibility of using ICT based life stories (a movie) with people with dementia.

The following sections present highlights of the findings of this programme of research and discuss them within the existing body of knowledge. The clinical implications of the findings and their limitations are presented and recommendations made for future research.

### Empirical study 1: Summary of Findings and Discussion

This section highlights and discusses the key findings in empirical study one (Chapter 3): the primary research questions were (a) Does a life review intervention, resulting in a life storybook, have a positive effect on quality of life (primary outcome), mood, and autobiographical memory among older adults with dementia living in care homes compared with care as usual?, and (b) Does a life story book produced through a life review process improve quality of life (primary outcome), mood and autobiographical memory among older adults with dementia living in care homes, when compared with a life story book produced for the participant without their involvement? The secondary research questions were (a) Does involving a relative in the production of a life story book for a resident with dementia lead to improvement in the quality of their relationship as perceived by relative and resident?, (b) Does providing a life story book for a resident with dementia lead to changes in staff knowledge and attitudes?

The current study recruited 23 participants with mild to moderate dementia living in care homes. Participants were randomly allocated into two groups, the ‘life review’ group and the ‘gift’ group after baseline assessment. The eleven participants in the first group received 12 life review sessions based on a structured process over the period of three months. Meanwhile, the 12 participants in the second group continued with their usual care. The outcome measures were then repeated approximately three months from baseline assessment (follow-up 1). This design allowed comparison over time between the two groups to evaluate the effect of the life review process against treatment as usual. After this assessment had been completed, participants in the life review group received their personal life story book, which they developed during the 12 sessions of the life review process. Participants in the second group also received a personal life story book, but as a gift, as it had been developed by their relative(s) during the first 12 weeks of the trial without involving the participant. The same outcome measures were then repeated at six weeks follow up

(follow-up 2), during which time both groups had their life story books. This allowed a comparison of the effects of a life story book resulting from a life review with those of a life story book produced without involving the person with dementia. For each participant, the duration of the trial was approximately five months.

All 23 participants had a relative who took part in the project, with those in the gift group involved in the creation of the life story book, without any input from the person with dementia. It was thought that the process would have a positive influence on the quality of relationship between the person with dementia and their relative. Relatives and people with dementia were each asked to rate the quality of the relationship from their own perspective. These data were collected at baseline, 12 weeks later before the books were presented to participants (follow-up 1) and then 6 weeks after the participants and relatives had the life story book (follow-up 2). This allowed a comparison between the two groups of the quality of relationship rated by relatives and people with dementia at each time point.

A total of 68 care staff participated in the study and completed questionnaires regarding their knowledge of the resident and their attitudes towards dementia. These aspects were also assessed at the three time points, as for the other measures. This allowed an examination of any changes in staff knowledge and attitudes scores before and after the life story books were available.

In general, the results indicate that the life review sessions produce positive psychosocial benefits to people with dementia living in care homes. Participants who engaged in 12 sessions of life review reminiscence reported improved quality of life and autobiographical memory in comparison to the treatment as usual group.

However, there was no difference between outcomes at follow-up 2, when the treatment as usual group had been given their own life story book, produced without their involvement. After receiving their book, these participants showed an increase in quality of life and autobiographical memory scores, whereas the group who had undertaken a life review did not show further improvement.

The quantitative findings of this trial are supported by feedback from participants and case vignettes.



There was an improvement in quality of relationship, rated by relatives, after having life story book. People with dementia who had undertaken a life review rated the relationship as better (in terms of warmth) at follow-up 2. Staff knowledge and attitudes also improved at follow-up 2 after the life story books were presented to participants.

### *The Selection of primary outcome measures*

Although there is evidence that quality of life is could be a useful outcome variable (Kane, 2001), and that people with dementia are able to give a consistent, valid and reliable view of their quality of life (Hoe, et al, 2009; Woods, 2012), there is very limited research using quality of life as an outcome variable in research on reminiscence work with people with dementia. The self-report measure used in this study, the QoL-AD has been widely used with people with dementia (Logsdon et al., 2002; Thorgrimsen, et al, 2003) and recommended as an outcome measure in psychosocial research (Moniz-Cook et al., 2008) and was the primary outcome measure in a major randomised controlled trial of joint-remembrance work (Woods et al, 2009). In the current study participants understood the statements in the QoL-AD and responded well without any difficulties. This was consistent with the assertion that people with mild to moderate dementia are capable of rating their own QoL (Crespo et al, 2011; Mozley et al, 1999) and justifies the selection of this measure. The pattern of results in this study, and the significant findings suggest that the QoL-AD was a sensitive instrument in picking up effects of intervention.

Autobiographical memory and reminiscence are two associated sub-domains of cognition that have received less attention from researchers (Webster, 2003). The development of the AMI (Kopelman, et al, 1990, 1992) to measure autobiographical memory ability provides an opportunity to use a validated cognitive measure of particular relevance to reminiscence work. A number of studies have successfully used the AMI with older adults with dementia (e.g. Addis & Tippett, 2004; Caddell & Clare, 2012a; Caddell & Clare, 2012b; Naylor & Clare, 2008). Furthermore, the major trial using reminiscence work with people with dementia in community settings (Woods et al, 2009) included the extended AMI measure as one of the key outcome measures. Of particular relevance to this study, Morgan & Woods (2010) successfully used the AMI to assess the effect of the life review process on people with mild to moderate dementia living in care homes. However, it has been recognised that the original AMI does not provide good coverage of the mid-life years for participants in

their 70s and 80s. Naylor & Clare (2008) made use of the additional mid-life component included in the extended AMI, developed by Jones & Woods (2006), but pointed out that as this was not part of the original AMI, thus would affect any results obtained. Therefore, to ascertain the reliability of the mid-life AMI, an inter-rater reliability study was conducted as part of the current research programme. The results (presented in Appendix C) show good inter-rater reliability for all AMI sections, including the mid-life section. In this study, on some occasions, the administration of the AMI-E was split between two or three sessions when participants appeared tired or needed rest. Since autobiographical memory and reminiscence are closely related, the AMI-E measure has again proved to be a very useful tool to study the effects of reminiscence work. However, other cognitive measures would have been required to evaluate whether there is a more general effect of reminiscence as a cognitively stimulating activity.

Depression and mood are important outcome variables with people with dementia in relation to the effects of reminiscence work. This was indicated in the Cochrane review (Woods et al, 2005), and the NICE-SCIE guidelines on dementia care recommend the use of reminiscence for depression co-morbid with dementia (NICE-SCIE, 2006). The Geriatric Depression Scale is one of the most common outcome measures used to assess the level of depression among older adults, including those with mild to moderate dementia, and has been recommended where self-report is required (Moniz-Cook et al., 2008). For example, Morgan & Woods (2010) successfully used a GDS short form (GDS-15; Sheikh and Yesavage, 1986) with the person with dementia. Although that specific short-form (GDS-15) is a well-accepted tool to assess depression, some of the items are irrelevant and ambiguous for older adults with cognitive impairment living in residential care (see Sutcliffe et al, 2000). Accordingly, Sutcliffe et al (2000) refined the GDS-15 and developed a form of the Geriatric Depression Scale which caters specifically for older people living in care homes. This new measure also can be used with people with dementia. Therefore, this current study used the Geriatric Depression Scale (Residential) (GDS-12R). However, scores on this measure were relatively low, so that any intervention effects on mood were more difficult to ascertain. It may be that some of the symptoms of depression that are omitted from this short-form are commonly reported by care home residents, meaning that in previous studies residents appeared to have a higher level of depression.

Involving family members in the intervention process is common practice in reminiscence work (e.g. Haight et al 2003; Thorgrimsen, Schweitzer, & Orrell, 2002; Woods et al, 2009). However not many studies have investigated the quality of relationship between both the carer (relative) and the person with dementia. Recently the major joint- reminiscence trial included the Quality of the Carer-Patient Relationship (QCPR) as an outcome measure. Relatives in the present study were actively involved directly or indirectly in the intervention programme. Relatives for participants in the gift group were involved actively in creating a life story book for people with dementia. Meanwhile, relatives for participants in the intervention group were also involved by providing information and material for the life review and life story book. It was clearly appropriate to measure the quality of relationship from the perspectives of both the person with dementia and the relative. The Quality of the Carer-Patient Relationship (QCPR) was a suitable tool to assess both people, the person with dementia and relative, in that people with dementia had no difficulty in responding to the questions. Some tendency to a ceiling effect for relatives' ratings was noted in the second empirical study.

Care home staff are important people in interacting and working with residents with dementia on a daily basis. Although some reminiscence work research has involved staff directly in the intervention process (e.g. Haight et al, 2006; Lai et al, 2004), very seldom has the effect of the intervention on staff been reported (Subramaniam & Woods, 2012; Woods et al, 2005). The present research did not involve care home staff directly in the intervention process. However, the effect of the life story book on staff knowledge regarding residents and attitudes to dementia was of considerable interest. The previous staff knowledge questionnaires created and used by Baines et al (1987) in a group setting were not available. Therefore a new questionnaire was designed to assess staff knowledge about the life and preferences of the person with dementia. The Approaches to Dementia Questionnaire, (ADQ); (Lintern et al, 2000) was specifically designed to evaluate the attitudes of staff towards person with dementia. A number of observational studies have successfully used the ADQ as a measure with staff (e.g. Kada, Nygaard, Mukesh &, Geitung, 2009; Kang, Moyle, & Venturato, 2010; Macdonald & Woods, 2005; Moyle, Murfield, Griffiths, & Venturato, 2010), and internationally it appears to be the most widely used attitudes scale, evaluating both person-centred attitudes and the degree of hopefulness and optimism experienced by the member of care staff in terms of the difference he/she can make to the person's life and well-being.

### *The Effect of Life Review Process on Quality of Life*

The effect of life review on people with dementia has been tested on various outcome measures (e.g. Haight et al, 2006; Morgan & Woods, 2010) but not with quality of life. The current findings show that the life review process was associated with significantly improved quality of life of people with mild to moderate dementia living in care homes in comparison with usual treatment. The results are consistent with the systematic review finding on individual reminiscence work, which concluded that the life review process in a one to one setting produced beneficial effects (Subramaniam & Woods, 2012).

There is some other evidence on individual reminiscence work indicating subjective or perceived psychosocial benefits. For example, one to one specific reminiscence work based on a life story approach significantly improved participants' well-being as reported by Lai et al. (2004). Other studies have also reported life review reminiscence improves the level of life satisfaction (Haight, 1992a; Hirsch & Mouratoglou, 1999).

The interpretation of the improvement in quality of life in the life review condition after engaging in the life review process is complicated by the lower quality of life score of this group at baseline compared with the group who had treatment as usual during this phase. In any distribution of scores, extreme scores at the first assessment are likely to be closer to the mean score at the second assessment, a well-known phenomenon described as 'regression to the mean'. Of course, the difference at baseline was controlled for statistically, using ANCOVA, and the difference arose by chance, as the randomisation procedure was rigorous and robust.

In support of this constituting a real effect, many participants in the life review reminiscence group indicated appreciation, excitement and feeling good about taking part in life review sessions. This is consistent with suggestions from Woods et al (1992) and Morgan & Woods, (2010) that participants enjoyed talking over life experiences and look forward to life review sessions. These positive feelings may be seen as contributing to the plausibility of the significant improvement in quality of life.

The recent large scale randomised controlled trial of group reminiscence work for people with dementia (Woods et al., 2012) did not show any improvement in quality of life for people with dementia. The benefits of individual work over group reminiscence work may be attributable to those undertaking life review having more time to engage in discussion and

conversation. The larger the group size, the less the opportunity for the person to speak and share his or her history. In addition, in individual settings a highly personalized approach was possible compared to a group setting, which typically involves general discussions based on specific themes. Therefore, when engaging in a one to one life review process, the person may feel valued and this could influence his or her perceived quality of life. Relevant earlier work also claimed that the life review process helps an older adult to adapt to their life environment (e.g. Beuchel, 1986; Molinari & Riechlin, 1984-85; Thornton & Brotchie, 1987) even in a state of transition and crisis, such as moving from home to long term care (e.g. Romaniuk & Romaiuk, 1981). Engaging in life review has been said to help an individual in residential care to cope with stress from his or her environment (Kiernat, 1979). These may all be relevant factors in understanding the results of the current study.

#### *Effect of the life review process on autobiographical memory*

Cognition is a common outcome variable to study in relation to the effects of reminiscence work (e.g. Baines, et al. 1987; Wang, 2007). It is well accepted that dementia involves progressive decline in cognitive function. Therefore, cognitive function is an important indicator of the progress of dementia. One cognitive marker could be how much information is retained about one's own personal autobiographical memories. Therefore, the AMI-E results in the current study could be related to disease progress.

Participants who attended life review sessions showed a marked improvement in the ability to recall autobiographical memories immediately after the completion of the life review. Clearly, the life review process had provided an opportunity for people with dementia to discuss and rehearse their own life history, which led to the stimulation of memories of past experiences and triggered 'forgotten' memories'. The findings are consistent with those reported in Morgan & Woods (2010) study.

