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# Reminiscence For People With Dementia In Long-Stay Care

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# Acknowledgements and Contents

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## Table of Contents

Chapter One	Introduction	1
Chapter Two	Dementia in Long-Stay Care Settings in Ireland	3
Chapter Three	Psychosocial Interventions for People with Dementia	5
Chapter Four	Reminiscence in Dementia: A Concept Analysis	8
Chapter Five	Study Methodology	10
Chapter Six	Quantitative Assessment of DARES	13
Chapter Seven	Qualitative Assessment of DARES	17
Chapter Eight	Methodological Issues in DARES	21
Chapter Nine	Discussion and Conclusion	26
	References	29

# 1 Introduction



**DEMENTIA** is a broad term used to describe a group of symptoms; these symptoms include impairment of mental functioning, progressive memory loss, language difficulties, confusion and disorientation. Dementia is a progressive condition with symptoms gradually worsening over a number of years. In the early stages, memory loss is often mild and may go unnoticed. However, by the late stages individuals often lose the ability to carry on a conversation or respond to their environment. There are several diseases and conditions that cause dementia, the most common of which is Alzheimer's disease; others include vascular dementia, dementia with Lewy bodies, and fronto-temporal dementia.

The World Alzheimer Report (Prince and Jackson, 2009) estimated that there were 36 million people living with dementia worldwide; however, with the ageing of the population this number is expected to increase to 66 million by 2030 and 115 million by 2050. While currently there is no cure for dementia, a person can live with the condition for a number of years. In Ireland, as in many other countries, there is an absence of precise data on the prevalence of dementia. However, in a recent report researchers in Ireland applied European age and gender-specific prevalence rates of dementia to Irish census data to provide an estimate of 41,470 people with dementia in Ireland, of whom 3,583 (or almost 9%) are aged less than 65 (Cahill et al., 2012). The vast majority of people with dementia continue to live at home, many without any formal diagnosis.

Dementia is a costly condition and one that differs from other conditions in the significant cost burden placed on informal carers. The worldwide cost of dementia has been estimated at US\$604 billion (Wimo and Prince, 2010), with 42% of these costs attributable to informal or unpaid care provided by family and friends in the community. Wimo et al. (2011), examining the economic impact of dementia in Europe, found that the total cost of dementia disorders was approximately €160

billion, 56% of which was attributable to the costs of informal care. In Ireland, the annual cost of the condition has been estimated at €1.69 billion, giving a cost per person with dementia of €40,511 (Connolly et al., 2012). Similarly to other studies, the largest cost burden in Ireland fell on family carers, followed by the long-stay care sector.

A number of issues arise when considering care for people with dementia in Ireland. These range from early diagnosis, through enhanced public awareness, to improvements in care provision and end-of-life care. In particular, community support services for people with dementia and their carers are under-developed and fragmented in Ireland (Cahill et al., 2012). The range of community services is small and only a minority of those with dementia are known to formal service providers. Similarly there is a dearth of dementia-specific services and specialist care units for those with dementia residing in the long-stay care setting. Within the long-stay setting, much of the care provided to people with dementia is processed and routine, and there is an acknowledgement of the need to change the culture of care to one of empowerment, dignity and personhood. For example, there is an over-reliance on biological approaches to caring for people with dementia that sometimes undermines the importance of communication and connectivity. Promoting a sense of well-being among people with dementia is likely to be enhanced by creating a supportive personal and social environment, thereby enabling people to communicate and remain connected with family and friends.

While at present there is no known means available to halt or reverse the symptoms of dementia, many people with dementia can benefit from psychosocial interventions. In that regard, integrating evidence-based psychosocial approaches with medical and nursing care models of delivery is key to developing a new person-centred approach for people with dementia. If healthcare professionals are to develop

the skills necessary for a holistic approach to care delivery, education about dementia and staff training in psychosocial approaches and treatments are essential. While psychosocial interventions can take a variety of forms, they have generally been classed into four main groupings - behavioural interventions, emotion-oriented interventions, cognition-oriented interventions and stimulation-oriented interventions. There are good examples of practice in each of these types of approaches, but there is less evidence on the effectiveness of such interventions.

The evidence base is strongest with regard to the potential of cognition-oriented interventions, particularly with regard to the restoration of cognitive deficits through cognitive stimulation therapy (CST) and reality orientation (Knapp et al., 2006; Spector et al., 2003). More recently, there has been increasing interest in the potential use of emotion-oriented interventions in the treatment of dementia. Such interventions include reminiscence therapy, validation therapy and supportive psychotherapy. Reminiscence therapy is probably the most popular of these activities and involves the discussion of past events and experiences with at least one other person, often with the aid of tangible prompts such as photographs or other familiar items. However, despite being relatively widely used in dementia care, evidence on the effectiveness of reminiscence remains scarce and uncertain (Woods et al., 2005).

This brings us to the genesis of our own work, which is a desire to explore the impact of reminiscence therapy on the quality of life of people with dementia in long-stay care. The aim of this report is to detail the methods, results, and policy and practice implications of a cluster randomised controlled trial (RCT), which sought to evaluate the effectiveness of reminiscence for people with dementia. The trial, which was funded by the Health Research Board, involved the delivery of a structured Dementia education programme incorporating Reminiscence to Staff (DARES) in long-stay settings,

who subsequently integrated reminiscence into the care of people with dementia, both formally and informally, over an 18-week period.

The DARES study has three main objectives:

1. To develop a comprehensive structured education reminiscence-based programme for staff that is specifically orientated toward enabling planned and spontaneous reminiscence to take place as part of the care of people with dementia.
2. To evaluate the impact and effectiveness of the structured education programme within the context of a cluster randomised trial.
3. To understand participants' qualitative perceptions of the education programme, their experience of care following the intervention and its impact on their lives.

This practical summary of the research undertaken for DARES sets out the background to the work, methodological issues, key findings, policy and practice implications, and recommendations for the future. The report is structured as follows: Chapter Two examines the care of people with dementia in long-stay residential care settings. Chapter Three describe the range and scope of potential psychosocial interventions for people with dementia. Chapter Four provides a conceptual description of reminiscence therapy. In Chapter Five, the methods of the DARES trial are outlined. Chapter Six reports on the main quantitative results of the study, while Chapter Seven covers the qualitative results. In Chapter Eight the methodological issues that arose during the course of the DARES trial are discussed. Chapter Nine provides an overview of the study and presents some conclusions in relation to both methodology and effectiveness. ■

# 2

## Dementia in Long-Stay Care Settings in Ireland



**ESTIMATING** the numbers of people with dementia in long-stay facilities in Ireland is hindered by the fact that there are multiple sources of information available on the number and type of long-stay facilities. In Ireland, long-stay care comprises a mix of public, private and voluntary providers, all of whom are required to register with the Health Information and Quality Authority (HIQA). While registered facilities are listed alphabetically on HIQA's website, summary information on the number or type of registered facilities is not provided, nor is information available on the number of dementia-specific units or specialist care units, or indeed the number of people with dementia accommodated within each facility. Information on the number of private (for-profit and not-for-profit) nursing homes is also available from Nursing Homes Ireland (NHI). Drawing on both the national register data and NHI data, it is estimated that there are circa 600 long-stay care settings for older people in Ireland, three quarters of which are either private or voluntary.

The most recent estimates suggest that there are 41,470 people with dementia in Ireland (Cahill et al., 2012), just over one-third of whom reside in long-stay units (Table 2.1). The estimate of 14,266 people with dementia in long-stay care suggests that approximately 63% of people in residential care in Ireland have dementia. This

is significantly higher than the official estimate of the Department of Health and Children (2009), which estimates that only 26% of people in long-stay care units have dementia. For many reasons, however, the latter figure is likely to be an underestimate arising from an overly narrow definition of dementia, multiple classification systems for people with dementia, and measurement error. Indeed, more recent evidence from Ireland suggests that 89% of nursing home residents may have some level of cognitive impairment, with 42% having severe cognitive impairment (Cahill and Diaz-Ponce, 2010). International evidence has shown estimates of dementia in long-stay care settings in Europe and the USA at between half and two-thirds of all residents (Cahill and Diaz-Ponce, 2010; Helmer et al., 2006; Knapp and Prince, 2007).

The vast majority of people with dementia in Ireland living in long-stay care, whether private or public, are cared for within generic care facilities for older people, most of which are not purpose-built for dementia or designed to cater for the complex, challenging and unique needs of residents with Alzheimer's disease and the related dementias. Research in several countries confirms that quality of life for people with dementia is problematic, particularly for those living in poorly designed and poorly staffed residential care settings (Hancock et al., 2006; Moise et al., 2004; Murphy et al., 2006). People with

**Table 2.1: Distribution of people with dementia across care settings in Ireland**

Care Setting	Number (%)
Community	26,104 (63)
Acute care	644 (2)
Psychiatric care	456 (1)
Long-stay residential care	14,266 (34)
All	41,470

Source: (Cahill et al., 2012)

dementia in long-stay care tend to adapt best to small-scale units which are purpose-built and appropriately designed for people with cognitive impairment. However, these types of facilities are the exception rather than the rule in Ireland, leading to calls for more dementia-specific and homelike models of care in the future (Cahill et al., 2012).

Research in a number of countries has focused on the broad determinants of quality of life within long-stay care settings (Ball et al., 2000; Edwards et al., 2003; Kane, 2001; Kane, 2003; Murphy et al., 2006; Tester et al., 2004). Findings emerging from this considerable literature suggest that the following elements are important in determining quality of life: health; resident autonomy; choice and control; connectedness to residents, staff, family and the outside community; the social and physical environment; and meaningful therapeutic activities, all of which reflect in some way the lived experience of residents in relation to their institutional surroundings. There is some evidence that older people living in long-stay care settings tend to have a better quality of life when they can replicate as closely as possible the life they would choose to live in their own home (Groger, 1995; Gubrium, 1975; Shield, 1988). Memories, attachments, status and associations that stem from living and ageing at home, which help to reinforce a sense of personal identity (Rowles, 1983) can be useful in adapting to and surviving life in an unfamiliar and regulated environment (Kontos, 1998). The centrality of home across a person's life-course means that it has the potential to serve as a "*mnemonic anchor*" for life

events, even if those events are recollected through a co-production of memory and imagination and at some distance from the original physical experience (Chaudhury and Rowles, 2005).

Very often it is staff attitudes and what might be termed "the culture of care" that determine the meaning that can be ascribed to "home" within long-stay care settings. Murphy et al. (2006) concluded that the quality of life in long-stay settings in Ireland is likely to be affected by: the care environment and ethos of care; expression of self and identity; and connectedness to family and community. Each of these elements, but particularly the first, are likely to influence and be influenced by psychosocial therapeutic interventions designed to impact on the morale and well-being of residents with dementia. Training and education are very important in developing a more person-centred culture of care among staff in long-stay care settings. Murphy et al. (2006) found that many nursing home staff reported that they lacked the skills to manage residents with dementia, particularly those with challenging behaviours. An important recent development in that regard has been the introduction of a National Dementia Education Programme for HSE nursing staff working within Older Person Services, with funding from the National Council for the Professional Development of Nursing and Midwifery. The DARES programme attempts to link education and training of staff with a reminiscence-based psychosocial intervention with a view to impacting on the quality of life of residents in long-stay care. ■



# 3

## Psychosocial Interventions for People with Dementia

**PHARMACOLOGICAL** interventions have long been the cornerstone of care for people with dementia despite evidence suggesting that, for some, they are ineffective in managing depression, agitation and problem behaviour, and do not always have a positive impact on quality of life. However, in the last 30 years, there has been an increasing focus on using psychosocial interventions for people with dementia, as an alternative to or in addition to pharmacological treatment. The current and growing prevalence of dementia is likely to place an increasing burden on healthcare resources, adding to the importance of identifying the treatments that have the greatest positive impact on people with dementia and on their carers, have minimal negative side-effects and are most cost-effective. In this chapter a range of psychosocial interventions will be discussed and the evidence for their potential effectiveness reviewed.

### What are Psychosocial Interventions?

Psychosocial interventions are defined as therapeutic endeavours involving human interactive behaviour between therapist(s) and client(s) throughout the course of the intervention (Bates et al., 2004). These interventions include a wide range of behavioural therapies, educational programmes, psychotherapy and support groups.

Psychosocial interventions can be classified into four groups:

- **Behaviour-oriented interventions** – these interventions aim to identify and reduce the frequency of activities that consistently precede problem behaviour, and the consequences of that behaviour. For example, a behavioural intervention such as scheduled toileting can reduce the frequency of urinary incontinence.
- **Emotion-oriented interventions** – these interventions aim to improve the emotional and social functioning and hence the quality of life of the person with dementia, by supporting them in the process of coping with the consequences of the disease and by seeing the functional potential rather than the limitations of the individual (Finnema et al., 2000). Emotion-oriented interventions focus on the experiences and perceptions of the person with dementia and can include supportive psychotherapy (Group for the Advancement of Psychiatry, 1984), reminiscence therapy (Burnside and Haight, 1994), validation therapy (Jones, 1985), sensory integration (Robichaud et al., 1994) and simulated presence therapy (Woods and Ashley, 1995).
- **Cognition-oriented interventions** – the aim of these interventions is to restore cognitive deficits. These interventions include reality orientation (where continuous and repeated reminders aim to orient the person with dementia in time and place), cognitive stimulation (which provides activities intended to stimulate thinking, memory and social interaction), and skills (or memory) training.
- **Stimulation-oriented interventions** – these interventions provide stimulation and meaningful activities and thus mobilise the available cognitive resources of the person with dementia. A number of different types of interventions fall into this category, including activities or recreational therapies, for example crafts, games, and use of pets; art therapies, for example music, dance, art; and interventions that work on the senses, for example multisensory stimulation and aromatherapy.

In reality, psychosocial interventions often overlap more than one category, and new psychosocial

interventions are constantly being introduced that have not yet been classified. Not all authors agree into which category a particular psychosocial intervention should fall, nor is there always agreement on which interventions are in fact psychosocial interventions.

Psychosocial interventions can be targeted at the person with dementia, at carers (either professional or family carers), or at both simultaneously, in the form of patient/carer dyads. Psychosocial interventions can be delivered individually, in small groups or in large groups, and it is possible to deliver the same psychosocial intervention in all three modes. For example, Wang (2007) evaluated reminiscence delivered to groups of 8-12 people, Ito et al. (2007) used reminiscence with groups of 2-4 people, while one-to-one reminiscence sessions were the focus of the DARES study. Moreover, Haslam et al. (2010) compared the use of group and individual reminiscence in the same study.

Interventions are delivered by different people: by trained researchers external to the intervention setting; by trained professionals, for example occupational therapists, counsellors or activity co-ordinators, who may or may not be normally working with participants; or by professional care staff or informal/family carers, who have been trained in the methods of the intervention. Psychosocial interventions have been tested with people with dementia living in the community and living in long-stay residential care, and with carers in both settings.

#### Evaluating the Effectiveness of Psychosocial Interventions

Studies evaluating the effectiveness of psychosocial interventions have measured many different outcomes, as well as different domains within an outcome. Common outcomes include changes in cognitive function, depression, agitation, problem behaviour, mood, anxiety, communication, life satisfaction, social

relationships and self-image, with a growing focus on quality of life and well-being.

The effectiveness of outcomes has been evaluated at different points in time: in some cases during an intervention, in others at the end of an intervention, and in yet others sometime after the end of the delivery of an intervention. Finally, in some evaluations the unit of analysis is the individual, while in others the unit of analysis is the cluster, such as the long-stay residential unit.

To date, evidence on the effectiveness of psychosocial interventions is inconclusive. Most of the available evidence comes from small-scale observational studies, with little blinding of outcome assessors and interventions of short duration. These methodological problems are often compounded by poor reporting, with inadequate detail provided on the nature of the intervention, the severity of dementia or the criteria for inclusion in the study.

Many systematic reviews have been conducted in an attempt to summarise the available evidence, with some reviews considering all psychosocial interventions and others focusing on particular psychosocial interventions. Verkaik et al. (2005) focused on studies using depression, aggression or apathy as an outcome measure and concluded that there is some evidence that multi-sensory stimulation/Snoezelen reduces apathy, and that behavioural therapy reduces depression in people with dementia living in the community, but the overall conclusion was that the number of studies of sufficient scientific quality on the effect of psychosocial interventions on people with dementia is limited. Bates et al. (2004) looked specifically at the impact of psychosocial interventions on people with milder dementia and reported some evidence in support of the use of reality orientation in this population, but warned that due to the small sample sizes and the uneven quality of available studies, more research is needed. A Cochrane review by Clare and Woods



(2003) evaluated the effectiveness of cognitive training and cognitive rehabilitation interventions aimed at improving memory and other aspects of cognitive functioning for people in early stages of Alzheimer's disease or vascular dementia. The authors concluded that the available evidence is too limited to confirm any significant benefits from individualised cognitive rehabilitation interventions in this population.

O'Connor et al. (2009) reviewed the impact of psychosocial interventions on behaviour symptoms in dementia and argued that it is not reasonable to apply the criteria used to evaluate pharmacological interventions to research in the area of psychosocial interventions. On this basis, O'Connor et al. concluded that there is sufficient evidence to support the use of aromatherapy, bed baths, gentle sounds, individualised music and muscle relaxation training as treatments of behaviour symptoms, but perhaps not all of these treatments fit the definition of a psychosocial intervention (Bates et al. (2004)). A Cochrane review by Bradt and Dileo (2011) reviewed the impact of music therapy for patients receiving end-of-life care, which includes people in the end stages of dementia, and concluded that although results indicated music therapy may have a positive impact on quality of life, the quality of evidence is not strong, as it is based on a limited number of small and poor quality studies. Neal and Barton Wright's (2009) Cochrane review on validation therapy also concluded that there is insufficient evidence from RCTs to reach any conclusion about the effectiveness of validation therapy for people with dementia or cognitive impairment.