Haight et al (2006) also reported that life review reminiscence using LREF improved cognitive ability. However, the tool they used to measure cognitive function was the Mini-Mental State Examination (Folstein, Folstein, & McHugh, 1975) a widely used cognitive screening tool, which includes items on orientation and new learning. Additionally, previous studies using reminiscence work in group settings have reported improvement in participants' cognition (e.g. Baines, et al. 1987; Wang, 2007). This is paralleled with literature review

reports that reminiscence work produces positive effects on cognition (e.g. Cotelli et al, 2012; Kim et al, 2006; Woods et al, 2005). Although the current study supports previous reminiscence work on improving cognition with people with dementia, the absence of a more general cognitive screen in the current study does not allow any conclusion regarding general cognitive function, although the domain of cognition evaluated – autobiographical memory – was studied in depth. Thus, this study is able to establish the direct link between reminiscence work and the ability to recall one's own past experiences, but not to indicate a general stimulation of cognitive function.

### *Effect of the life review process on Depression*

Surprisingly participants in the current research had depression scores, assessed using the GDS-12R, on average well below the clinical range from baseline to the end of the research trial. This was in contrast with previous reports that depression is highly prevalent among older adults living in residential care homes (see e.g. Seitz et al, 2010; Snowden, 2010; Snowden & Purandare, 2010). Apart from the use of a slightly different measure discussed previously, a possible explanation is that participants with a low level of depression were selectively referred to the project, perhaps being seen by the home manager as the best potential candidates from their home. This may have led to participants with less mood disturbance. So this study could not replicate the effects of life review reminiscence on depression with people with dementia as reported by Haight et al (2006) and Morgan and Woods (2010). These studies demonstrated that people with dementia improved in mood or reduced in depression after engaging in life review sessions. They reinforced the suggestion that the life review process is a useful treatment for reducing depression for older adults in institutional settings (Haight et al, 1998; 2000). This is consistent with previous findings that reminiscence work in group setting improves the mood of a person with dementia (e.g. Bass & Greger, 1996; Huang, Li, Yang, & Chen, 2009; Kiernat, 1979; Wang, 2007).

The present research is a good indicator that the life review process is not associated with an increase in depressed mood, as no negative impact on the participant's mood was observed at the end of the life review process. This is in contrast to some reports showing that reminiscence work may increase depression level (e.g. Hewett, Asamen, Hedgespeth & Dietch, 1991 ; Malde, 1988). In the current study, life review maintained participants' mood below the clinical level despite some of the LREF questions having the potential to trigger

unhappy memories. This may be due to the nature of the life review process which required participants to review their experiences, evaluate them, accept or cope with negative memories and move forward, thus providing some relief for them. Also, it is suggested that life review helps older adults to cope with past conflicts and unpleasant memories and finally to bring meaning into their life (Westerhof, Bohlmeijer, & Webster, 2010). The therapeutic relationship, based on Rogerian principles between reviewer and therapist, provides emotional support and other psychological assistance for participants to successfully engage with difficult past experiences in the life review process and so helps a reviewer to engage in life review more positively.

### *Effect of the Life Story Book*

The findings on the effect of the life story books on participants show that there is no difference between the life review group and life story book as a gift group at follow-up 2 assessment (having adjusted for baseline scores). This can be interpreted as indicating that life story books created either by the person with dementia through a life review process or by relatives without involving the person have similar effects, with both related to improved quality of life. As expected, the effect of the life story book was viewed positively and encouraged by participants, family members and care home staff.

The effects of the 'gift' life story books are consistent with Morgan & Woods (2010) argument that life story books could be a major therapeutic vehicle in their own right. Additionally, they support the idea that recalling past life events is more likely using the life story book rather than actively recalling their memories (Naess, 1998). The use of memorabilia to prompt memories in the life review process is highlighted (Sherman, 1995). Even during the life review sessions, recalling and engaging in life review process was much easier with relevant personal pictures and other significant tangible items than when relying on the LREF alone. The life story book acts as an external stimulus to stimulate and trigger information from memory storage. For example, the case vignette of Nell was representative of participants in the life story book as a gift group, where she stated the book triggered memories for her.

The life story book could also play a role as a 'maintaining tool' that maintains and prolongs the effects of the life review process for participants in the life review group. The

improvement obtained from the life review process in quality of life and autobiographical memory was reasonably well maintained after participants received their own life story book as observed at the follow-up assessment. The life story book as a ‘maintaining tool’ was highlighted in the case vignettes of Mary and Gwen, where the effect of the life review process was maintained at six weeks follow –up assessments.

The life story book appears to be a valuable therapeutic approach to aid a person living with dementia. Although, from this study, we can conclude that the life story book is a major therapeutic tool regardless of the way it is created, either involving the person with dementia or without them, experts have argued strongly that the life story book must be produced by involving the person with dementia (e.g. Gibson, 2004; Haight et al, 2003). For instance, Gibson (2004) argued the process of creating the life story book is more important than the final product itself i.e. the life story book. Putting the person’s life into perspective is vital for the older adult (e.g. Gibson, 2004, Kunz and Soltys, 2007) and engaging in a life story book involving a person with dementia would help the person shape the narrative of his or her life as they lived or as they want to see it. The life story book created by relatives or others without involving the person with dementia cannot be completely from the person with dementia’s perspective. One way forward may be for the life story book to be created involving the person with dementia but not necessarily by the life review process.

### *The Effect on Quality of Relationship*

For the QCPR, total scores, incorporating both subscales Warmth and Absence of conflict or criticism, of 42 and above are seen as an indication of a good quality relationship. It is worth highlighting that all the participants and relatives in the study were on these criteria enjoying a good quality of relationship throughout the study. Therefore, in the present study, the QCPR results reflect potential for additional improvement rather than indicating that relationship difficulties have been resolved.



i. Rated by person with dementia

There were no significant changes in perceived quality of relationship for participants in both groups for the first three months (at follow-up 1). However, there was a significant difference at follow-up 2, with the life review group showing higher ratings of warmth than those in the gift group. However there is no difference noted in the absence of conflict and criticism sub-scale throughout the study.

ii. Rated by relative (s)

The finding was contrary to our initial assumption, which was that relatives in the gift group preparing a life story as a gift for the person with dementia would show improved quality of relationship. There are no significant differences on the QCPR's subscales between the groups at any assessment. However, regardless of group, relatives reported a significant improvement in the quality of relationship on both subscales after the life story book had been available for 6 weeks at follow-up 2. This may be due to the life story book's role in increasing communication and enhancing interaction (Woods et al, 2007). This finding was supported by relatives' comments after having the life story book, such as 'now we can have more meaningful conversation...less repetitive questions'. It is interesting to note that relatives report less conflict and criticism in the relationship at the final assessment than the people with dementia, a reversal of the typical discrepancy.

In general, participants in the present trial were receiving at least a weekly visit from their relatives, with some of the participants receiving multiple visits from a number of different relatives in a week. Apart from engaging in casual conversation, sometimes participants and their relative engaged in other activities e.g. a short walk outside the care home, tour by car around town, enjoying tea or coffee together at a shop and so on. Therefore it is likely that participants referred by care homes for the present study were already enjoying a good level of relationship with relatives. In fact, an inclusion criterion of the present research was to have a committed relative able to give consent and to assist in the project. This does mean the sample does not include the many residents without relatives, where it may be more difficult

to produce a life story book, as it is more difficult to obtain information, pictures and memorabilia.

### *The effect on care staff*

The present study showed a significant improvement in staff knowledge after having life story book, consistent with previous findings from reminiscence groups (Baines et al., 1987). Also for the first time the present study reported improvements in staff attitudes towards residents with dementia after the life story book was produced. This empirical evidence shows the richness of the life story book's impact on care staff. The link with the life story book is strengthened by the lack of change at the intermediate assessment.

These findings are important, and reinforce the role of life story work and biography in developing person-centred care.

### Empirical study 2: Summary of Findings and Discussion

The aim of the second study was to establish an evidence-base for the acceptability and efficacy of using multimedia digital life story books with people with dementia in care homes, in comparison with conventional life story books, taking into account the perspectives of people with dementia, their relatives and care staff. To pursue this aim, the existing traditional life story book created in study 1, was reconstructed and incorporated using information and communication technology into a movie format. A total of 6 participants were purposively selected and a participatory design was used. Each participant was given full control over their own movie and the researcher acted as a co-editor together with the participant. Family members also helped in providing relevant information and material for the ICT based life story movie. The product was presented as a life story movie to participants, relatives and care home staff to be watched with the person with dementia. The same questionnaires used in study 1 were repeated, together with semi structured interview questions with participants, relatives and staffs.

The findings clearly established that the process of creating a life story movie was a feasible approach with involvement of the person with dementia. This was consistent with Smith et al. (2009), which qualitatively established the feasibility of developing multimedia

biographies with people with dementia. However, the process of creating a life story movie using participatory design is time consuming as has been highlighted in several previous studies (e.g. Massimi et al, 2008; Topo et al 2004). The researcher in the present study developed the movie without any previous training or experience in using ICT in this way. The participatory design worked well with the person with dementia and was in keeping with person centred care. The person with dementia and his/her relatives were actively able to engage in the development process of the life story movie, giving valuable input. The idea that the participant's role is as director of their own life story movie was evident in several previous studies (e.g. Damianakis et al, 2009; Massimi et al, 2008; Topo et al, 2004; Waller et al, 2008). However not all the previous research involved the person with dementia in the process of selecting material or in exercising editorial control (e.g. Alm et al, 2004; Cohen, 2000; Cohene et al, 2005; Kuwahara et al, 2006; Sarne-Fleischmann and Tractinsky, 2008; Tamura et al, 2007; Yasuda et al, 2009:). The present study showed that the creation process and usability of ICT based life story book was feasible with people with dementia. The digital life story movie was well accepted by people with dementia, relatives and care staff.

In this personalised approach, the materials used were significant and meaningfully related to participants. Apart from photos, the other items included were favourite songs, music, clips and so on. This was in accordance with the majority of the previous ICT systems which were created with a personalised focus (e.g. Damianakis et al, 2009; Massimi et al, 2008; Sarne-Fleischmann & Tractinsky, 2008; Yasuda et al, 2009). However the approach was contrary to some studies that used generic material (e.g. Tamura et al, 2007). Participants' quantitative and narrative reports clearly support the personalised approach in a one to one setting as producing beneficial effects, and was preferred by most participants, relatives and staff.

The core finding of this research indicated that participants with dementia, relatives and staff members viewed the life story movie positively. Five participants showed additional improvement in quality of life after receiving their life story movie. The improvement in participants' perceived quality of life was also supported by the participants' positive narrative feedback about their life story movie. Although Nia showed a reduction in her perceived quality of life, her feedback on having her life story movie was positive and encouraging. The possible reason for Nia having a reduced QoL-AD score may be due to her rapid health deterioration and pain that seriously limited her mobility. On the autobiographical memory measures, five participants showed additional improvement in the

ability to recall past factual experiences. This is consistent with the narrative findings based on semi-structured interviews with participants. However, there did not appear to be parallel improvements on the autobiographical incidents sub-scale, suggesting that the movie is not encouraging story telling abilities. Five participants showed improvement in depression and the sixth had a stable depression score. This finding was consistent with participants' excitement towards their movie which included favourite personal songs, clips and music. There is a clear indication that most participants preferred their life story movie over the traditional life story book. The indication of a preference for the ICT approach over traditional ways of presenting material for reminiscence work was also highlighted by Waller et al. (2008).

The qualitative data were used to understand responses towards life story movie from participants with dementia, relatives and care staff. The qualitative approach was consistent with previous research (e.g. Sarne-Fleischmann and Tractinsky, 2008). Generally, the development of the life story movie was seen as easy, fun and enjoyed by people with dementia and their relatives. The key theme emerging from the participants' point of view was that the movie is very stimulating and triggers and brings back memories. This was consistent with previous findings (e.g. Damianakis et al, 2009; Waller et al, 2008). People with dementia also perceived watching their personalised life story movie as an enjoyable activity, bringing happiness and satisfaction. This is parallel with other findings (e.g. Sarne – Fleischmann, 2008; Waller et al, 2008; Alm et al, 2004). Relatives, reporting on behalf of the person with dementia also reported similar themes. Staff as proxy's key themes related to the enjoyment for the person with dementia, and its encouragement of conversation.

Relatives also reported positive emotions in response to the movie: 'happy', 'enjoyed', 'excited' and 'feeling good' were common comments. These findings on relatives' experiences in the life story movie project are consistent with prior ICT based reminiscence work (e.g. Alm et al, 2004; Massimi et al, 2008; Damianakis et al, 2009). Staff feedback was mainly around the improved knowledge and information about the person with dementia that they now had, and how this could lead to a better relationship, interaction, and enable positive care. The staff reactions and responses about ICT based life story book are consistent with numerous previous studies (e.g. Alm et al, 2004 & Sarne-Fleischmann and Tractinsky, 2008). Overall, based on participants', relatives' and staff narrative information, the use of ICT to 'upgrade' existing paperback life story book with personalized multimedia effects presented

as a life story movie appears worthwhile and could provide important psychosocial benefits. The present study did not observe any major side effects of the system.

### *Generic vs. Personal Items*

This study also suggested that people with dementia were able to reminisce happily using personalised items. Usage of personal materials, mostly significant photos of participants throughout their life cycle, provides opportunities for the participant to actively engage and reminisce. This finding is consistent with earlier findings of Yasuda et al (2009) that the majority of participants increased in their attention to a personalised video compared with a generic video. Even carers recommended the use of personal materials when only generic material was provided for people with dementia in one of the pilot studies (Alm et al, 2004). However, these results contrast with the findings and arguments of Astell & Ellis (2010), who have suggested personal item are perceived as a memory test, and are less effective prompts, whereas generic materials spark off multiple recollections that enrich the reminiscence process. The present results do not support this view. Almost all the participants indicated their personal life story book and movie was very stimulating and triggered their past memories. Relatives and care staff also reported that the person with dementia provided rich and new information each time he/she went through their personal life story book. The current study concludes that engaging with a personal life story book or movie helps the person with dementia to be more involved in conversation and to tell their life stories; this leads to positive emotions and improved quality of life.

### *Promote Person Centred Care*

This study also clearly supports the idea that life review/life story book or movie approach promotes person centred care as indicated in previous research (e.g. Haight, 2006; Mckeown et al, 2010; Wills & Day, 2008). The person with dementia, as a living person with a unique mixture of personal history and their individuality has been recognized by using the life review/life story book and movie approach. As emphasised by Gibson (2004) good quality care follows from respecting individuality. The creation of a life story book and movie upholds the individuality and provides dignity to a person with dementia. Kitwood (1997) pointed out that people with dementia lose their past experiences which makes it difficult for

them to make sense of their situation and understand their self. Therefore the life story book is an essential element to understanding people with dementia and moving towards person centre care. Life story books provide information and knowledge and help in understanding a person's behaviour and emotions, thus fostering sensitivity, kindness, appreciation and empathy towards the person with dementia (Pointon, 2010). As said by Gibson (2004) the book 'enlarges' people's capacity to feel for the person with dementia.

### *Issues with Life Review Process*

Experts have indicated that the life review process is not a therapy but can be viewed as a therapeutic tool (Birren & Cochran, 2001). The implementation of the life review process is not without any issues. The practical issues faced in implementing the life review process in the present study are consistent with Morgan & Woods (2010) study, for example;

Based on the present research experience, not everyone willingly or happily wanted to take part in a life review process. This contrasts with Butler's (1974) idea that life review is a universal occurrence. He emphasised older adults in their final phase of life would become involved in reviewing their own life. But in this study not everyone wanted to review their own life history. This was apparent in the difficulties faced by the researcher in recruiting participants. Although many older adults with dementia were eligible for the study, a number refused to get involved in the life review research. This is supportive of the idea that not all people enjoy reminiscence and reminiscence does not suit everyone (Gibson, 1994). This also was consistent with Naess (1998) report that the life review process is not suitable for all older adults, some older adults may be reluctant and not interested in talking about their personal life history. Thus, no one should be coerced into reminiscence (Gibson, 1994).

Researchers in the reminiscence field have pinpointed the possible danger of reminiscence work and that it may not be suitable for everyone (Coleman, 1986). For example Butler (1980) lists at least 3 types of person that would not benefit from engaging in a life review process; (a) a future oriented person that still wanted to achieve in his/her life, (b) criminals, who intentionally harmed others and (c) those who are arrogant and full of pride. These 3 types of people would be unable to resolve issues in their life and could end in despair as not all reviewers would achieve ego integrity by engaging in the life review process. Recently, experts have postulated that the type of reviewer also plays an important

part in the life review process. For example, Haight & Haight (2007) named six types of reviewers; storyteller, reluctant reviewer, external reviewer, creative reviewer, denying reviewer and bleeding reviewer. Briefly, the reluctant reviewer is not ready to talk about past memories; external reviewer is not ready to talk about personal past memories; creative reviewer's stories influenced by what he or she wishes to be true and sometimes not aware of the difference; the denying reviewer blocks or refuses to acknowledge his or her past unpleasant memories; and the bleeding reviewer who believes they went through unimaginable difficulties in life and feel self-pity. Only the storyteller reviewer is seen as the ideal type of reviewer for the life review process. In the current research, the majority of participants in the life review group fitted with the 'storyteller reviewer' type. However, there was variation between sessions and stages of the life review progress in the LREF. For example, some participants would usually be a 'storyteller reviewer' but in the following session would be 'reluctant reviewer' or perhaps 'creative reviewer'. This variation may be due to participants having a bad day or bad mood as highlighted by Tabourne (1995) contributing to participants' responses to the LREF. On the other hand, stages in the LREF also play an important role in influencing participants' activity level and engagement in the life review process. For example, most participants provided rich information and were very responsive reviewing their childhood section in the LREF compared to the mid-life section or late adulthood. This supports the idea that people with dementia perform better in their remote memories compared with recent memories. The more recent the memories, the more difficult, cognitively, the life review process becomes. This was very evident especially with a few participants who were on the borderline between moderate and severe dementia. However, different participants might also have particular emotion-based difficulty with certain life periods, of course.

Individual progress in life review sessions moves at a different pace according to the person's cognitive and emotional abilities. This observation is consistent with Morgan & Woods (2010) report. Some individuals wanted to spend more time and sessions talking about certain life events or a period in their life over other life periods. The life review process is accordingly more feasible in a one to one approach that takes into consideration a person's cognitive ability and emotional needs. This makes life review in the individual modality more efficient (Haight & Dias, 1992). Life review in the individual setting allows the review process to be adjusted according to individual needs. This is important because life review is a type of reminiscence work that can be cognitively demanding (Woods et al,

1992), and requires more cognitive skills and organizational sequencing that may pose difficulty for a person with dementia (Haight et al, 2006). Therefore, no one should be hurried in the reminiscence process and the process must be according to the participant's wishes (Gibson, 1994).

It was apparent in the present study that it was difficult to conduct life review with older adults with dementia without tangible items e.g. photos and other memorabilia. Recall and recollection is very much facilitated and helped by external prompts. For example, a few childhood pictures would help the reviewer to engage in the LREF childhood section. The pictures would help participants be more focused and at the same time the researcher was able to ask questions surrounding the participant's childhood memories based on the LREF questions. The life story book is also very important as a tangible aid to link or bridge between sessions. For example, the start of each session was much easier with a draft life story book from the previous session. The person has difficulty recalling what was he or she was reviewing in the previous session. Therefore the draft life story book will remind the person about the previous discussion and help him/her engage in the following session. Thus the role of the draft life story book is important to give a feeling of continuity for the person with dementia in the life review process.

Almost half of the participants in the present research experienced sadness and grief during the life review process due to discussion of losses of significant people in their lives e.g. death of wife, children, husband. Also, a few participants shared memories of traumatic experiences e.g. war experiences, domestic violence and sexual harassment during the life review process, which were associated with a range of emotions, including distress, anger, guilt, and sadness. As the life review process progressed and with continued support from the therapist, participants were able to 'settle' and move forward. No serious harmful effect was observed or reported in the present research but recalling painful memories did make participants emotional, saddened and distressed. Lewis & Butler (1974) point out that life review has the tendency to evoke regret and sadness. The main possible harmful effect recorded in the literature is depression (Hewett et al, 1991; Malde, 1988), but in extreme cases there is the potential for a person to feel that he or she had an unworthy life and may lead to suicidal ideation (Butler, 1974). The present findings do not give any indication of increased risk of depression. By providing professional support and assistance, participants were able to cope and move forward to the next life cycle stage in the life review process. This was consistent with Kunz and Soltys (2007) suggestion that recalling and sharing past



painful memories provide a good chance for accepting negative life events, emotional healing and also that painful experiences could help a person to face current difficult times. Lewis & Butler (1974) accept that most reviewers are able to reconcile, accept and find meaning in their life. The support of a well-equipped listener is important to facilitate life review process to induce positive effects.

The process may not be suitable for everyone and only those you are willing and accepting to engage in the life review process should continue with the process. The therapist must respect the reviewer's choice and decision including the person's choices for avoiding any of the questions in the LREF. Therefore, the application of the LREF should be used flexibly as a guideline to conduct the life review process. If the person demonstrates highly disturbing emotion or behaviour at some point in the life review process, it may be necessary to discontinue and provide support before continuing with sessions. Understanding something of the person's history from relatives before engaging in the life review process would be useful preparation for the sessions. It is suggested then that the life review process requires a trained helper equipped with knowledge and skills, in relation to the nature of dementia, Kitwood's person centred approach, cognitive processes, the life review model and counselling skills (Rogers' approach, 1980). Trained staff need supervision from a person with experience in the field as observed in Haight et al (2006) and Morgan & Woods (2010) studies. The important of good preparation, including resources (e.g. photos) and training (Haber, 2006) before commencing life review sessions was also apparent in this study. As for the present research, the therapist benefitted from training and supervision from experienced professionals in the reminiscence field.

Overall, the life review process is an enjoyable experience for people with mild to moderate dementia living in residential settings. Almost all the participants engaged in the life review process were pleased with the opportunity to 'see back their life'. The present results together with qualitative and anecdotal evidence strengthen the argument that the life review process based on LREF is a useful therapeutic approach. However the implementation of LREF should be flexible and individually tailored according to the person's cognitive and emotional ability. The life review process should facilitate the person to review his or her life in the way they want to view it. The therapist should play an active listening role according to Rogerian counselling principles. Personal items and the draft life story book are important ingredients in facilitating the person with dementia to engage in the life review process. Finally, the life review process needs to be conducted with caution in order to maximize its

therapeutic effects and minimize the risks of unwanted effects e.g. grief, sadness, anger etc. predominating.

### *Clinical/therapeutic Implications*

Generally, dementia is seen as an irreversible condition and progressive, leading to an expectation that treatment may have very few benefits. However in this research, despite the progressive nature of dementia, people with dementia still showed the potential to improve in both memory function and, more importantly, their perceived quality of life. These improvements were associated with life review reminiscence and life story books developed either by involving or without involving the person with dementia. These results should provide the impetus for care staff, activity officers and mental health professionals to use life review and life story books as a part of care plans to improve and maintain the quality of life, cognitive function and mood of individuals with dementia as long as possible.

The present study confirms that life story books have a rich therapeutic value. This study provided empirical evidence about the usefulness of life story books. The book either developed with or without the person with dementia has positive effects. Although the current scientific evidence supports the usefulness of a structured life review process with people with dementia, the life story book is observed to have a uniquely useful therapeutic role. The life story book itself emerges as a therapeutic agent, able to induce psychosocial benefits for people with dementia even if the book was developed without their involvement. This is a novel finding. As commented by some of the participants, relatives and care staff, the life story book is a 'great gift at right time'.

The life story book also has therapeutic elements to improve the quality of relationship as indicated by relatives. The book has a positive effect on care staff knowledge of and attitudes towards people with dementia. Therefore, the clinical recommendation from this study is that the creation of life story books should be integrated in care homes as part of the care management plan.

The life story books and life story movies had a significant impact on the care homes involved in the current study. Even some of the senior management were surprised with the amount of new information they had gained from the life story books of the residents that took part in this project. Care home staff and relatives suggested that each resident should

move in to the care home together with their own life story book. Many care home senior staff agreed that life story books and movies are the way forward for person centred care. Some of the care homes that took part in the present trial went on to start to develop life story books and movies for their residents.

The participants' relatives felt that they had done something good and meaningful for the person with dementia. For example, several relatives reported that the book enabled them to spend quality time with participants and reduced repetitive questions from the participant. Relatives also made extra copies of the life story book/movie for other significant family members of the participant. Some relatives also started to develop a life story book and movie for other older adults in their family. Perhaps it is timely to consider making a life story book a compulsory activity plan for each person with memory difficulties in a care home. As indicated in this study, relative(s), with some guidance, also can play an important role by developing a life story book before the person with dementia moved to care home. Entering the care home with a, life story book will enhance the prospect of person centred care.

The life review process (carried out by a trained and supervised practitioner) and the life story book/movie intervention are not associated with adverse or negative effects as typically associated with pharmacological treatments. No side effects outside sessions were observed or reported throughout the project. As stated previously, for beginners to use the life review process the person needs some counselling skill, training and supervision. However the life story book and movie is suitable to be developed by a relative or member of care staff (with input from a relative) with the person with dementia as part of individualized care. Certainly the process of developing a life story book can be a highly enjoyable activity.

The clinical effectiveness of digital life story books for people with dementia shows great potential as an alternative mode for developing and presenting the life story book. The life story movie with multimedia effects was very well received by people with dementia, relatives and care staff. People with dementia reported more excitement and perceived enjoyment by engaging with the life story movie compared with the life story book. This was reflected in one of the participant's spontaneous comments on his life story movie 'Initially I thought the life story book was the best until I see the movie'. These findings imply that people with mild to moderate dementia may be highly entertained, and have memories stimulated in an enjoyable way by watching the movie. Therefore, a recommendation from

the project would be that life story movies should be incorporated into care home activity to create enjoyable reminiscence activities with people with dementia.

## Limitations of the study

### *Baseline Differences*

It was unfortunate that the baseline score or starting point before intervention begins for the life review group was much lower on the primary outcome measure compared with the gift group. As planned, all possible measures were taken; (a) the randomization method was determined using expert advice from NWOORTH, an accredited trials unit; (b) the randomization system was set up and controlled by an independent person from NWOORTH; (c) All the participants were strictly selected according to explicit inclusion criteria (d) All the data were only entered for analysis after all the participants completed the trial. However demographically there is no statistical difference between the groups. As discussed previously, the baseline difference is likely to be a chance finding, and has been controlled for in the analyses statistically. Measurement error is associated with the various assessments (in people with and without dementia), and some extent of variability in people with dementia is to be anticipated.