Cognitive stimulation therapy (CST) is currently the only non-drug intervention to be recommended for cognitive symptoms and maintenance of function in people with dementia in the UK. The National Institute for Health and Clinical Excellence (NICE) in that country state that people with mild/moderate dementia of all types should be given the opportunity

to participate in a structured group cognitive stimulation programme. Similarly, Alzheimer's Research UK advocates the use of cognitive stimulation for people with dementia. The rationale for these recommendations stems from accumulated evidence that CST is equally effective as dementia drugs in improving cognition, on its own and in combination, for example with specific drugs such as donepezil (Chapman et al, 2004; Onder et al, 2005; Spector et al., 2003). Moreover, there are no reported side-effects of CST. Furthermore, the available evidence suggests that CST leads to significant improvements in quality of life, as rated by the participants themselves using the Quality of Life - Alzheimer's Disease (QoL-AD) scale (Spector et al., 2003).

The existing research literature on trials-based reminiscence therapy for people with dementia has also been summarised in the form of a Cochrane review (Woods et al., 2005). The trials together identified significant improvements in cognition and mood 4–6 weeks after treatment, and reduced stress in carers who participated with the person with dementia in a reminiscence group. However, only five randomised controlled trials were included in this review, of which only four had extractable data, comprising a maximum of 144 participants. The studies, therefore, were small in scale and also incorporated diverse forms of reminiscence, resulting in far from robust conclusions on overall effectiveness. It is unsurprising that the authors of the review recommended more and better designed trials of reminiscence therapy for dementia before a decision on overall effectiveness could be reached. This dearth of evidence is reflected in the NICE Guidelines on the management and treatment of dementia in the UK, which found insufficient evidence to recommend that reminiscence should be routinely offered to people with dementia, although its potential impact on the mood of the person with dementia was highlighted. ■

# 4

## Reminiscence in Dementia: A Concept Analysis

**AS DISCUSSED** in the previous chapter, the evidence on the effectiveness of reminiscence is inconclusive. In a review, Woods et al. (2005) concluded that a number of factors contributed to the difficulty in providing conclusive evidence of the effectiveness of reminiscence, including variation in the operational definitions of reminiscence used in the literature and subsequently in clinical trials. The aim of this chapter is to provide a summary of some of the key issues around the meaning of reminiscence in dementia, as a background to developing a working definition of reminiscence for use in the DARES study.

### Defining Reminiscence

Rodgers (2000) contends that evolutionary concept analysis begins with identifying and naming the particular concept of interest and locating surrogate terms and relevant uses of the concept. Reminiscence has no standard definition in the health literature, leading to multiple definitions of the concept and contributing to overlapping components, terminologies and meanings. For example, reminiscence can be “the recalling of personally relevant memories from the past” (Cappeliez et al., 2008 p.266), or “a selective process in which memories are evoked and reconstructed” (Cohen and Taylor, 1998 p.601), or “the vocal or silent recall of events in a person’s life either alone or with another person or group of people” (Bohlmeijer et al., 2007). The definition offered by Woods et al. (2005 p.1) appears quite frequently in the literature on dementia and gives a more detailed account of the various processes involved in a reminiscence activity: “reminiscence therapy involves the discussion of past activities, events and experiences with another person or group of people, usually with the aid of prompts such as photographs, household and other familiar items from the past, music and archive sound recordings.” This definition highlights the importance of prompts or triggers in order to evoke a response from an individual.

From all of this complexity, it is possible to identify three main attributes of reminiscence which help to differentiate the concept from other types of psychosocial interventions involving memory recall:

1. Reminiscence is a process of recall which occurs in stages.

2. Reminiscence is an interaction which involves recalling or telling of early events or a memorable early experience which may occur with or without specific purposes.
3. Reminiscence is an interaction between the person recalling the memory and one or more individuals.

Most definitions share some or all of these attributes which can then be assigned individually or collectively, in home or residential care settings, with various prompts used to elicit the desired memory responses.

Woods et al.’s (2005) multi-attribute definition is applicable to individuals with dementia but would benefit from indicating the purpose of undertaking reminiscence and possible outcomes predicted in this population. Taking into consideration the key findings in dementia research, the definition used to inform our approach to reminiscence in DARES was as follows:

*Reminiscence is the deliberate use of prompts, for example photographs, smells, music and questioning, to promote the recall of pleasant memories. In the context of this study reminiscence is viewed as a one-to-one interaction between the person with dementia and a staff member, except in the case where working in a small group is appropriate as determined by the capacity and needs of the individual with dementia. Reminiscence may be spontaneous, i.e. the opportunistic use of reminiscence while delivering nursing care, or planned, i.e. where reminiscence is the specific focus of care. The focus of reminiscence work is to stimulate the person, provide enjoyment and foster a sense of achievement and self-worth. The anticipated outcomes of reminiscence work are enhancement of the person’s quality of life, behaviour and mood.*

### Related Concepts

Related concepts are “concepts that bear some relationship to the concept of interest but do not seem to share the same set of attributes” (Rodgers, 2000 p.92). Two frequently used concepts related to reminiscence are life review and nostalgia. The terms reminiscence and life review are often used interchangeably in the literature but



are quite different in their goals, theory base, approach, content, client role, facilitator roles and short-term goals. Life review demands high levels of inner skills and is not necessarily confined to older adults. It also implies a search for meaning through reflection on one's life experiences and may lead to transformation goals and changed values (Coleman, 2005), something to which reminiscence does not necessarily aspire. Similarities between reminiscence and life review lie in the fact that they are therapeutic interventions mainly implemented with older people and each involves eliciting memories. Butler (1963) believed that reminiscence is observed more frequently in older people, mainly because the act of recalling the past or reviewing one's life is triggered by the realisation of approaching death. Common to both reminiscence and life review is the construction of life stories, and the associated anticipated and desired long-term outcomes are adaptation, increased life satisfaction and increased quality of life (Burnside and Haight, 1992; Lin et al., 2003; Woods et al., 2005).

Nostalgia is described as a longing for things, persons or situations that are not present or a longing for a perceived utopian past (Merchant and Ford, 2008). Nostalgia affects the young as well as the old, although as individuals age there may be a greater tendency to recall bygone days, with a longing not only for a past which has been personally experienced but for a past paradise which was never actually experienced. The literature suggests that nostalgic reverie often revolves around momentous life events, reflects more positive than negative emotions, contains more desirable than undesirable features and leads to a more positive than negative mood (Wildschut et al., 2006). Significant life events such as marriages, the birth of a child and graduations, when recalled, evoke a stronger, more intense memory and recall is better than with less significant life events. Nostalgia and reminiscence are similar concepts in that both involve remembering past events, both are primarily conducted by older people and both activities, when effectively carried out, produce a positive outcome for the person recalling the past event. However, reminiscence normally recollects actual life events, in opposition to nostalgia which often is longing for a past that never was.

## Outcomes

There are many documented positive outcomes associated with reminiscence, some of which are a positive mental health, successful adaptation to old age, sense of identity, increased self-esteem, improved communication skills, increased interaction between individuals, a preparation for death, helping to master personal losses experienced in later life, facilitating important decision-making, allowing for examination of one's conscience, preparing for the future, and evaluating a past life (Bohlmeijer et al., 2007; Cappeliez et al., 2008; Egan et al., 2007; Schweitzer and Bruce, 2008; Tadaka and Kanagawa, 2007; Yamagami et al., 2007; Woods et al., 2005;).

A concern when using reminiscence, even when focused on the recollection of pleasant memories, is the prompting of unhappy memories about the past. Stressful situations may occur when prompts or triggers used to elicit reminiscence in individuals with dementia evoke unhappy memories that impact negatively on mood and quality of life for people with dementia. Older people may have encountered pain or loss in their earlier life and recalling certain past events related to either or both may cause distress to them during and after reminiscence (Cappeliez et al., 2005). Without appropriate emotional support, sometimes delivered by a relevant health professional, an individual may be left with overwhelming feelings evoked by painful remembrances.

## Conclusion

Testing the effectiveness of reminiscence on people with dementia is an ongoing process. The need for robust randomised controlled trials, with clear treatment protocols, has been highlighted as important in the literature. More care and attention is required when making decisions on the meaning, form and structure of reminiscence to be used in such trials. Agreeing on the core attributes of reminiscence and distinguishing it from life story and nostalgia are important parts of designing an effective intervention. ■

# 5 Study Methodology

**AS INDICATED** in Chapter One, the central piece of work included in this report relates to the randomised controlled trial (RCT) used to evaluate the effectiveness of reminiscence for those with dementia in long-stay care. Details of the methods of the trial are provided below.