### *Participant recruitment*

- The sample size was 23 participants, 11 in the life review group and 12 in the gift group. This sample size was the minimum requirement for the current preliminary study, based on the effect size reported by Morgan and Woods (2010). Initially, the target number of participants was 34, but this figure allowed for loss of participants through attrition, which was largely avoided in the current study. Participant recruitment was one of the most challenging aspects of the present research. The difficulties in recruitment were attributable to the strict inclusion criteria for the project; the need to involve both the person with dementia and their relatives; and lack of interest from management in some care homes. Some family members and people with dementia see 'no hope' with dementia illness, and so saw taking part in research as a 'waste of time'. The lack of awareness among family members and care home

management about reminiscence therapy as an enjoyable activity made it difficult to interest them in the research project. The participants were selected by care home management. Usually the senior management staff would shortlist people with dementia from the total list of residents in their care home. Based on staff experience, often the most 'cooperative' or 'easy to work with' person would be shortlisted and given the opportunity to enrol into the trial. Therefore there is a high probability that the sample is biased towards the 'best' volunteers. As mentioned previously, less depressed residents may have been selected by care home managers, producing a potentially biased sample. Also based on observation, not all the residents with dementia were given the opportunity with their relatives to be considered for the research by care home management. Thus there may be limits to the generalizability of the current findings.

- The study was powered to detect a large effect size, and so if there were a small to moderate difference between the life review and 'gift' groups this would not have been detected – a Type II error. We can only conclude that any difference was not large.

#### *Lack of active control group*

It is not clear whether the improvement in the life review group is mainly due to the life review process per se. Potentially, the improvement noted may be due to social contact and attention, or to a combination of life review and social contact. The lack of active control in the present study is a limitation in relation to conclusions regarding the specific effects of life review therapy.

#### *Single therapist*

The generalizability of the research is also limited as all the life review therapy was delivered by a single therapist. It is not certain if the same result would be produced if a different therapist conducted the intervention. There may be non-specific factors specific to individual therapists.

### *Multiple statistical tests*

The multiple statistical tests used across the study may increase the possibility of obtaining statistically significant result by chance. For example, the finding of a significant change in the person with dementia rating of the relationship at the final follow-up may be a chance finding. In general, efforts were made to mitigate this effect e.g. by pre-planning analyses and by the use of Bonferroni corrected post-hoc tests, and so this was not a major limitation.

### *Floor and Ceiling effects*

As mentioned previously, depression scores were generally low throughout the project, offering little room for significant change. The effects of the digital life story book on quality of relationship rated by both participants and relatives achieved near-maximum scores after the life story books had been completed, leaving little scope for further positive change. The six participants in the digital life story book study were clearly amongst those with the highest quality of person with dementia / relative relationship.

## Research Design Limitation

### *The lack of a systematic qualitative approach*

The present study mainly focused on quantitative approaches to evaluation. The qualitative aspect of this research in the first empirical study was not systematically planned. As the trial progressed the researcher realized the ‘rich’ information that was being provided spontaneously by participants, relatives and staff was invaluable qualitative data, and attempted to record as much as possible in note form. In retrospect, permission to tape record interviews with participants should have been sought from the NHS Ethic Committee. Most of the participants’ reactions to the LREF and life story book were recorded verbatim in written form and reported as a qualitative data. In fact the qualitative data so obtained were very useful in reinforcing the quantitative findings. In the second empirical study, a more systematic approach was taken, but it is acknowledged that the data collected and the thematic analysis employed provide qualitative information at a largely descriptive level. More in-depth interviews may have allowed richer analysis of the experience of participants

viewing their life story as a movie. Observational techniques might also have been adopted, looking for example at non-verbal reactions to the movie.

### *Short Follow up Period*

The first empirical study only conducted a six week follow –up assessment to evaluate the effects of the life story book, developed with or without involving the person with dementia. At six week follow-up assessment the results show a very positive effect of the life story book. It would be important to know whether the books continue to have value after more time has elapsed, and how much of the effect is related to the novelty of the experience. The same consideration would apply to the movie also, of course.

### Key Recommendations for Future Research

Researchers could consider the many limitations highlighted above to improve future research. Further research should validate these findings by replicating the present research to establish the positive effects of life story books with people with mild to moderate dementia. Nonetheless the replication of the study should include a larger sample size to overcome the limitations faced in the current trial. The increase in sample size also would facilitate the generalization of future findings. Also, the same outcome measures that have proven sensitive to the intervention effect should be retained. Additional cognitive measures could be used to establish whether there are general effects on cognitive function beyond those identified in autobiographical memory. Efforts to include more people with dementia with depression should be made. Additionally, the follow–up phase also should increase to 3 months or more. There is also scope for future studies to focus on a qualitative approach to fully understand the effects of life review/life story book. The relatives and care staff also should be considered as part of the assessment.

The future design should include another condition to control for social contact. The social contact should be equal in terms of number of visits and time engaged in general conversation as for the life review group. The general conversation during social contact needs to be carefully outlined to avoid discussing past memories e.g. general reminiscence or simple reminiscence. Basically the social contact should act as a placebo for the life review

process. The need for having a placebo for reminiscence work was highlighted by Cotelli et al (2012).

However, perhaps the priority for future research is to explore further how to produce an effective life story book or movie, without going through a life review process, but allowing the person with dementia some input into and control over the process. Here the 'placebo' might be a special book about a topic of interest to the person, presented to the person with dementia, or a DVD perhaps of generic interest (such as those that recount news stories from a particular year). Each might stimulate the person's memory and interest, but would not have the personal relevance and impact of the materials developed in the current study.

So far there is no large scale research on the application of ICT based reminiscence work with people with dementia either in community or residential care settings. Therefore it is timely to improve the methodological approach using a larger population with dementia to study the psychosocial benefits of using ICT based reminiscence work. For example future research may be able to use experimental design to understand the benefits.

## Conclusion

In conclusion, this thesis has reported on some of the most recent literature and empirical evidence in the field of individual reminiscence work. Individual reminiscence work, based on a life story book has been shown to have benefits for people with dementia, in terms of quality of life and autobiographical memory. However, it requires a trained, skilled and supervised therapist to deliver. Life story books produced by relatives without the involvement of the person with dementia have been shown to have comparable effects. The effects of life story books on relatives, in terms of an improvement in relationship, and staff, in terms of improved knowledge and attitudes have been clearly demonstrated. Digital life story books have been shown to be feasible, and some indication provided that they may result in further improvements in quality of life and factual autobiographical memory. Apart from contributing to existing knowledge, the findings of the thesis also provide hope for relatives and care staff to improve quality of life for people with dementia. The thesis adds to the weight of recommendations for life story books to be widely used in dementia care.



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## Appendix

### Appendix A: NHS Ethical Approval Letters



**Pwyllgor Moeseg Ymchwil Gogledd Orllewin Cymru  
North West Wales Research Ethics Committee**

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**PRIVATE & CONFIDENTIAL**

Mr Ponnusamy Subramaniam  
Bangor University  
DSDC Wales  
Ardudwy, Normal Site  
Bangor  
LL57 2PX

Betsi Cadwaladr University Health Board  
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Clinical Academic Office  
Bangor, Gwynedd  
LL57 2PW

Telephone/ Facsimile: 01248 - 384.877  
Email: Rossela.Roberts@wales.nhs.uk

29 March 2010

Dear Mr Subramaniam,

**Full title of study:**                    **The effects of different approaches to reminiscence work with people with mild to moderate dementia living in care homes**

**REC reference number:**            **10/WNo01/7**

**Protocol number:**                    **2**

Thank you for your letter of 26 March 2010, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chairman.

#### **Confirmation of ethical opinion**

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

#### **Mental Capacity Act 2005**

I confirm that the committee has approved this research project for the purposes of the Mental Capacity Act 2005. The committee is satisfied that the requirements of section 31 of the Act will be met in relation to research carried out as part of this project on, or in relation to, a person who lacks capacity to consent to taking part in the project.

#### **Ethical review of research sites**

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

## Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Sponsors are not required to notify the Committee of approvals from host organisations.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

## Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>	
REC application	25350/92866/1/754	08 February 2010	
Response to Request for Further Information		26 March 2010	
Protocol	2	07 February 2010	
<del>Participant Information Sheet: Participant</del> Superseded	<del>2</del>	<del>07 February 2010</del>	
Participant Information Sheet: Participant	3	23 March 2010	
Participant Information Sheet: Personal Consultee	2	07 February 2010	
Participant Information Sheet: Nominated Consultee	2	07 February 2010	
Participant Information Sheet: Relative	2	07 February 2010	
Participant Information Sheet: Staff	2	07 February 2010	
<del>Participant Consent Form: Participant</del> Superseded	<del>2</del>	<del>07 February 2010</del>	
Participant Consent Form: Participant	3	23 March 2010	
Participant Consent Form: Personal Consultee	2	07 February 2010	
Participant Consent Form: Nominated Consultee	2	07 February 2010	
Participant Consent Form: Relative	2	07 February 2010	
Participant Consent Form: Staff	2	07 February 2008	
GP/Consultant Information Sheets	3	23 March 2010	
Questionnaire: Participant Identification Sheet			
Questionnaire: Clinical Dementia Rating Scale			
Questionnaire: Quality of Life in Alzheimer's Disease			
Questionnaire: Geriatric Depression Scale			
Questionnaire: Tennessee Self-Concepts Scale			
Questionnaire: Twenty Statement Test			
Questionnaire: Autobiographical Memory Interview			
Questionnaire: Quality of Care-giving relationship			
Questionnaire: Staff Identification Sheet			
Questionnaire: Staff Knowledge of Care recipient Questionnaire			
Questionnaire: Approaches to Dementia Questionnaire			
Questionnaire: Quality of Care-giving relationship (relative)			
Investigator CV (Mr Ponnusamy Subramaniam)		05 January 2010	
Supervisor CV (Prof R Woods)		05 January 2010	
Evidence of insurance or indemnity (employer liability)	UMAL	01 August 2009	
Evidence of insurance or indemnity (professional indemnity)	UMAL	01 August 2009	



## Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

## After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document “*After ethical review – guidance for researchers*” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email [referencegroup@nres.npsa.nhs.uk](mailto:referencegroup@nres.npsa.nhs.uk).

10/WNo01/7

Please quote this number on all correspondence

Yours sincerely



**Dr Rossela Roberts**  
**Committee Co-ordinator**

*Enclosure:* “After ethical review – guidance for researchers”

*Copy to:* Academic supervisor: Prof. Robert T. Woods, IMSCaR, Bangor University  
Sponsors’ Representative: Prof. Lew Hardy, Bangor University  
*R&D office for NHS Betsi Cadwaladr University Health Board – West division*

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**Chairman/Cadeirydd – Mr David Owen, CBE, QPM**

Betsi Cadwaladr University Health Board  
Ysbyty Gwynedd  
Clinical Academic Office  
Bangor, Gwynedd  
LL57 2PW

**PRIVATE & CONFIDENTIAL**

Mr Ponnusamy Subramaniam  
Ph.D Student, School of Psychology  
Bangor University  
DSDC Wales  
Ardudwy, Normal Site  
LL57 2PX

Telephone/ Facsimile: 01248 - 384.877  
Email: Rossela.Roberts@wales.nhs.uk

18 June 2010 Dear Mr Subramaniam

**Study title:** The effects of different approaches to reminiscence work with people with mild to moderate dementia living in care homes

**REC reference:** 10/WNo01/7  
**Protocol number:** v.3 dated 09/06/2010  
**Amendment number:** AM01 - Substantial  
**Amendment date:** 10 June 2010

The above amendment was reviewed at the meeting of the Sub-Committee held on 17 June 2010.

*Ethical opinion*

Favourable Opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

**Approved documents**

The documents reviewed and approved at the meeting were:

Document	Version	Date	
Protocol	3	09 June 2010	
Notice of Substantial Amendment (non-CTIMPs) 25350/126901/13/89/3071/179453		10 June 2010	

*Membership of the Committee*

The members of the Committee who took part in the review are listed on the attached sheet.

**R&D approval**

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

*Statement of compliance*

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

**10/WNo01/7:**

**Please quote this number on all correspondence**

Yours sincerely



**Dr Rossela Roberts**

*Committee Co-ordinator*

*Enclosures:*

*List of names and professions of members who took part in the review*

*Copy to:*

*Sponsor's representative: Professor Lew Hardy, Bangor University  
R&D office for BCUHB - West*

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**Chairman/Cadeirydd – Mr David Owen, CBE, QPM**

**North West Wales Research Ethics Committee**

**Attendance at Sub-Committee of the REC meeting on 17 June 2010**

**Committee Members**

<i>Name</i>	<i>Profession</i>	<i>Capacity</i>	<i>Present</i>
Dr. Derek James Crawford	Consultant Surgeon (Vice-Chairman)	Expert	Yes
Mr. David Owen	Retired Chief Constable (Chairman)	Lay +	Yes
Dr. Philip Wayman White	General Practitioner	Expert	Yes

**In attendance**

<i>Name</i>	<i>Position (or reason for attending)</i>
Dr. Rossela Roberts	Coordinator

# File Copy

## North Wales Research Ethics Committee - West

Bangor  
Clinical Academic Office  
Ysbyty Gwynedd Hospital  
Betsi Cadwaladr University Health Board  
Bangor  
Gwynedd  
LL57 2PW

Tel: 01248 -384.877  
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Mr Ponnusamy Subramaniam  
Ph.D Student  
School of Psychology  
Bangor University  
DSDC Wales, Ardudwy, Normal Site  
LL57 2PX

23 May 2011

Dear Mr Subramaniam,

**Study title:** The effects of different approaches to reminiscence work with people with mild to moderate dementia living in care homes  
**REC reference:** 10/WNo01/7  
**Amendment number:** AM02  
**Amendment date:** 10 February 2011

The above amendment was reviewed at the meeting of the Sub-Committee held on 19 May 2011.