## Study Design and Participants

The DARES study is a two-group, single-blind cluster randomised trial conducted in public and private long-stay residential settings in Ireland. Individual long-stay residential units were randomised to either a control or an intervention group. Nursing and healthcare assistant staff within the long-stay residential units allocated to the intervention group received a structured education reminiscence-based programme. Residents in long-stay settings allocated to the control group received usual care. A cluster design was chosen because it would have been unreasonable to have expected staff to provide reminiscence for some residents and not for others had individual residents, rather than the unit, been randomised to control and intervention groups.

Public and private long-stay units across the western half of the Republic of Ireland were recruited. Each participating unit had between 15 and 17 residents with dementia who agreed, either directly or through proxy, to take part in the study. Residents were eligible for participation if they had lived in the residential unit for at least one month and were likely to be there for the duration of the study. Given the reality that formal clinical diagnosis of dementia in residential care is rare in Ireland, diagnosis of dementia in residents ranged from a formal diagnosis of dementia determined by the DSM-IV or ICD-10 criteria for dementia to the nurses' judgement and/or nursing records advising that the person had dementia.

## Randomisation and Blinding

Randomisation took place once all residential units and participating residents with dementia had been recruited. Residential units were allocated to either the intervention or control group (on a 1:1 ratio) by an independent researcher, based on a computer-generated random allocation sequence, stratified by public and private residential units to ensure an appropriate representation of public and private facilities (i.e. one-third public to two-thirds private).

Outcome assessment was protected by blinding the research nurses involved in data generation and collection to the group allocation of participating units, staff and residents. Data analysis was undertaken by researchers and statisticians blinded to group allocation.

## Intervention

The process involved in developing the structured education intervention included a literature review on psychosocial interventions and a concept analysis of reminiscence; interviews with persons with dementia, their relatives and care staff; and interviews with experts from the field of dementia. A holistic three-day education programme was developed based on a philosophy of autonomy and empowerment. The programme was facilitated by nurse educators and delivered to staff participants in two stages. The first two consecutive days focused on informing staff about the study, the aims and expectations, rationale and approach, and provided detailed information on dementia, memory, communication, reminiscence and implementation. The third day, held six weeks later, focused on staffs' experiences of implementing the education programme and addressing any problems or queries.

A nurse and a care assistant who completed the education programme were linked to three/four resident participants. Each staff dyad was responsible



for implementing reminiscence with each of these residents, including embedding reminiscence within their care plans, engaging the resident in reminiscence at least four times a week (one formal planned session and three spontaneous sessions), and keeping a record of same. Staff were also asked to complete a life history for each resident enabling the identification of information around which the reminiscence sessions could be based.

Residents in the control group were not exposed to staff who had received the education programme, and they continued to receive usual care.

## Outcomes

Outcomes were measured for both the control and intervention group at baseline (Time 1 (T1)) (following consent and prior to randomisation and cluster allocation) and again at 18-22 weeks post-randomisation (Time 2 (T2)). The following outcomes were assessed:

**Quality of life:** The quality of life of residents was measured using the Quality of Life – Alzheimer’s Disease (QoL-AD) instrument. The QoL-AD instrument includes 13 items on quality of life and was designed to provide a resident’s and carer’s report of the resident’s quality of life (Logsdon et al., 1999). The primary outcome measure was quality of life of the resident as assessed by the resident themselves, while the carer’s report on quality of life of the resident was a secondary outcome measure. The instrument is administered as a structured interview using standardised instructions. A research nurse administered the QoL-AD form with the resident. A staff member who was familiar with the resident completed the carer proxy version of the QoL-AD.

**Agitation:** The level of agitation in resident participants was measured using the Cohen-Mansfield Agitation Inventory (CMAI). The CMAI is a 29-item scale specifically developed to assess the frequency of agitated

and disruptive behaviours (Cohen-Mansfield and Billig, 1986). The questionnaire has four domains: physical/aggressive, physical/non-aggressive, verbal/aggressive, verbal/non-aggressive.

**Depression:** Depression in resident participants was assessed using the Cornell Scale for Depression in Dementia (CSDD) (Alexopoulos et al., 1988). The scale was specifically developed to assess signs and symptoms of major depression in people with dementia across five broad categories.

**Staff care burden:** Staff care burden was assessed using a modified version of the Zarit Burden Interview (Zarit et al., 1980). The scale was initially developed to assess carer burden on the relatives of impaired older people.

## Quantitative Data Analysis

The sample size was estimated using methods appropriate for trials randomised at the level of cluster rather than at the level of the individual (Devane et al., 2004). Sample size estimates were based on the primary outcome of quality of life of people with Alzheimer’s disease as measured by the recipient version of the QoL-AD scale.

Based on a mean QoL-AD score of 32.5 for people with dementia in long-stay care homes (Hoe et al., 2009) and an intraclass correlation coefficient (ICC) value of 0.1 identified from pilot work on reminiscence groups for people with dementia for the REMCARE trial (Woods et al., 2009), a total of 18 residential units were required, each containing 17 people with dementia, to detect a four-point difference in mean QoL-AD scores between control and intervention groups, for power of at least 80% with alpha levels of 0.05. This calculation allowed for a loss to follow-up of 20% of residents and up to three long-stay units.

The focus of data analysis was on the long-stay care setting with the resident as the unit of analysis. Quantitative data were analysed, in aggregate, using the Statistical Package

for the Social Sciences (SPSS, v20). Data were coded and entered into SPSS. Levels of statistical significance for the final analyses were set at 5% (two-sided).

We conducted the following analyses:

- Intention to treat analysis on primary and secondary outcomes using complete cases (or cases with available data) only;
- Intention to treat analysis on primary and secondary outcomes using imputed missing data;
- A per protocol analysis of primary and secondary outcomes retaining only the units in the intervention arms in which the education programme had been fully administered as prescribed. This was done using both (i) complete cases only and (ii) imputed data.

The analysis of data also included the search for, and control of, potential confounding variables.

### Qualitative Analysis

The DARES study includes a substantial embedded qualitative arm structured around three specific objectives:

- 1) Supporting the development of the structured education programme. This consisted of interviews with nurses and healthcare assistants, experts in the field of dementia, people with dementia, and relatives of those with dementia.
- 2) Exploring the use of reminiscence with residents with moderate to severe dementia living in long-stay care settings. This was achieved through a grounded theory study involving interviews with 30 participants comprising residents with dementia,

healthcare assistants and registered nurses. The constant comparative technique was used to analyse data, that is, information generated at each data collection point was analysed in full prior to moving to the next stage. This enabled data analysis to guide ongoing data collection and sampling decisions (theoretical sampling).

- 3) Understanding and defining usual care in the control sites. This consisted of interviews with clinical nurse managers in the control sites.

### Rigour

Threats to the reliability and validity of the intervention were minimised by providing the structured education programme within the context of a comprehensive, formal curriculum delivered by experienced educators. Strategies to assess the level of reminiscence being conducted in the intervention units were implemented and included visits to the units, telephone support and remedial action plans where necessary and possible.

Data validation was enhanced by having data collection performed by a small number of trained research nurses and by adherence to assessment protocols. Single data entry into SPSS with visual verification of a sample of records from the data set created from the single entry using a continuous sampling plan (CSP-1) (King and Lashley, 2000) was used.

A pilot study was conducted with two residential units, one public and one private. This pilot was used to: identify problems with the research design/processes; refine data collection and analysis; assess adequacy of data sources; examine selection and enrolment processes; test instruments; and assess resident and staff perspectives on participation in a trial of this complexity. Data from the pilot study are not included in the main analyses of the trial. ■



# 6

## Quantitative Assessment



**THIS CHAPTER** details the results of the quantitative component of the DARES study.

The education programme was delivered successfully in all nine intervention sites; however, three of the long-stay units did not fully implement reminiscence with their residents as prescribed (n=51 residents). Failure to return reminiscence records was the primary indicator of non-compliance, supported by research nurse observation of fragmented reminiscence activity within the site. Two of the sites proffered no reminiscence records at all, while the third provided records for only one dyad within the cluster of four dyads. Each of the three sites were offered additional support from the DARES research team during the trial. The main reason for not fully implementing the intervention in the three sites was staffing difficulties. Although the vast majority of staff were remained committed to implementing reminiscence, they sometimes lacked the resources and the resolve to make full use of the knowledge gained on the education programme. The effects on outcomes of excluding the three sites which did not fully implement the study intervention with their designated residents as prescribed were explored in the per protocol analysis.

### Resident Characteristics

Table 6.1 details the demographic and clinical characteristics at baseline of residents assigned to the intervention (n=153) and control (n=151) groups. As expected, as randomisation was stratified by public and private residential units to reflect the current distribution of public and private beds, there were more residents in private than public units. Sixty-nine per cent (n=209) of participating residents were female, with a slightly higher proportion of males in the control compared to the intervention group. Mean scores on the Mini-Mental State Examination

(MMSE) indicate that residents in the intervention and control groups had moderate levels of cognitive impairment.