### Ethical opinion

The Sub-Committee reviewed the above amendment and noted that this amendment involves changes in the research aim in experiment 2. In the original protocol, the second experiment aims to evaluate the implementation of reminiscence work via computer/ICT in groups and individuals with mild to moderate dementia residing in care homes. The research team would now like to amend this to examine the usefulness and feasibility of using information and communication technology based reminiscence work for people with dementia as highlighted in our systematic review (Subramaniam & Woods, 2010). Therefore the current participants in experiment will be approached and their consent sought to convert their existing life story book into a multimedia format. Participants will act as their own controls and the team will evaluate whether the ICT format leads to changes additional to any associated with the conventional life story book. A revised Protocol and new Participant Information Sheet and Information Sheet for Relatives have been submitted.

On the basis of the information provided, the Sub-Committee concluded that this amendment does not raise ethical issues

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

### Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Notice of Substantial Amendment (non-CTIMPs) Submission code: 25350/211770/13/61/5682	AM02	10 February 2011
Protocol (Experiment 2)	4	10 February 2011
Participant Information Sheet (Group 2)	1	10 February 2011
Participant Information Sheet: Relative (Group 2)	1	10 February 2011
Participant Consent Form: Relative (Group 2)	1	10 February 2011
Participant Consent Form (Group 2)	1	10 February 2011

### Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

### R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

<b>10/WNo01/7:</b>	<b>Please quote this number on all correspondence</b>
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Yours sincerely



**Mr David Owen**  
**Chairman**

E-mail: [rossela.roberts@wales.nhs.uk](mailto:rossela.roberts@wales.nhs.uk)

*Enclosures: List of names and professions of members who took part in the review*

*Copy to: Sponsor: Prof. Lew Hardy, Bangor University  
R&D office for Betsi Cadwaladr University Health Board*

**North Wales Research Ethics Committee - West**

**Attendance at Sub-Committee of the REC meeting on 19 May 2011**

**Committee members:**

<i>Name</i>	<i>Profession</i>	<i>Capacity</i>
Mr Derek James Crawford	Consultant Surgeon	Expert
Mr David Owen	Retired Chief Constable	Lay Plus
Dr Philip Wayman White	General Practitioner	Expert

**Also in attendance:**

<i>Name</i>	<i>Position (or reason for attending)</i>
Dr Rossela Roberts	Committee Coordinator

Childhood, family and home

1. What is the very first thing you can remember in your life? Go as far back as you can.
2. What other things can you remember about when you were very young?
3. What was life for you as a child?
4. What were your parents like? What were their weaknesses, strengths?
5. Did you have any brothers or sisters? Tell were their weaknesses, strengths?
6. Did someone close to you die when you were growing up?
7. Did someone important to you go away?
8. Do you ever remember being very sick? Do you remember feeling ashamed?
9. Do you remember having an accident?
10. Do you remember being in a very dangerous situation? Did you ever feel guilty as a child?
11. Was there anything that was important to you that was lost or destroyed?
12. Was church a large part of your life?
13. Did you enjoy being a boy/girl? Did you ever have an unhappy sexual experience?
14. Did you enjoy starting projects as a child (with toys or in scouts)?
15. How did your parents get along?
16. How did other people in your home get along? Did you feel that you were guided through childhood?
17. What was the atmosphere in your home? Did you always feel cared for?
18. Were you punished as a child? For what? Who did the punishing? Who was the 'boss'?
19. When you wanted something from your parents, how did you go about getting it?
20. What kind of person did your parents like most? the least?
21. Who were you closest to in your family?
22. Who in your family were you most like? In what way?

Adolescence

1. When you think about yourself and your life as a teenager, what is the first thing you can remember about that time? Did you feel good about yourself?
2. What other things stand out in your memory about being a teenager?
3. Who were the important people for you? Tell me about them. Parents, brothers, sisters, friends, teachers, those you were especially close to, those you admired, and those you wanted to be like.
4. Did you attend church and youth groups? Did they have cliques in your day?
5. Did you go to school? What was the meaning for you? Were you a hard working student?



6. Did you work at other jobs during these years? Did you have a sense of belonging?
7. Tell me of any hardships you experienced at this time.
8. Do you remember feeling that there wasn't enough food or necessities of life as a child or adolescent?
9. Do you remember feeling left alone, abandoned, not having enough love or care as a child or adolescent?
10. What was the pleasant thing about your adolescence?
11. What was the most unpleasant thing about your adolescence?
12. All things considered, would you say you were happy or unhappy as a teenager?
13. Do you remember your first attraction to another person? Did you establish a close relationship?
14. How did you feel about sexual activities and your own sexual identity?

### Adulthood

1. Did you do what you were supposed to do in life?
2. What place did religion take in your life?
3. Now I'd like to talk to you about your life as an adult, starting when you were in your twenties and up to today. Tell me of the most important events that happened in your adulthood.
4. What was life like for you in your twenties and thirties?
5. What kind of person were you? What did you enjoy? Did you think of yourself as responsible?
6. Tell me about your work. Did you enjoy your work? Did you earn an adequate living? Did you work hard during those years? Were you appreciated?
7. Did you form significant relationship with other people?
8. Did you marry?
  - (Yes) What kind of person was your spouse?
  - (No) Why not?
  - Were you happy with your choice?
9. Do you think that marriages get better or worse over time? Were you married more than once?
10. On the whole, would you say had a happy or unhappy marriage?
11. Was sexual intimacy important to you?
12. What were some of the main difficulties you encountered during your adult years?
13. Do you think you've helped the next generation?

## Summary

1. On the whole, what kind of life do you think you've had?
2. If everything were to be the same would you like to live your life over again?
3. If you were going to live your life over again, what would you change? Leave unchanged?
4. We've been talking about your life for some time now. Let's discuss your overall feelings and ideas about your life. What would you say the main satisfactions in your life have been? Try for three. Why were they satisfying?
5. Everyone has had disappointments. What have been the main disappointments in your life?
6. What was the hardest thing you had face in your life? Please describe it.
7. What was the happiest period of your life? What about it made it the happiest period? Why is your life less happy now?
8. What was the unhappiest period of your life? Why is your life more happy now?
9. What was the proudest moment in your life?
10. If you could stay the same age all your life, what age would you choose? Why?
11. How do you think you've made out in life? Better or worse than what you hoped for?
12. Let's talk a little about how you are now. What are the best things about the age you are now?
13. What are the worst things about being the age that you are now?
14. What are the most important things to you in your life today?
15. What do you hope will happen to you as you grow older?
16. What do you fear will happen to you as you grow older?
17. Have you enjoyed participating in this review of your life?

## Appendix C: AMI Inter rater Reliability Report

### Autobiographical Memory Interview-Extended Version (AMI-E): A brief Inter-rater reliability report

The Autobiographical Memory Interview (AMI) was developed by Kopelman (1989, 1990). The AMI covers recall of life time period memories in chronological order within 2 subdomains; personal semantic memory and personal incident memory. The personal semantic schedule requires the respondent to recall factual memories (e.g. first school, holiday place). Meanwhile, the personal incident schedule requires the respondent to recall significant incidents or experiences throughout the life span with as rich and detailed a description as possible. According to Kopelman (1990), the AMI has good inter rater reliability ( $r = 0.83 - 0.86$ ) and concurrent validity with other retrograde memory tests. Jones & Woods developed an expanded version of the Autobiographical Memory Interview (AMI-E) to include a mid-life section as the original version of AMI did not have good coverage of this period.

The AMI-E was successfully used with older adults with dementia in several studies (e.g. Naylor & Clare, 2008; Woods et al., 2009). However the AMI-E inter-rater reliability has never been reported. Therefore the present study aimed to establish the inter-rater reliability of AMI-E.

### **Method**

The inter-rater reliability of the AMI-E was assessed with 25 people with dementia taking part in the on-going REMCARE trial (Woods et al., 2009). The researcher (PS) would sit quietly in the corner of room, whilst the REMCARE researcher conducted the interview using the AMI-E with the person with dementia. Both the REMCARE researcher and PS would rate the AMI-E scores independently. The data were collected from March 2009 until June 2010. Later, the agreement between the 2 raters was correlated using Bivariate Pearson correlation coefficient using SPSS version 16.

## Results

The result (Table 1) indicated correlation coefficients between testers ranging from 0.70 – 0.98 for the different sections in the AMI-E. Correlation coefficient for the middle life section for the Personal Semantic Schedule between raters was 0.92 and for the Autobiographical Incident Schedule was 0.90. Overall the inter-rater reliability was 0.97 for the AMI-E Personal Semantic Schedule and 0.91 for the AMI (extended) Autobiographical Incident Schedule.

**Table 1: AMI Inter-rater reliability correlations between testers**

AMI Life Period	Pearson Correlation
Period before school factual (Pss)	0.97**
Period before school memory (Ais)	0.75**
First school factual (Pss)	0.94**
First school memory (Ais)	0.86**
Main secondary school factual (Pss)	0.91**
Main secondary school memory (Ais)	0.90**
Career factual (Pss)	0.82**
Career memory (Ais)	0.70**
Wedding factual (Pss)	0.96**
Wedding memory (Ais)	0.85**
Children and meeting people factual (Pss)	0.89**
Children and meeting people memory (Ais)	0.77**
Mid to late adulthood factual (Pss)	0.92**
Mid to late adulthood memory (Ais)	0.90**
Recent life factual (Pss)	0.98**
Recent memory (Ais)	0.80**
Total AMI factual score (Pss)	0.97**
Total AMI memory score (Ais)	0.91**

\*\*p<0.01 (2-tailed)

Pss – Personal Semantic Schedule  
 Ais - Autobiographical Incident Schedule

## Discussion

A preliminary study was conducted to established AMI-E inter rater agreement using correlation between 2 raters. These results indicate that the AMI-E has good inter-rater reliability values consistent with Kopelman’s report (1990) for the original instrument.

Although there are several different ways the inter-rater reliability can be calculated e.g. correlation coefficient, intra-class correlation coefficients, percentage agreement and kappa, for interval level measure as for the AMI-E the correlation coefficients are adequate to establish rater agreement between 2 raters.

### **Conclusion**

This aspect of the psychometric properties of the AMI-E has been demonstrated to be satisfactory.

Appendix D: Interview transcribed tables

Table 1: Feedback from Participants

	John	Sam	Nia	Betty	Mary	Ann
How did you feel about taking part in this project?	I'm happy to be part of this & it is a good idea	I'm happy taking part in this movie project...Brilliant idea...great!	It is good...I like it! I feel like I'm famous	Yes, I liked very much. Thank you for the opportunity.	Wonderful! Best thing that ever happen to me after meeting my husband.	Very good & I'm happy to be part of this project
What do you think about your movie?	Very good! Make me to feel good	I think it is very good...good idea. The DVD movie is first class.	Very fine & I'm happy with it	Great Idea & I'm proud	Very nice / wonderful	Good idea & should make for all
The movie helped you in anyway?	Yes! It bring back my memories...I remembered that I love to play golf.	Yes! The movie brings back my memories. I remember all that in my mind. The movie brings back all that memories. The movie tells my wonderful life, the childhood was very great...church!	I don't know but; I like to watch again & again...I don't know! I feel happy to watch it.	It remind me many things, bring back my memories. Make me feel good. The movies make me feel happy... Very triggering.	I enjoyed. I have tear (This is my life in movie & not everybody to get this)	I think so. I can see back my life stage by stage...Wonderful
Any benefit from the movie?	I can see all them again! I can see my wife...nice to see her again & again...make me to feel nice. I like all the songs. The songs that I & my wife used to dance. Nice...very nice!	Lots of enjoyment...It brought back the time again! The right type of music, that I liked...I enjoyed...My own voice is good.	I can see them all again! Just by sitting! Nice memories ...I feel happy...very happy.	Stimulating my memories. It make me to look back my life 'I had good life'...I'm happy about my life. I'm happy about my life.	Good memories. Stimulating & trigger memories (very good one)	I can see my life again...I remember many things that I never able to remember. The movie tells about me...songs and ballet make me happy.
How did the movie make you feel?	Yes! This movie make me to feel good	Make me feel great! Bring back my memories. (Feel like 'sitting in the moon', can't believe)	As I said...feel good, I'm happy, thank you. I like all the songs! I'm Welsh you see!	Make me very happy, all my family can understand my life & see them over-over again	The movie bring back happy memories (in tears)	Really good! I'm happy person now. I can sit and watch it !