Table 6.2 shows the mean scores (and standard deviations) for the intervention and control groups at baseline and follow-up for each of the primary and secondary outcomes. At baseline, the average QoL-AD resident score (as perceived by the resident themselves) was 34.32 in the intervention group and 33.76 in the control group; the carer QoL-AD score for the resident was lower than that reported by the resident themselves. There was a slight improvement in the QoL-AD resident score for the intervention group over the follow-up period and a decline in the control group; a similar pattern was observed for the QoL-AD carer score, though the magnitude of change was less.

As scores less than six on the Cornell Depression Scale are generally associated with an absence of significant depressive symptoms, there were relatively low levels of recorded depression in the control and intervention groups at both baseline and follow-up. Over the follow-up period, there was an increase in the CSDD score in the intervention group and a decrease in the control group.

In Table 6.3 the estimate of the treatment effect (as well as the associated 95% confidence intervals (CIs) and p-values) for the intention to treat complete case analysis are shown for the primary and secondary outcomes. The minimum clinically important difference (MCID) between intervention and control group for the primary QoL-AD outcome was set at four points (O'Shea et al., 2011). The effect, on average, of the intervention on the quality of life of residents was 3.54 (p=0.1; 95% CI -0.83, 7.90), implying that there was a positive, but clinically non-significant improvement in the mean quality of life of residents in the intervention group compared to the control group.

**Table 6.1: Baseline demographic and clinical characteristics of participating residents assigned to intervention and control groups**

	Intervention (n=153)	Control (n=151)
<b>Residential unit type</b>		
Private – number (%)	102 (67)	100 (66)
Public – number (%)	51 (33)	51 (34)
<b>Age in years</b>		
Mean (standard deviation)	85.2 (7.1)	85.7 (7.1)
<b>Gender</b>		
Male – number (%)	43 (28)	52 (34)
Female – number (%)	110 (72)	99 (66)
<b>Mini Mental State Examination score (MMSE)</b>		
Mean (standard deviation)	12.98 (5.5)	11.70 (5.4)
<b>Ethnicity</b>		
White Irish – number (%)	151 (99)	146 (97)
Other – number (%)	0	3 (2)
Unrecorded – number (%)	2 (1)	2 (1)
<b>Type of dementia diagnosis</b>		
ICD-10 or DSM-IV – number (%)	5 (3)	15 (10)
Clinician diagnosis – number (%)	93 (61)	74 (49)
Prescribed anti-Alzheimer drug – number (%)	53 (35)	39 (26)
Nurses' judgement – number (%)	152 (99)	144 (95)
<b>Type of consent</b>		
Resident – number (%)	148 (97)	134 (89)
Proxy – number (%)	5 (3)	17 (11)

There was a statistically significant negative difference in CSDD scores between the intervention group and control group (-1.33,  $p=0.03$ , 95% CI -3.04, 0.36) strongly influenced by a reduction in mean depression scores in the control group relative to the intervention group (Table 6.2). However, there was an absence of significant depressive symptoms among the majority of participants in the trial, as evident by an average score

of less than six on the CSDD scale, at baseline and at follow-up for intervention and control groups.

The effect of reminiscence did not reach statistical significance on any of the remaining secondary outcome measures. The analysis was re-run with adjustment for missing values (results not shown); however, no significant differences were observed in the overall results.

**Table 6.2: Comparison of outcomes at baseline and follow-up in intervention and control groups: mean scores (and standard deviation).**

	Baseline		Follow-up	
	Intervention group	Control group	Intervention group	Control group
QoL-AD resident score	34.32 (4.54)	33.76 (5.27)	35.22 (4.29)	31.77 (6.55)
QoL-AD carer score	30.38 (5.54)	30.13 (5.83)	30.42 (6.31)	29.09 (6.01)
CMAI score	41.39 (13.68)	43.90 (14.51)	43.13 (15.65)	43.78 (15.76)
CSDD score	4.12 (4.53)	4.64 (4.81)	5.19 (5.36)	3.62 (4.50)
MZBI nurse score	9.74 (8.49)	11.58 (8.50)	9.30 (7.29)	10.21 (7.97)
MZBI healthcare assistant score	8.55 (7.02)	11.03 (8.87)	7.41 (6.91)	9.57 (8.24)

**Table 6.3: Effect estimates for primary and secondary outcomes: intention to treat complete case analysis**

	Estimated effect <sup>1</sup> (95% confidence interval (CI))	p-value	Intraclass correlation coefficient	Covariates adjusted for <sup>1</sup>
QoL-AD resident score	3.54 (-0.83, 7.90)	0.10	0.17	Dementia diagnosis 1
QoL-AD carer score	1.14 (-0.35, 3.62)	0.35	0.04	Dementia diagnosis 2,3; Type of consent, MMSE
CMAI score	-3.35 (-8.10, 1.82)	0.19	0.00	Type of consent; Age; Dementia diagnosis 2,3
CSDD score	-1.33 (-3.04, -0.36)	0.03	0.28	Age
MZBI nurse score	0.97 (-1.13, 3.08)	0.36	0.13	MMSE; Dementia diagnosis 1,2
MZBI healthcare assistant score	0.42 (-1.83, 2.67)	0.70	0.15	Age; Type of consent

1 – Baseline and covariates adjusted mean difference between intervention and control group

**Table 6.4: Effect estimates for primary and secondary outcomes: per protocol complete case analysis**

	Estimated effect (95% CI)	p-value	Intraclass correlation coefficient	Covariates adjusted for
<b>QoL-AD resident score</b>	5.22 (0.11, 10.34)	0.04	0.15	Dementia diagnosis 1
<b>QoL-AD carer score</b>	1.40 (-1.75, 4.55)	0.35	0.01	Dementia diagnosis 2, 3; Type of consent; MMSE
<b>CMAI score</b>	-2.14 (-7.94, 3.67)	0.43	0.02	Type of consent; Age in years; Dementia diagnosis 2, 3
<b>CSDD score</b>	-0.86 (-2.66, 0.93)	0.32	0.29	Age in years
<b>MZBI nurse score</b>	1.50 (-0.73, 3.74)	0.18	0.10	MMSE; Dementia diagnosis 1, 2
<b>MZBI healthcare assistant score</b>	0.86 (-1.22, 2.94)	0.40	0.15	Age in years; Type of consent

Table 6.4 shows the results of the per protocol analysis, that is, including only those units that fully implemented reminiscence with their residents. Including only those long-stay units that followed protocol suggests that there was a clinically and statistically significant effect of the intervention on the quality of life of residents, with those in the intervention group experiencing a 5.22-point improvement in quality of life, compared to those in the control group ( $p=0.04$ , 95% CI 0.11, 10.34). Again, these effects were insensitive to the inclusion of missing data. For all other outcomes, including depression, no significant effect of the intervention was found. ■

# 7 Qualitative Assessment



**IN ADDITION** to the quantitative component, the DARES study sought to understand residents, staff and relatives perceptions and experience of reminiscence and how it impacted on their lives. Study participants were recruited from the long-term care settings included in the intervention arm of the study. The preliminary results presented in this chapter focus only on staff and relatives in two public and two private long-stay facilities. More detailed analysis, which will include the views of people with dementia, will be available at a future date. Table 7.1 shows the demographic characteristics of the care staff analysed for the purposes of this summary report.

The qualitative analysis was undertaken using a grounded theory approach. Data were collected using semi-structured interviews and analysed using constant comparison (Corbin and Strauss, 2008). The aim of grounded theory is to build theory that is grounded in and emerges out of the data. Theory is expressed in the form of a core category and its associated subcategories, properties and relationships.

The core category emerged as comprising four interrelated components: “*seeing and knowing the person*”, “*reminiscence... a key*”, “*understanding and accommodating*” and “*organisational impact*”. Through reminiscing and engaging with the person with dementia, staff began to see the person through the mirror of their stories and memories (or their families’/others’ stories if the person was not able to tell their own story). Thus reminiscence enabled nursing and health care assistant staff (S) to begin to “*see and know the person*” beneath the dementia.

*“She’s not just a confused resident. She has had a life.” (S1)*

*“... you wouldn’t think she did this and all that, you know. Kind of, you’re amazed.” (S2)*

Staff noticed that through their continued interaction, residents began to form a bond with them, knew them as an individual, reacted to them and were more likely to engage with them.

**Table 7.1 Demographic characteristics of staff participating in the qualitative analysis**

	Nurse (n=9)	Healthcare assistant (n=10)
<b>Gender</b>		
Male	0 (0%)	1 (10%)
Female	9 (100%)	9 (90%)
<b>Age</b>		
21-30	2 (22%)	0 (0%)
31-40	2 (22%)	4 (40%)
41-50	2 (22%)	1 (10%)
50+	3 (33%)	5 (50%)
<b>Years working with older people</b>		
< 1	0	1 (10%)
1-10	6 (67%)	6 (60%)
11-20	2 (22%)	1 (10%)
21-30	1 (11%)	1 (10%)
31-40	0	1 (10%)

*"I got to know them [assigned residents with dementia] all really, really well ... and our relationship was much, much stronger and I could get through to [Name] about certain issues that she would have had. She used to fight an awful lot with this other client that we have and I could get through to her an awful lot quicker because we had that special bond because we had sat and talked about her loved ones." (S3)*

Reminiscence therefore acted as a key or mechanism to unlock the person's past, thereby enabling staff to engage with the person with dementia in a different way. Reminiscence facilitated "meaningful" conversation and interaction in a way that hitherto had not been possible.

*"We were buttering bread and his mum used to make butter, so we were talking about how he used to make the butter and milking the cows ... I suppose it makes me feel that I'm connecting with him on a level he remembers, that is specific to him. That it's not just general chit-chat ... but it's actually important to him because it's something he can relate to and again he wouldn't be somebody who would be chatty." (S4)*

One staff member reported that residents' began to initiate some meaningful communication and enjoyed the ensuing interaction.

*"I brought in [a] book [on Place] and there was a factory and [Resident] worked there and she was in the sewing room and she made bags and that seems to be quite a fond memory for her ... She loved us to go back ... and see where she worked [through photographs in the book] ... the next day when I went in and I wasn't going to do reminiscence that day, she said 'Remember that thing you done the pictures? Can we do that again?'" (S1)*

Relatives (R), too, appreciated staff's attempts to "get to know" their loved ones better. They valued staff's interest in their relatives' lives, likes, dislikes and needs.

"And do you think the staff know enough about your Dad to understand his needs?"

*"I think they do now because I have spoken to them and the fact that this [DARES] is going on as well is a real help. I think it's a great help to give them a better insight into what his interests were before he went into them and what he liked." (R1)*

Understanding the person's past sometimes helped staff to interpret, understand and accommodate the person's behaviour in the present.

*"He used to just wander the corridors, right, and it was only afterwards when we started doing this that we asked him and he was putting sheep in the pen. That's what he was doing. He used to take all the fire extinguishers and he'd put them all in the corner and we said, 'what in God's name ...' but he was actually making the pen for the sheep and this was why he was doing it, we found out through communication that that was... [Before] you'd be saying 'for God's sake, would you ever nail them on?' Whereas ... I find now, I let them do it." (S5)*

Staff were extremely positive about the benefits of reminiscence but did have some concerns, particularly in the early stages of the programme. Their concerns centred on a fear of getting it wrong and upsetting a resident, or perpetuating what they viewed to be "inaccuracies" about the person's life. These concerns were not always realised in practice. Few staff reported that residents became "upset" (i.e. beyond the normal sadness associated with bereavement or loss), but if it happened they used the strategies they were taught on the programme to move the discussion on to a less contentious and emotive topic. More often than not, however, staff already knew the areas to avoid and focused on the positive memories.

*"[One resident] probably would have aspects of her life that she wouldn't want to discuss. What*



*she wants to discuss is fine, you know, you allow the discussion to go ahead. You don't probe you know deeper ... I didn't go there. It was all pleasant times really." (S2)*

Staff also worried that they would be viewed by their co-workers as "slackers" if they spent time talking to a resident. This was not a universal experience, however, but reflective of what was viewed as legitimate work in the facility.

*"... we actually are able to make the time and we don't feel guilty ... before this you might feel guilty, maybe someone [a co-worker] would come in and see you sitting down on somebody's bed talking to them ... [now] no one is critical." (S6)*

The deeper understanding of the individual resident and of dementia in general had a wider impact on the "organisation". One nurse manager flagged that there was a shift in organisational culture, a greater emphasis on person-centeredness and a concomitant shift away from task-centeredness.

*"We have a happier house ... it was very task-orientated ... now, the tasks have to be done ... but looking really more and more and more into a biopsychosocial model, rather than a medical model ... A man came in the other day now [post-DARES]. He has a lot of problems. You know, he was up and about three months ago but now he's looking for care. He's exhibiting some behavioural problems, but to see, now he was only here about four days, but the staff had got around him and chatted to him and chatted about stuff, about when he was here before and their interaction with him is so much better than if he had come maybe before DARES." (S7)*

This shift in culture brought other changes, including differences in staff's evaluation of "risk" in the context

of personal freedom and choice, and a reduction in what staff termed "complaints", which were more likely attempts on the part of the resident to engage and interact with staff.

*"[Name] has a great love of animals and she would have been going down to the conservatory and trying to go out the conservatory door. Now, the reason she wanted to keep going out the conservatory door is she wanted to go out to feed the cats. Now everybody knows she wants to go down there because she loves cats and she wants to go out ... She'll pick at the flowers that are out the back. That's what she did [when at home]. That's what she loved to do. I think people before were trying to, you know, not keep her in but were concerned about the fact she was going out and she might be going out and getting wet in the rain or, you know, she might hurt herself. Now, there's a chance that she will fall out there at some stage, but so what? She's out there doing something she likes." (S7)*

The biggest barrier flagged by staff was the lack of time to reminisce "properly" with residents. Their solution was either to give the "job" to somebody else or allocate dedicated time to reminiscence.

*"I have to be honest ... it's very difficult to find the time and I don't want it to be a chore ... I want to be able to do it as it flows really and whoever needs it at the time. I only had the three residents and that's all very nice, but I look after a lot of residents here." (S8)*

*"I have enormous amount of faith in the power of the reminiscence. I do ... but I would prefer to have somebody that is specifically assigned to that and that would be their job and I think it would be a very worthy job." (S9)*

The pressure of “lack of time” caused some staff to say that they would not continue using reminiscence, even while acknowledging it was time well spent.

*“It is worth the time. It is worth doing ... but it's time ... and getting to do it properly, because when you were kind of doing it in bits and pieces [it isn't as good] ... myself, I found it very good but as a nurse in charge I wouldn't do it again because I haven't enough of time to do it and I haven't enough of time to give to do it. I know the other girls found it hard as well to find the time to do it.” (S10)*

*To help support the cultural change one nurse manager has changed how she allocates work to reflect the value she places on interacting with residents.*

*“[I've changed] the allocation for a supervisory role in all day rooms and, you know, even just taking the newspaper [and reading it out loud] ... I'm emphasising that that should be done ... I'm emphasising 'sit with them, have a chat with them' ... ” (S7)*

In essence, the organisational culture, particularly what is valued and supported, will determine whether reminiscence continues or not in these facilities.

Overall, reminiscence acts as a “key”, mediating resident-staff interaction, enabling staff to “see” and “know” the person as an individual and increasing the potential of “understanding” (and potentially accommodating) his/her behaviour in the present (in the context of his/her past). The use of reminiscence

in the long-term care setting is, however, mediated by several related factors that are individual to the member of staff (interest, motivation, knowledge, skill, confidence and persistence), the person with dementia (severity of cognitive impairment, comorbidity (particularly deafness) and personal preferences (e.g. enjoys socialising or prefers solitary pursuits)), and the organisation (other staff attitude and response, manager's attitude, what is valued by the organisation (e.g. facilitates a shift to person-centredness) and effectiveness (e.g. contributes to managing behaviours that challenge)). These factors are referred to as “mediators” because they mediate the likelihood of reminiscence being supported and integrated into care and sustained in the long term.

The outcomes of reminiscence for the person with dementia included: opportunities to socialise and interact; enjoyment from the recall of pleasant memories; and changes in own behaviour (these “changes” may sometimes have resulted from staff interpreting the person's behaviour differently rather than change per se). Families valued the new relationships that were formed, including the fact that their relative was now better known and cared about, as well as being cared for. For staff, knowing the person better and having a meaningful relationship with the person and the associated job satisfaction that this brought was a major benefit. A positive response by the person with dementia (e.g. smiles, recognition or interest) was also likely to reinforce staff's commitment to reminiscence work. For the organisation, the gains were enhanced person-centredness (a key policy objective), improvements in overall levels of happiness, and potential gains to quality of life. ■

# 8

## Methodological Issues



**THIS CHAPTER** focuses on some of the methodological issues that emerged in carrying out research with people with dementia and their care staff. A number of issues are discussed, including research with people with dementia, recruitment, the diagnosis of dementia and outcome measures.

### Research with People with Dementia

Undertaking research with people with dementia living in long-stay facilities is a real challenge. As well as having cognitive impairment, residents with dementia are living in unfamiliar institutional surroundings separated from family and friends. For that reason, the DARES research team believed that it was important to involve people with dementia in the research so that they had a voice, not through the use of a proxy, although that was warranted in some cases, but by involving them directly in the work. To achieve this goal, a small number of people with dementia were interviewed in the early stages of the research to explore the best ways of embedding their perspective into the process. This raised a number of methodological issues, including the right of people with dementia to participate, gaining their consent for the research process and reporting the results of the work in a meaningful way.