	John	Sam	Nia	Betty	Mary	Ann
Anything that you would change about your movie?	No! not really	I'm happy...don't change anything	I want to carry on with this, don't change anything	No! Please don't. My voice alright! Don't change anything	No...all fine!	Please don't change anything...please! I wish I can have this from long time ago!
Do you will watch again & with other?	Oh Yes! of course	Please show it to all people in town  Oh yes! Of course. I will show it to all...my mother, she will be over the moon...All people (my family) should watch it. My mother will watch all the time.	Yes! Sure! But no one help me. Everybody alright, they can watch it.	Yes, of course & I want all others (family members) to watch it	Yes & Yes	Yes of course! Yes with my family.
Which one do you prefer, the book or the movie?	The movie, more then everything. In the movie we have music and songs.	Both of them (Q: If I ask you to choose one?) The movie, because it involve all other parts that I like, music, songs etc.	I like the book; I always can open & read. The movie...I like too but no one wants to show me! I feel nice if you show to me! Only you show the movie.	Movie, because I can see it & remind me more. Very relaxing compare to book	Movie , because of the music (The participant start to shake & sing together with movie)	Both are the same! I like both. Sometimes I want to read & sometimes I want to watch

Table 2: Feedback from Relative

	John	Sam	Nia	Betty	Mary	Ann
How did you feel about taking part in this project?	It is good!	I was really great! Honestly I feel, I'm doing good for Sam. What else I want	I feel happy & glad to take part in this research. Lot of homework for me to understand Nia better.	Ok. It was quite enjoyable. It made me feel good.	I think it is lovely & really good things	I felt excited and pleased on mum's behalf and the family and myself. Mum would really enjoy seeing it.
What do you think about your movie?	It is good idea	Wonderful idea...Really, really good because it make Sam happy while watch it.	Fantastic idea! The movie make my relative happy & I'm glad to see her (Nia) face full of happiness	It made me think about the past	Wonderful idea	It is very good considering the financial constrains. On the IT program used and the sound quality.
The movie helped you in anyway?	Help me to spend good ½ hour with John... very productive & not like before.	Worth it...make me feel better if Sam feel better.	Help me to go back to understand Nia's life better. The movie helped me to match her story that she used to tell me. It makes more sense to me now.	It helped me to remember things	Old pictures & songs bring back good memories. Trigger many-many memories. Very precious moment. The movie bring backs everything.	It made me feel good about public speaking
Any benefit from the movie?	Not really, but make me feel better because John happy by watching the movie	I think the research you doing in future will find some effectiveness to help people with dementia. The movie gives me hope. (Daughter; sad & happy times remembered)	I glad that I helped Nia to left her legacy & I did something very good for her. (Nia would ask different questions every time she watch together with me)	It helped my memory	The movie brings memories/ we feel good. Sometimes make us feel sad (e.g. mother & father pictures)	Pleasure in seeing photos of mum's life; obviously it covers some of my life too. Enjoyment in showing my daughters and watching their reactions and particular pleasure seeing the ballet & listening to some of the music.



	John	Sam	Nia	Betty	Mary	Ann
How did the movie make you feel?	Feel better	Feel good & happy. At least for ½ hour Sam happy.	Make me to feel good. The songs are very good for Nia. The voice from Cath, Brilliant.	Reminiscent	Make sad but also make you happy about life... We miss our childhood life.	Nostalgic, happy, moved by the ballet section & some of the music. Emotional at times.
Anything that you would change about your movie?	Need more voice (narration) explaining the pictures.	Include more Sam's voice	It is perfect & no need to change anything.	My mother- Elizabeth was called Eliza not Betty.	All ok but Mary talking too much	Improve sound quality & change opening music which feels a bit too dramatic.
Do you will watch again & with other?	I will watch again. I want others (relative & staff) to watch. People look after him (John) should watch the movie for better understanding of him.	Yes of course & show to everyone	Oh yes! I watched few times now & I will watch again. Yes, all the staff watched & I want more people to watch to understand Nia's life better (The manager arranged the staffs to watched & everyone think it is wonderful. They said, every resident should have one.	Yes & Yes but only the family	Yes & Yes	Yes, I'm sure I will periodically. Yes, relatives & interested friends of my mother.
Which one do you prefer, the book or the movie?	The movie because I feel better by watching it. The book and movie serve different purpose. Both need 'someone' (staff) to sit, talk or watch to bring more benefits.	Both are very good. Without doubt the movie much better; movie content, background music. Sam's voice...many things...	The movie, more informative; make me remember about Nia when she listen to radio, sing and used to say something about the song (same behaviour again). Make me to back to see Nia's life again. The book not really brings that feeling.	The book	The Movie...songs, voice...so on!	Hard to say, the book I think. Now when I read it I hear the music of the movie in the background.

Table 3: Feedback from Staff

	John	Sam	Nia	Betty	Mary	Ann
How did you feel about taking part in this project?	I felt it was a good idea. When residents come into a care home, we know very little about their history.	Very good	Thought it was a good idea to help people remember their past.	Great Idea / Excellent	Fantastic/excellent	A very good idea, that will assist staff in caring for the individual
What do you think about your movie?	The movie is very good. I was especially glad to hear John speak on the movie.	They are very good.	Thought it was very good and well put together. Nice for family to keep.	I was very excited.	I was very excited.	This movie is very good, with a very high content of information.
The movie helped you in anyway?	Yes, I feel I know John much more than I did before.	Help us know a lot more things about the person, also nice to see a background of the person pictures etc. Enjoy chatting about the past and it seems more real with the movie now.	I got to know more about Nia and her family even though I have cared for her ten years and know some family members, still learnt a lot from the movie.	Yes I was able to discuss it & I learned from it	Yes I was able to discuss it & Yes I learned from it	Yes, it helped me understand Ann more. Their past/history makes them who they really are, and without information like this, we really don't know them.
Any benefit from the movie?	I gained more information about Sam. What music he liked etc. I know about his interests and his family.	Same as above	I will be able to relate more with Nia when she talks about her family.	I learned even more about the client	I leaned even more about client	I found out things that I never knew about Ann and her life. People who suffer with dementia may goes back to a certain point in their life, and knowing more about Ann's past life / history will benefit staff in assisting to Ann's needs.
How did the movie make you feel?	That I would like to learn even more about John.	good	Make me feel sad as Nia is so forgetful but happy that Nia is so proud of her family (watching movie)	Great - happy	Feel great inside	Very moved

	John	Sam	Nia	Betty	Mary	Ann
Anything that you would change about your movie?	I would have liked to have seen more photographs of John as a child and I would have preferred if Andrew spoke when the photographs were showing, rather than having a written dialogue of what he was saying.	no	no	No! everything great	No! everything great	There is nothing I would change about Ann's movie
Do you will watch again & with other?	Yes! Yes, so that they can also get to know John properly.	Yes & very much so	Yes, would like watch it with Nia & Yes, think it would help people understand Nia more.	Yes & Yes	Yes & yes	yes
Which one you prefer, the book or the movie?	No preference	Both very good	Movie	Both, cannot choose	Both, cannot choose	The movie – This movie had a lot of feeling in it. The music was relaxing and Lily spoke in a relaxed tone

Table 4: Feedback from relative as a proxy

	John	Sam	Nia	Betty	Mary	Ann
How did you feel your relative taking part in 'This is Your Movie' project?	Good idea.	We were totally surprised with the project. We never thought it will be that good. Sam's voice really surprised me.	I think it is fantastic idea for Nia.	She very pleased	She thinking it is lovely & very good.	Mum was puzzled at first but agreed to take part. Very keen, excited & thought she would benefit a lot from it.
What does your relative think about the movie?	Its brings back memories to him & encourages him to think. Its seems he is happy.	Every time Sam will sit until the movie finish & he will do a 'thumb up'.	She liked because all about herself and her family.	Surprised she's been chosen.	Wonderful & very good.	She thinks it most interesting, dramatic music at beginning but likes it very much.
Do you think this movie helped your relative in anyway?	Bring back memories & stimulating	That seconds (when he watching the movie) is happy with smiles, triggers lots of discussion & stimulating memories (bring back memories)	Bring back her memories, stimulating with good expression from her	Yes, helped her to recall people and events from the past	Yes 'memory comeback'. The movies bring back her memory & good to see 'them' back.	I'm sure it stimulated her. She responded to the music & The ballet section. She really enjoyed
In your opinion, what 'benefit' did your relative gain from this movie?	I'm not sure whether give any long term benefits but short term yes!	Help him calm, sit down & enjoy	It is good reminder, she can see her life in chronological order. The music make her to sing together...she stop singing for past 20 years & now she singing back, shaking her hand and leg.	Helped to stimulate her memories	Make her to feel good and she wanted to show to everyone.	Stimulation, experiencing the music on conjunction with the film of her life. Enjoyed the company and interaction with researcher.
How did the movie make your relative feel?	Make him feel happy	Make him feel good without doubt & he enjoyed very much	Happy, good mood & she feel famous	Happy and reminiscent	Make her feel good	Stimulated, happy, nostalgic at times

	John	Sam	Nia	Betty	Mary	Ann
Anything that your relative want to change about his/her movie?	More dialogues / narration approach will be good. Voice should explain about content of the pictures (movie)	Honestly, I don't think we should change anything but I hope Sam can talk little more in DVD. Talk about pictures "This is my mother..."	No	No, it recovered most important events, and was neither too long or short.	No! lots of background (pictures & music). Good!	The music – A pause option but I feel she would never reach the end of the movie as she spend a lot of time on each picture.
Do you think that your relative will watch it again? & Would your relative like others to see it?	Yes of course, he watched many times & every time for him a new movie & Oh ya, his sister (living in Midlands) very much enjoyed with other family member, niece thinks, it is good idea, she going make one for her. she made 3 copies of John's movie, 1 for relative in Brighton,....	I'm sure he will & yes sure.	Yes / oh yes	Yes, I will encourage her to do so & Yes, she would like all the family to see it.	Yes & Yes for sure	Yes, she will if encouraged by residential home staff and family. She doesn't seem to mind anyone watching it at all.
Which one does your relative prefer the book or the movie?	The book is good idea, the staff will look it more compared to movie. The DVD more for relative & participant but book for staff	When you make the book, I thought that is wonderful idea but after you do DVD, I'm amazed with music, Sam's voice made it more smashing.	She like both; The book make her to look back (forward & backward). The movie make her to enjoy more because of voice & music.	Definitely the movie	She believe the movie much better, the movie includes many things e.g. songs, music, voice etc...	She like them both. Possibly the movie.

Table 5: Feedback from staff as a proxy

	John	Sam	Nia	Betty	Mary	Ann
How did you feel your client taking part in the 'This is Your Movie' project?	Very pleased. All our residents must have had an interesting life. I think everyone, should have a 'life' movie or book	No feedback	Thought it was a good idea	I thought it gave them something to be proud of	I thought it gave them something to be proud of	I was excited to be able to learn more about Ann and her history. We only know about the reason they are admitted to care home, and their medical history. We have very little or no information about
What does your client think about the movie?	John thinks his movie is good	Does not remember seeing it but would like to see it	She doesn't remember seeing it	Very excited / all smiles	Excited/all smiles	She thinks it very good
Do you think this movie helped your client in anyway?	Yes, it helped John remember parts of his life that he had forgotten	He can't remember it	No feedback	Told all her family about it	Yes she talked to friends about it	Encouraged Ann to talk about her history
In your opinion, what 'benefit' did your client gain from this movie?	Encouraged John to ask questions about people he may not have recognized and asking about their whereabouts now.	Will enjoy it while it's on, but does soon forget about it.	It probably help her remember things	It seemed to put something back into her life	Give them something to be proud of / discuss	Encouraged and motivated Ann to remember parts of her history
How did the movie make your client feel?	Happy – He enjoyed the photographs and was able to remember some members of his family	Good while he is watching it.	No feedback	Very happy	Very happy	Ann enjoys talking about her family
Anything that your client wants to change about his/her movie?	As Question 6 (carer)	-	Little bit long?	no	no	I would change nothing

	John	Sam	Nia	Betty	Mary	Ann
Do you think that your client will watch it again? & Would your client like others to see it?	Yes, definitely & yes	Yes & yes very much so	No feedback	Yes & Yes	Yes & Yes	Yes, Ann would enjoy watching her movie over and over. Yes, as she enjoyed talking about her family. She would definitely watch it with her family.
Which one does your client prefer the book or the movie?	I think he prefers the book. John has easier access to the book. He can just pick it up when he wants. Operating a DVD would be difficult for him	He does not remember either of them until we look at them.	No feedback	Both	Both	I think Ann has no preference.