Many researchers and policy makers argue that people with dementia have the right to participate in dementia research (Fisk et al., 2007; Slaughter et al., 2007), given their ability to communicate subjective experiences of their quality of life up to and into the late stages of the illness (Edelman et al., 2005; Hoe et al., 2005; 2006; 2009; Thorgrimsen et al., 2003). Researchers must, therefore, be sensitive to a person with dementia's right to equality, inclusion, respect and autonomy (Fisk et al., 2007; Kitwood, 1998; Slaughter et al., 2007), particularly those living in residential care settings away from familiar surroundings. To exclude people with dementia from the research process is to potentially exacerbate an already existing vulnerability (Dewing, 2002).

Issues of consent and meaningful participation are, however, particularly challenging to manage for people with dementia. Within this research we had to pay particular attention to how the capacity of the person with dementia to consent to participate or not was determined. The easy option would have been to identify a score on a specific cognitive scale, such as the MMSE, and automatically exclude those who did not meet this score. We did not do this, however, as it may have led to the exclusion of many people with dementia who had a valuable perspective on one or more aspects of their quality of life. Instead, research nurses, based in the long-stay care setting, were used to generate information on the suitability or otherwise of residents for inclusion in the trial, based on their informed consent. The starting point in relation to consent was that the person with dementia was capable of making informed decisions in the absence of evidence to the contrary (Health Information and Quality Authority, 2009). Timing and patience were essential ingredients in generating consent but the additional costs of a person-centred approach to consent were worth it, given the success rate. In DARES, proxy measures were only required for 7% of all residents. Moreover, residents' assent, defined as an ongoing willingness to participate (Slaughter et al., 2007), was assessed continually throughout the duration of the study.

Dewing (2002), an advocate of Kitwood's (1997) philosophy of personhood, recommends that during the consenting process, the researcher must include face-to-face encounters with the person with dementia in order to seek and maintain permission or consent. By getting to know the person with dementia the researcher gains an understanding of the person's needs and subsequently comprehends their readiness or reluctance to become involved in the research process. This appraisal, however, must ensure that the rights and needs of the person with dementia are the key consideration rather than the requirements of the trial process. The consent process for DARES was complex, therefore, and included specific training for research assistants in the process of seeking consent from the person with dementia.

The focus of the training was on the nature of consent, ensuring voluntary consent without coercion, the need to get to know the resident, ways of building rapport, and relating to the person with dementia. This approach was resource-intensive but was central to the person-centred nature of the trial.

Even when people with dementia were able to participate, their response to questions asked were often short, not fully focused and open to interpretation. Residents with more severe dementia had the greatest difficulty in responding to questions. The dilemma for the DARES team was how to use resident data meaningfully without being guilty of mere tokenism, that is, including people with dementia because it was the “right” thing to do but failing to use their data in any meaningful way, thereby allowing the views of staff and families to dominate the narrative. To overcome this difficulty, grounded theory was used as the main qualitative research method in the study. Grounded theory requires constant comparison, theoretical sampling and the use of memoing as an aid to understanding the data produced, however fragmented and incomplete (Corbin and Strauss, 2008). This enabled the voice of the person with dementia to be renewed and recalibrated throughout the data collection process.

### Recruitment

The selection of long-term care facilities within which to conduct the research is an important first decision in the research process. The cooperation and flexibility of facility staff is paramount to the successful implementation of the intervention, as there is likely to be opposition to taking part related to concerns that it might add to current workloads and interrupt routines and ongoing activity schedules. The recruitment of sites was, therefore, a primary task for the project manager. This task was made more difficult by the fact that there is no unique population frame for private nursing homes in Ireland. Consequently, multiple sources needed to be checked and cross-checked to allow a valid population frame to be developed. Once a frame was established, the

focus had to be on larger facilities, since only in these sites were there likely to be sufficient numbers of people with dementia to be considered for inclusion in the study. But checking for adequate numbers of people with dementia was itself a time-consuming process since facilities did not normally have formal internal procedures for the diagnosis of dementia. Some sites where it was initially thought there would be a sufficient number of residents with dementia were subsequently found by the research nurses not to have enough eligible participants during on-site checking and screening. This slowed down data collection processes considerably.

Some facilities did not respond to repeated requests to become involved in the research process; others initially said yes and then declined when they became fully aware of the level of work involved. For example, one private nursing home which declined an invitation to participate and opted instead to pay for private dementia training commented that “DARES sounded like it would require a long-term commitment”, which the facility was not able or willing to give. Some units were currently involved in education/training courses which ruled them out, while some public units were subject to cost-cutting training embargoes, even when training was provided free of charge. Having said that, the offer of free training was a major attraction for most of the private long-stay units contacted about the study, including a promise to provide training following completion of the trial to facilities allocated to the control arm of the study. Another motivation for participation was the desire to meet HIQA requirements in regard to education and training opportunities for staff.

A major task of the project manager and the research nurses was to ascertain the ability of the participating long-stay settings to support the research, including the assessment of staffing levels and general enthusiasm for the research. Not all sites were willing participants even when agreement had been reached with them to become involved. Sometimes this reluctance related to disappointment that their site had been randomised to the control arm and not the intervention, while other

times staff complained that they had not been fully consulted about inclusion in the study. This meant that staff who had been “volunteered” by the nursing home owner or nurse manager for the study sometimes arrived for the two-day training programme in a negative frame of mind.

Existing workload was high for all care staff and was usually the most common complaint for those who had difficulties sustaining the reminiscence programme over the duration of the intervention. Tensions between management and staff were often a major source of turbulence for the successful completion of the intervention, given the resource and time commitments required for the study. This was compounded by facilities having to release up to 10 staff to attend a two-day training programme, which impacted significantly on the care roster. Moreover, not all private facilities paid staff for the days they attended the training programme. Sickness and absenteeism also had an effect on attendance at training and sustained commitment to the intervention. Holidays and part-time working also made it very difficult to schedule support visits to a facility for days when most participating staff would be on duty. Similarly, staff turnover led to changes in dyad membership over the course of the study, leading to non-compliance and incomplete records in some units.

Having to work around the day-to-day activities within long-stay facilities was always likely to cause problems and simply reflected the complexity of trying to carry out an intervention for cognitively impaired people in a busy and challenging care environment. In hindsight, the exclusion of care managers from the structured education programme was unfortunate, given their importance in establishing the care ethos and values within a facility, not to mention their control over routines and practices on the ward. For example, management decisions sometimes led to avoidable alterations in work patterns and routines, which impacted negatively on attendance at the education programme and the subsequent ability of staff to carry out reminiscence. While the potential for reminiscence to be fully integrated into the daily life

and routine of a long-stay facility is high, success is more likely if management are fully supportive and directly involved in bringing about the necessary culture change in regard to the centrality of the person with dementia in the process. Changing the approach to nursing home care is a complex undertaking that often requires a shift from a routine, task-oriented approach to a more holistic and flexible care-centred model. Nurse managers are key to the formulation and implementation of such a transformation and perhaps should have been more central to this study.

## Dementia Diagnosis

Cahill et al. (2012) report that the official prevalence figures for dementia in long-stay care in Ireland at 26% (DOHC, 2009) are likely to be a “gross underestimate” and suggest that the true figure is likely to be more than double that at 63%. International data covering the USA and Europe also suggest that the proportion of people in long-stay care with dementia is likely to lie somewhere between 60% and 70% (Helmer et al., 2006; Knapp and Prince, 2007). The discrepancy between the official data and the estimated data is caused by the absence of formal diagnosis for people with dementia in Ireland, whether living at home or in residential care.

The DARES team were aware that focusing only on long-stay residents with a formal clinician-based diagnosis of dementia would exclude many residents who had dementia but not a formal medical diagnosis of it. Every effort had to be made, therefore, to ensure as comprehensive an approach as possible to identifying people with dementia in long-stay care, otherwise it would have been impossible to generate the requisite number required for the study (17 in each facility). The study used four different approaches to identify potential participants in the study:

- A formal diagnosis of dementia determined by the DSM-IV (American Psychiatric Association, 1995) and/or ICD-10 criteria (WHO, 1992) for dementia;

- Any other diagnosis of dementia by a medical clinician;
- Resident was on anti-Alzheimer's medications, including Aricept (donepezil), Ebixa (memantine) and Exelon (rivastigmine);
- Nurses' judgement advised and/or nursing records noted that the person had dementia.

The data from the patient records suggest that almost all residents recruited to the study were identified as having some form of dementia. While the study mainly relied on the judgement of nurses on whether a potential participant had dementia, more than half of the residents included in the study (55%) had a medical confirmation of a diagnosis of dementia. However, very few people (7%) had received a formal diagnosis of dementia. Following acceptance into the trial, participants were screened using the MMSE to identify their current stage of cognitive impairment. While diagnosis remains problematic for people with dementia in long-stay facilities, leading to uncertainty in regard to the overall number in care, this study has shown that it is possible to generate reliable estimates of people with dementia in such settings. But doing so requires intensive and time-consuming investigation of patient records, as well as eliciting the judgement of nurses. Until we have a common instrument for the diagnosis of dementia in long-stay care, generating participants for studies of this kind will always be expensive.