Appendix E: Clinical Dementia Rating Scale (CDR; Hughes et al, 1982)

**Clinical Dementia Rating Scale**



Category	Healthy CDR 0	Questionable dementia CDR 0.5	Mild dementia CDR 1	Moderate dementia CDR 2	Severe dementia CDR 3
Memory	No memory loss or slight inconstant forgetfulness	Mild constant forgetfulness; partial recollection of events; 'benign' forgetfulness	Moderate memory loss, more marked for recent events; defect interferes with everyday activities	Severe memory loss; only highly learned material retained; new material rapidly lost	Severe memory loss; only fragments remain
Orientation	Fully oriented		Some difficulty with time relationships; oriented for place and person at examination but may have geographic disorientation	Usually disoriented in time, often to place	Orientation to person only
Judgment + problem solving	Solves every day problems well; judgment good in relation to past performance	Only doubtful impairment in solving problems, similarities, differences	Moderate difficulty in handling complex problems; social judgment usually maintained	Severely impaired in handling problems, similarities, differences; social judgment usually impaired	Unable to make judgments or solve problems
Community affairs	Independent function at usual level in job, shopping, business and financial affairs, volunteer and social groups	Only doubtful or mild impairment, if any, in these activities	Unable to function independently at these activities though may still be engaged in some; may still appear normal to casual inspection	No pretence of independent function outside home	
Home + hobbies	Life at home, hobbies, intellectual interests well maintained	Life at home, hobbies, intellectual interests well maintained or only slightly impaired	Mild but definite impairment of function at home; more difficult chores abandoned; more complicated hobbies and interests abandoned	Only simple chores preserved; very restricted interests, poorly sustained	No significant function in home outside of own room
Personal care	Fully capable of self care		Needs occasional prompting	Requires assistance in dressing, hygiene, keeping of personal effects	Requires much help with personal care; often incontinent
Score using box overleaf. Score as 0, 0.5, 1, 2, 3 only if impairment is due to cognitive loss.					

Hughes CP et al, *Br J Psychiatry* 1982; 140:566-572. Reprinted by permission.



**ASSIGNING THE CLINICAL DEMENTIA RATING**

There are two methods of combining the domain scores to give the overall CDR. The domain scores can either be summed to give the CDR-SB (Sum of Boxes) score, or an algorithm can be used as follows:

The global CDR score is derived from the scores in each of the six categories. Memory (M) is considered the primary category and all others are secondary. CDR = M if at least three secondary categories are given the same score as memory. Whenever three or more secondary categories are given a score greater or less than the memory score, CDR equals the score of the majority of secondary categories that are on whichever side of M has the greatest number of secondary categories. If there are ties in the secondary categories on one side of M, the CDR score closest to M is chosen.

When M = 0.5, CDR = 1 if at least three of the other categories are scored one or greater. If M = 0.5, CDR cannot be 0; it can only be 0.5 or 1. If M = 0, CDR = 0 unless there is questionable impairment in two or more secondary categories, in which case CDR = 0.5.

Score	0	0.5	1	2	3
M					
O					
JPS					
C					
HH					
PC					

Mark in only one box for each category. To assign the CDR, see grids on the right. Shaded areas indicate defined range within which the scores of individual subjects must fall to be assigned a given CDR.

Clinical Dementia Rating

Score	0	0.5	1	2	3
M					
O					
JPS					
C					
HH					
PC					

Score	0	0.5	1	2	3
M					
O					
JPS					
C					
HH					
PC					

Score	0	0.5	1	2	3
M					
O					
JPS					
C					
HH					
PC					

Score	0	0.5	1	2	3
M					
O					
JPS					
C					
HH					
PC					

Score	0	0.5	1	2	3
M					
O					
JPS					
C					
HH					
PC					

Appendix F: Quality of Life in Alzheimer’s disease (QOL-AD; Logsdon et al, 2002)

Instruction: Interviewer administer according to standard instructions. Circle your response.

1	Physical health	Poor	Fair	Good	Excellent
2	Energy	Poor	Fair	Good	Excellent
3	Mood	Poor	Fair	Good	Excellent
4	Living Situation	Poor	Fair	Good	Excellent
5	Memory	Poor	Fair	Good	Excellent
6	Family	Poor	Fair	Good	Excellent
7	Marriage	Poor	Fair	Good	Excellent
8	Friends	Poor	Fair	Good	Excellent
9	Self as a whole	Poor	Fair	Good	Excellent
10	Ability to do chores around the house	Poor	Fair	Good	Excellent
11	Ability to do things for fun	Poor	Fair	Good	Excellent
12	Money	Poor	Fair	Good	Excellent
13	Life as a whole	Poor	Fair	Good	Excellent

Comments:

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Appendix G: Geriatric Depression Scale (Residential) (GDS-12R; Sutcliffe et al, 2000)

Instructions: Choose the best answer for how you felt over the past week.

No.	Question	Answer	Score
1	Are you basically satisfied with your life?	YES / NO	
2	Have you dropped many of your activities and interests?	YES / NO	
3	Do you feel that your life is empty?	YES / NO	
4	Do you often get bored?	YES / NO	
5	Are you in good spirits most of the time?	YES / NO	
6	Are you afraid that something bad is going to happen to you?	YES / NO	
7	Do you feel happy most of the time?	YES / NO	
8	Do you often feel helpless?	YES / NO	
9	Do you think it is wonderful to be alive?	YES / NO	
10	Do you feel pretty worthless the way you are now?	YES / NO	
11	Do you feel full of energy?	YES / NO	
12	Do you feel that your situation is hopeless?	YES / NO	

Appendix H: Autobiographical Memory Interview (extended version) (AMI-E; Kopelman et al, 1990; Woods et al, 2009)

**Autobiographical Memory Interview (extended version)**  
**Section A: Childhood**

**Part 1: Period before school**

Name of grandfather

Correct	<input type="checkbox"/>
First name only	<input type="checkbox"/>
No response/missing	<input type="checkbox"/>

Name of grandmother

Correct	<input type="checkbox"/>
First name only	<input type="checkbox"/>
No response/missing	<input type="checkbox"/>

Mother's maiden name

Correct	<input type="checkbox"/>
First name only	<input type="checkbox"/>
No response/missing	<input type="checkbox"/>

Participant's address before going to school

Correct	<input type="checkbox"/>
Street and town only	<input type="checkbox"/>
Town or street only	<input type="checkbox"/>
No response/missing	<input type="checkbox"/>

Names of 3 friends or neighbours from the period before the participant went to school
1.
2.
3.

Correct	First name only	No response / missing
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Recall an incident from the period before the participant went to school. (Prompts: Your first memory? Involving a brother or sister?)

Score
Tick one box
3 <input type="checkbox"/>
2 <input type="checkbox"/>
1 <input type="checkbox"/>
0 <input type="checkbox"/>

**Part 2: First School (5-11 years)**

Name of first school

Correct   
 No response/missing

Location of first school

Town or city   
 No response/missing

Participant's age when starting school

Correct   
 No response/missing

Participant's address when starting at this school

Correct   
 Street and town only   
 Town or street only   
 No response/missing

Names of 3 teachers or friends from this school. (Prompts: The head teacher? Your teacher? A friend?).
1.
2.
3.

Correct	First name only	No response / missing
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Favourite TV or radio programme from this period

Correct   
 No response/missing

Names of any pets

Correct   
 No response/missing

Hobbies or interests whilst at primary school

Correct   
 No response/missing

Recall an incident occurring while at primary school (age 5-11 years). (Prompts: Involving a teacher? Involving a friend?)	<p>Score</p> <p>Tick one box</p> <p>3 <input type="checkbox"/></p> <p>2 <input type="checkbox"/></p> <p>1 <input type="checkbox"/></p> <p>0 <input type="checkbox"/></p>

**Part 3: Main secondary school (i.e. 11-18 years)**

Name of secondary school	Correct <input type="checkbox"/>
	No response/missing <input type="checkbox"/>

Location of secondary school	Correct <input type="checkbox"/>
	No response/missing <input type="checkbox"/>

Number and level of examinations obtained at secondary school	Correct number and level <input type="checkbox"/>
	Level only <input type="checkbox"/>
	No response/missing <input type="checkbox"/>

Participant's address whilst attending secondary (or high) school	Correct <input type="checkbox"/>
	Street and town only <input type="checkbox"/>
	Town or street only <input type="checkbox"/>
	No response/missing <input type="checkbox"/>

Names of 3 teachers or friends from secondary school. (Prompts: The head teacher? Your form teacher? A friend?).	Correct	First name only	No response / missing
1.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Recall an incident occurring while at secondary school (age 11-18 years). (Prompts: Involving a teacher? Involving a friend?)	<p>Score</p> <p>Tick one box</p> <p>3 <input type="checkbox"/></p> <p>2 <input type="checkbox"/></p> <p>1 <input type="checkbox"/></p> <p>0 <input type="checkbox"/></p>

Age when you left school	Correct <input type="checkbox"/>
	No response/missing <input type="checkbox"/>

Favourite TV or radio programmes whilst at secondary school	Correct <input type="checkbox"/>
	No response/missing <input type="checkbox"/>

Hobbies or interests whilst at secondary school	Correct <input type="checkbox"/>
	No response/missing <input type="checkbox"/>

Place where you went on a holiday or trip out	Correct <input type="checkbox"/>
	No response/missing <input type="checkbox"/>

Year this took place	Correct <input type="checkbox"/>
	No response/missing <input type="checkbox"/>

Name of person you went on holiday or trip with	Correct <input type="checkbox"/>
	No response/missing <input type="checkbox"/>

Where did you stay?	Correct <input type="checkbox"/>
	No response/missing <input type="checkbox"/>

How did you get there?	Correct <input type="checkbox"/>
	No response/missing <input type="checkbox"/>

Recall of an incident that took place on this holiday or trip.	<p>Score</p> <p>Tick one box</p> <p>3 <input type="checkbox"/></p> <p>2 <input type="checkbox"/></p> <p>1 <input type="checkbox"/></p> <p>0 <input type="checkbox"/></p>

## Section B: Early Adult Life

### Part 4: Career

Qualifications after leaving school	<p>Correct recall of qualifications or stating 'no qualifications' <input type="checkbox"/></p> <p>No response/missing <input type="checkbox"/></p>

<b>Either:</b> if qualifications obtained: name of course <b>and</b> institution	Correct	No response / missing
Course:	<input type="checkbox"/>	<input type="checkbox"/>
Institution:	<input type="checkbox"/>	<input type="checkbox"/>

<b>Or:</b> if no qualifications: first job <b>and</b> name of firm or organisation	Correct	No response / missing
First job:	<input type="checkbox"/>	<input type="checkbox"/>
Firm / organisation:	<input type="checkbox"/>	<input type="checkbox"/>

<b>Or:</b> if no job (e.g. homemaker), what was spouse's / partner's job <b>and</b> name of spouse's/partner's firm or organisation?	Correct	No response / missing
Spouse's / partner's job:	<input type="checkbox"/>	<input type="checkbox"/>
Spouse's / partner's firm / organisation:	<input type="checkbox"/>	<input type="checkbox"/>



Participant's address at this time

- Correct
- Street and town only
- Town or street only
- No response/missing

Names of 3 friends or colleagues from this period. (Prompts: The boss? The tutor? The foreman? Any class or work mates?)
1.
2.
3.

- | Correct                  | First name only          | No response / missing    |
|--------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Recall an incident from college or first job or, if no job recall, recall an incident in the first few years after leaving school (e.g. birth of a child, moving house).

- Score
- Tick one box
- 3
- 2
- 1
- 0

How did you celebrate your 21 <sup>st</sup> birthday?

- Correct
- No response/missing

Any hobbies or interests at this time? (e.g. sports, member of club).

- Correct
- No response/missing

**Part 5: Wedding / Early adulthood**

<b>Either:</b> if married in late teens, twenties, or thirties, date of marriage <b>and</b> place where marriage was held	Correct	No response / missing
Date of marriage:	<input type="checkbox"/>	<input type="checkbox"/>
Place where marriage held:	<input type="checkbox"/>	<input type="checkbox"/>
<b>Or:</b> If not married in this time period, name of someone else whose marriage the participant attended <b>and</b> place where marriage was held	Correct	No response / missing
Date of marriage:	<input type="checkbox"/>	<input type="checkbox"/>
Place where marriage held:	<input type="checkbox"/>	<input type="checkbox"/>
Participant's address before this wedding	Correct	<input type="checkbox"/>
	Street and town only	<input type="checkbox"/>
	Town or street only	<input type="checkbox"/>
	No response/missing	<input type="checkbox"/>
Participant's address after this wedding	Correct	<input type="checkbox"/>
	Street and town only	<input type="checkbox"/>
	Town or street only	<input type="checkbox"/>
	No response/missing	<input type="checkbox"/>
Name of best man or other guest	Correct	<input type="checkbox"/>
	First name only	<input type="checkbox"/>
	No response/missing	<input type="checkbox"/>
Name of bridesmaid or other guest	Correct	<input type="checkbox"/>
	First name only	<input type="checkbox"/>
	No response/missing	<input type="checkbox"/>
Bride's or own maiden name (or a guest)	Correct	<input type="checkbox"/>
	First name only	<input type="checkbox"/>
	No response/missing	<input type="checkbox"/>

Recall of an incident from this wedding. (Prompts: An incident involving a guest? Or an incident at the reception?)	<p>Score</p> <p>Tick one box</p> <p>3 <input type="checkbox"/></p> <p>2 <input type="checkbox"/></p> <p>1 <input type="checkbox"/></p> <p>0 <input type="checkbox"/></p>

Any hobbies or interests during this period	Correct <input type="checkbox"/>
	No response/missing <input type="checkbox"/>

Make and model of your first car	Make & model (or no car/ no-driver) <input type="checkbox"/>
	Make or model only <input type="checkbox"/>
	No response/missing <input type="checkbox"/>

Place where you went on a holiday or trip out	Correct <input type="checkbox"/>
	No response/missing <input type="checkbox"/>

Year this took place	Correct <input type="checkbox"/>
	No response/missing <input type="checkbox"/>

Name of person you went on holiday or trip with	Correct <input type="checkbox"/>
	No response/missing <input type="checkbox"/>

Where did you stay?	Correct <input type="checkbox"/>
	No response/missing <input type="checkbox"/>

How did you get there?	Correct <input type="checkbox"/>
	No response/missing <input type="checkbox"/>

Recall of an incident that took place on this holiday or trip.	<p>Score Tick one box</p> <p>3 <input type="checkbox"/></p> <p>2 <input type="checkbox"/></p> <p>1 <input type="checkbox"/></p> <p>0 <input type="checkbox"/></p>

**Part 6: Children and meeting people new in participant's twenties**

Name of participant's first child (or a nephew, niece, or child of a close friend).	Correct <input type="checkbox"/>
	No response/missing <input type="checkbox"/>

Date of birth of this child <b>and</b> place of birth of this child	Correct year and place (town or city) <input type="checkbox"/>
	Correct year or place (town or city) <input type="checkbox"/>
	No response/missing <input type="checkbox"/>

Name of participant's second child (or a nephew, niece, or child of a close friend).	Correct <input type="checkbox"/>
	No response/missing <input type="checkbox"/>

Date of birth of this child <b>and</b> place of birth of this child	Correct year and place (town or city) <input type="checkbox"/>
	Correct year or place (town or city) <input type="checkbox"/>
	No response/missing <input type="checkbox"/>

Recall of first encounter with someone while the participant was in his/her twenties. (Prompts: Meeting someone in an interview? Or on holiday? Or at work?)	<p>Score Tick one box</p> <p>3 <input type="checkbox"/></p> <p>2 <input type="checkbox"/></p> <p>1 <input type="checkbox"/></p> <p>0 <input type="checkbox"/></p>

**Section C: Middle to late Adulthood (40-65) New section**

Name of first son or daughter to get married or name of first niece or nephew to get married

Correct   
 No response/missing

Name of first born grandchild or first born great niece or nephew

Correct   
 No response/missing

Hobbies or interests in your forties and fifties

Correct   
 No response/missing

Favourite TV or radio programme from this period

Correct   
 No response/missing

What was your job when you retired or what was your spouse's/partner's job when he/she retired

Correct   
 No response/missing

Who were you working for just before you retired or who was your spouse/partner working for

Correct   
 No response/missing

Names of 3 friends or colleagues from this period
1.
2.
3.

Correct	First name only	No response / missing
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

How did you mark your own / your spouse's/partner's retirement? Recall an incident from this time (e.g. a leaving do).

Score Tick one box
3 <input type="checkbox"/>
2 <input type="checkbox"/>
1 <input type="checkbox"/>
0 <input type="checkbox"/>

Make and model of your car when you retired

Make & model (or no car/ no-driver)   
 Make or model only   
 No response/missing

Place where you went on a holiday or trip out

Correct   
 No response/missing

Year this took place

Correct   
 No response/missing

Name of person you went on holiday or trip with

Correct   
 No response/missing

Where did you stay?

Correct   
 No response/missing

How did you get there?

Correct   
 No response/missing

Recall of an incident that took place on this holiday or trip.

Score Tick one box
3 <input type="checkbox"/>
2 <input type="checkbox"/>
1 <input type="checkbox"/>
0 <input type="checkbox"/>

**Section D: Recent life**

**Either: if participant interviewed at a hospital or other institution:**

Name of hospital, or place where seen

Correct   
 No response/missing

Location of this hospital

Correct   
 No response/missing

Date of arrival or visit at this hospital

Correct   
 No response/missing

Participant's current address

Correct   
 Street and town only   
 Town or street only   
 No response/missing

Names of 3 friends, colleagues, or acquaintances connected with this hospitalisation (or 3 people who have visited in the last year).
1.
2.
3.

Correct	First name only	No response / missing
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Or: if participant interviewed at home:**

Participant's address

Correct   
 Street and town only   
 Town or street only   
 No response/missing

Participant's telephone number

Correct   
 No response/missing

How many other people are at home with the participant?

Correct   
 No response/missing

Year when participant moved to this address

Correct   
 No response/missing

Names of 3 current friends or neighbours
1.
2.
3.

Correct	First name only	No response / missing
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Participants at any location:**

Name of last hospital you have visited in the past five years, or name of your doctor / dentist

Correct   
 No response/missing

Location of this hospital / doctor / dentist

Correct   
 No response/missing

When did you visit this hospital / doctor / dentist?

Correct month (if within last 12 months), otherwise correct year   
 No response/missing

Participant's address when they made this visit

Correct   
 Street and town only   
 Town or street only   
 No response/missing

Names of 3 friends/ relatives who have visited you in the last 5 years.
1.
2.
3.

Correct	First name only	No response / missing
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



Recall of an incident involving a relative or visitor in the last 5 years. (Prompts: A visit by, or to, a relative? Involving some news about a relative).

Score
Tick one box
3 <input type="checkbox"/>
2 <input type="checkbox"/>
1 <input type="checkbox"/>
0 <input type="checkbox"/>

Where did you spend last Christmas?

Correct	<input type="checkbox"/>
No response/missing	<input type="checkbox"/>

Name of a person you spent last Christmas with

Correct	<input type="checkbox"/>
No response/missing	<input type="checkbox"/>

Recall of an incident connected to last Christmas. (Prompts: could be going to church, visiting relatives).

Score
Tick one box
3 <input type="checkbox"/>
2 <input type="checkbox"/>
1 <input type="checkbox"/>
0 <input type="checkbox"/>

Name a place that you visit on a regular basis

Correct	<input type="checkbox"/>
No response/missing	<input type="checkbox"/>

Who do you go with?

Correct	<input type="checkbox"/>
No response/missing	<input type="checkbox"/>

If day care, club, or church: names of 3 other people you meet there. If shops: name of 3 articles you regularly buy.
1.
2.
3.

Correct	First name only	No response / missing
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Place where you went on a holiday or trip out in the last 5 years

Correct	<input type="checkbox"/>
No response/missing	<input type="checkbox"/>

Month or Year this took place

Correct	<input type="checkbox"/>
No response/missing	<input type="checkbox"/>

Name of person you went on holiday or trip with

Correct	First name only	No response / missing
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Where did you stay?

Correct	<input type="checkbox"/>
No response/missing	<input type="checkbox"/>

How did you get there?

Correct	<input type="checkbox"/>
No response/missing	<input type="checkbox"/>

Recall of an incident that took place on this holiday or trip

Score
Tick one box
3 <input type="checkbox"/>
2 <input type="checkbox"/>
1 <input type="checkbox"/>
0 <input type="checkbox"/>

Appendix I: Quality of the Care-giving relationship (Participant & Relative) (QCPR; Spruytte et al, 2002)

1. My relative and I often spend time together in an enjoyable way.  

<b>Totally disagree</b>	<b>Disagree</b>	<b>Not sure</b>	<b>Agree</b>	<b>Totally agree</b>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. My relative and I often disagree  

<b>Totally disagree</b>	<b>Disagree</b>	<b>Not sure</b>	<b>Agree</b>	<b>Totally agree</b>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. There is a big distance in the relationship between my relative and myself.  

<b>Totally disagree</b>	<b>Disagree</b>	<b>Not sure</b>	<b>Agree</b>	<b>Totally agree</b>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. My relative and I accept each other as we are.  

<b>Totally disagree</b>	<b>Disagree</b>	<b>Not sure</b>	<b>Agree</b>	<b>Totally agree</b>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. If there are problems my relative and I can usually resolve these easily.  

<b>Totally disagree</b>	<b>Disagree</b>	<b>Not sure</b>	<b>Agree</b>	<b>Totally agree</b>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. I get on well with my relative.  

<b>Totally disagree</b>	<b>Disagree</b>	<b>Not sure</b>	<b>Agree</b>	<b>Totally agree</b>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. My relative and I are tender towards each other.  

<b>Totally disagree</b>	<b>Disagree</b>	<b>Not sure</b>	<b>Agree</b>	<b>Totally agree</b>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. My relative often annoys me.  

<b>Totally disagree</b>	<b>Disagree</b>	<b>Not sure</b>	<b>Agree</b>	<b>Totally agree</b>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. I feel very good if I am with my relative.  

<b>Totally disagree</b>	<b>Disagree</b>	<b>Not sure</b>	<b>Agree</b>	<b>Totally agree</b>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. My relative and I often try to impose our opinions on each other.  

<b>Totally disagree</b>	<b>Disagree</b>	<b>Not sure</b>	<b>Agree</b>	<b>Totally agree</b>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. I blame my relative for the cause of my problems.  

<b>Totally disagree</b>	<b>Disagree</b>	<b>Not sure</b>	<b>Agree</b>	<b>Totally agree</b>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. My relative and I appreciate each other as people  

<b>Totally disagree</b>	<b>Disagree</b>	<b>Not sure</b>	<b>Agree</b>	<b>Totally agree</b>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. My relative does not appreciate enough what I do for him/her.  

<b>Totally disagree</b>	<b>Disagree</b>	<b>Not sure</b>	<b>Agree</b>	<b>Totally agree</b>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. I am always glad to see him/her if I have not seen him/her for some time.  

<b>Totally disagree</b>	<b>Disagree</b>	<b>Not sure</b>	<b>Agree</b>	<b>Totally agree</b>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Appendix J: Staff Knowledge of Care Recipient Questionnaire

Staff Name: \_\_\_\_\_

INSTRUCTION: Please write you answer in the line provided and If you don't know or not sure, please leave the line blank. Please do not ask, discuss or refer to anyone or any documents for the answer. Please write your response about the person below:

Participant Name: \_\_\_\_\_

1. What was the resident's main hobby or interest?  
\_\_\_\_\_
2. What was the resident's favourite food or drink?  
\_\_\_\_\_
3. Favourite place or holiday destination? \_\_\_\_\_  
\_\_\_\_\_
4. Number of children? \_\_\_\_\_  
\_\_\_\_\_
5. Where did the resident go to school? \_\_\_\_\_  
\_\_\_\_\_
6. Favourite activities or sports? \_\_\_\_\_
7. Previous job/last job or career? \_\_\_\_\_
8. Favourite Radio or TV programme? \_\_\_\_\_
9. Partner or spouse name? \_\_\_\_\_
10. Place of birth? \_\_\_\_\_
11. When is the resident's birthday? \_\_\_\_\_
12. Home address (where he/she from)?  
\_\_\_\_\_  
\_\_\_\_\_
13. Close relative name? \_\_\_\_\_
14. Grandchildren (No & Names)? \_\_\_\_\_

Appendix K: Approaches to Dementia Questionnaire (ADQ; Lintern et al, 2000)

*Please indicate to what extent you agree or disagree with each of the following statements:*

- 1. It is important to have a very strict routine when working with dementia sufferers.**

Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
----------------	-------	----------------------------	----------	-------------------
- 2. People with dementia are very much like children.**

Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
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- 3. There is no hope for people with dementia.**

Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
----------------	-------	----------------------------	----------	-------------------
- 4. People with dementia are unable to make decisions for themselves.**

Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
----------------	-------	----------------------------	----------	-------------------
- 5. It is important for people with dementia to have stimulating and enjoyable activities to occupy their time.**

Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
----------------	-------	----------------------------	----------	-------------------
- 6. Dementia sufferers are sick and need to be looked after.**

Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
----------------	-------	----------------------------	----------	-------------------
- 7. It is important for people with dementia to be given as much choice as possible in their daily lives.**

Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
----------------	-------	----------------------------	----------	-------------------
- 8. Nothing can be done for people with dementia, except for keeping them clean and comfortable.**

Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
----------------	-------	----------------------------	----------	-------------------
- 9. People with dementia are more likely to be contented when treated with understanding and reassurance.**

Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
----------------	-------	----------------------------	----------	-------------------

10. **Once dementia develops in a person, it is inevitable that they will go down hill.**
- Strongly Agree                      Agree                      Neither Agree nor Disagree                      Disagree Strongly Disagree
11. **People with dementia need to feel respected, just like anybody else.**
- Strongly Agree                      Agree                      Neither Agree nor Disagree                      Disagree Strongly Disagree
12. **Good dementia care involves caring for a person's psychological needs as well as their physical needs.**
- Strongly Agree                      Agree                      Neither Agree nor Disagree                      Disagree Strongly Disagree
13. **It is important not to become too attached to residents.**
- Strongly Agree                      Agree                      Neither Agree nor Disagree                      Disagree Strongly Disagree
14. **It doesn't matter what you say to people with dementia because they forget anyway.**
- Strongly Agree                      Agree                      Neither Agree nor Disagree                      Disagree Strongly Disagree
15. **People with dementia often have good reasons for behaving as they do.**
- Strongly Agree                      Agree                      Neither Agree nor Disagree                      Disagree Strongly Disagree
16. **Spending time with people with dementia can be very enjoyable.**
- Strongly Agree                      Agree                      Neither Agree nor Disagree                      Disagree Strongly Disagree
17. **It is important to respond to people with dementia with empathy and understanding.**
- Strongly Agree                      Agree                      Neither Agree nor Disagree                      Disagree Strongly Disagree
18. **There are a lot of things that people with dementia can do.**
- Strongly Agree                      Agree                      Neither Agree nor Disagree                      Disagree Strongly Disagree

**19. People with dementia are just ordinary people who need special understanding to fulfil their needs.**

Strongly Agree

Agree

Neither Agree nor  
Disagree

Disagree Strongly Disagree