### Outcome Measures

The primary outcome in this study was quality of life of residents as measured by the Quality Of Life in Alzheimer's Disease (QoL-AD) instrument (Logsdon et al., 1999). The QoL-AD is a dementia-specific measurement tool and for many people it is the recommended instrument of choice when measuring quality of life in dementia care (Moniz-Cook et al., 2008; Sansoni et al., 2007). The QoL-AD has two versions: (i) a care recipient self-report version and (ii) a carer proxy

version. There is considerable evidence that people with mild, moderate and even severe dementia can rate their own quality of life using the QoL-AD instrument (Hoe et al., 2005; Logsdon et al., 1999, 2002; Thorgrimsen et al., 2003). The former examined the usefulness of the QoL-AD instrument in people with severe dementia and found that only people with a score less than 3 were likely to have difficulty with self-reporting. This robustness has convinced many people, including the DARES research team, that subjective rating of quality of life by the older person with dementia is a gold standard measurement and the last decade has seen an emerging consensus towards self-evaluation in the measurement of quality of life in dementia (Hoe et al., 2007).

Proxy ratings circumvent the cognitive limitations that are associated with dementia and can be used for all stages of the illness, particularly for advanced dementia (Sansoni et al., 2007). From a methodological perspective, proxy measures may help minimise the potential for missing data and low completion rates associated with self-report measures in severe dementia (Hoe et al., 2005). They can also provide objective evidence to support the subjective valuations attached to self-reporting. Nevertheless, there are real issues about using proxies, particularly as researchers have found weak correlation between self-report and proxy measures. Proxy ratings may be influenced by the proxy's own expectations, belief system, relationship with the person being rated, current levels of depression or burden of care (Logsdon et al., 1999). In general, proxy valuations rate the quality of life of the person with dementia consistently lower than self-reported valuations (Edelman et al., 2005; Hoe et al., 2005, 2006, 2007; Logsdon et al., 2002).

Irrespective of objective or subjective measurement, it is not at all clear what level of change to quality of life could be considered clinically significant as a result of the structured education reminiscence-based programme. Based on the available information, which unfortunately in relation to reminiscence interventions is weak and fragmented, given the paucity of earlier work, we settled



on a four-point difference in self-rated quality of life as the key indicator of success and powered our study accordingly (O'Shea et al., 2011). There is a certain arbitrariness and subjectivity about this figure that is unsettling, given the absence of good quality information from previous work and concerns about quality of life generally in long-stay care in Ireland. Arguing about whether a four point gain is significant or not seems more a philosophical question than a clinical question. Certainly, for some people, and not only for those with dementia in long-stay facilities, improving quality of life by even one point would yield benefits that many would consider worthwhile and deserving of public support. Similarly, arguing against an intervention because it only yields a 3.5-point gain instead of a four-point gain may be to behave unethically and uneconomically (although this study did not explore cost-effectiveness) in the face of the reasonable expectations of people with dementia, their families and care staff.

Residents' level of depression was measured using the Cornell Scale for Depression in Dementia (CSDD) (Alexopoulos et al., 1988). The CSDD was developed to assess signs and symptoms of major depression in patients with dementia. It is the measure of choice for assessing patients' mood and it is used widely in dementia research (Moniz-Cook et al., 2008; Sansoni et al., 2007). The CSDD is claimed to be particularly appropriate in the long-stay setting as it facilitates the rating of depression scores across the whole range of dementia severity (Alexopoulos et al., 1988). The DARES research nurse completed two semi-structured interviews with the resident and a member of the dyad. During each of the interviews, the research nurse assigned a provisional score to each of the items on the Cornell scale. Each interview focused on the extent to which depressive signs and symptoms occurred during the week preceding the interview. If there were discrepancies in ratings between the resident and dyad member, the research nurse re-interviewed both parties to resolve the discrepancies. The final ratings of the CSDD items represent the research nurses' clinical

judgement, and while all research nurses underwent a rigorous two-day training programme, inter-rater reliability in data collection remained an issue. In a study the size of DARES it was not possible to use only one person for data collection, giving rise to the possibility of measurement error; moreover, some research assistants had a background in mental health while others did not, thereby potentially compounding the measurement difficulties.

A final point to note in relation to the chosen outcome measures is that they may not be the most appropriate tools to measure the effectiveness of the intervention. Reminiscence may influence aspects of resident and staff well-being that are not captured by the instruments used. This is particularly the case if reminiscence is more beneficial in the short term than in the longer term. It may be the case that reminiscence only has short-term effects that are confined to the hours during and immediately after the session. People enjoy reminiscence and are happy during the sessions, but these effects wear off quickly and may not be sustained over the long run. Consequently, the benefits may not always show up in the more formal assessment of residents' more general health status, functioning and quality of life. For contemporaneous measures, we relied on the testimony of care staff who reported strong and significant benefits during reminiscence and the absence of any adverse events. Reports from staff on the happiness and well-being of residents during reminiscence reinforce the argument for contemporaneous and ongoing measurement of benefits, and perhaps less reliance on comparisons of baseline and end-point differences in outcomes. While the calculation of mean differences for primary and secondary outcomes assessed over a given time period are necessary, they are not sufficient to allow judgement to be made on the effectiveness of a reminiscence intervention. They need to be supplemented by contemporaneous measurements that provide data on process utility derived by residents and staff from the programme. ■

# 9

## Discussion and Conclusion

**AT ITS SIMPLEST**, reminiscence can be described as “the vocal or silent recall of events in a person’s life, either alone or with another person or group of people” (Woods et al., 1992). Reminiscence, as in the DARES study, is done usually with the aid of tangible prompts, such as photographs, music, household and other familiar items from the past, and other memorabilia. Reminiscence concentrates mainly on developing communication, interaction and discourse in an enjoyable, engaging manner with the objective of enhancing well-being and quality of life. It is related to, but different from, life review which has its origins in psychotherapy and usually involves some form of self-evaluation and/or reflection. Reminiscence is a popular form of psychosocial intervention for people with dementia, for those living at home and in residential care settings, mainly because it seems to connect with the preserved cognitive abilities of older people rather than emphasising their limitations. Despite its popularity, the evidence on the usefulness of reminiscence in the care of people with dementia is neither strong nor robust. Only a handful of randomised controlled trials have been undertaken, most of which were small and of poor quality, leading to the only Cochrane review to have been undertaken on the topic to conclude that “there is an urgent need for more quality research in the field” (Woods et al., 2005).

The DARES study is an attempt to provide new information on the effectiveness of reminiscence as a psychosocial intervention based on a robust trial methodology that is superior to previous studies in the area. The study yields some interesting and complex results that may help inform future research in this area. The results show that reminiscence had a positive effect on the QoL-AD care recipient measure of quality of life. On an intention to treat basis the difference between intervention and control just fails to reach the clinical significance of four points, while that difference is exceeded by one point when the data are analysed on a per protocol basis. The beneficial impact of the

intervention holds up when missing data are imputed in relation to intention to treat and per protocol analyses.

The potentially positive effect of reminiscence on quality of life in the DARES study is in contrast to Thorgrimsen et al. (2002) who found no effect on quality of life, Goldwasser et al. (1987) who estimated that any benefits of reminiscence were likely to be short-term and not realisable in the medium to long term, and Lai et al. (2004) who reported no significant differences in outcomes between intervention and control over time. The DARES results are strongest when analysed on a per protocol basis, highlighting the presence of site effects and the importance of adherence to the programme and completion of the intervention. The fact that there was a difference between intention to treat and per protocol is perhaps not that surprising given the pragmatic nature of the trial and the reality of trying to carry out the intervention in a busy, complex and evolving long-stay sector, particularly in relation to care structures and processes, staff duties and staff-management relationships.

The significantly negative effect of reminiscence on depression found in the DARES trial is counter-intuitive, given the positive effect of the intervention on quality of life. While there is evidence from Goldwasser et al. (1987) that reminiscence can increase depression in people with dementia, and Lai et al. (2004) report restricted effects on psychological well-being, it might have been expected that should the intervention lead to a positive effect on quality of life, depression would also have been reduced. It may be that Woods et al. (2005) are correct in saying that for older adults with dementia reminiscence may be very worthwhile, but restricted effects on psychological well-being can be expected. However, there are three reasons why the significantly negative effect of reminiscence on depression reported in this study should be treated with caution. The first relates to the low levels of depression reported in both the control group and the intervention, neither reaching

levels considered to be clinically meaningful on the Cornell measurement scale pre- or post-intervention. Second, an unexplained improvement in depression score in one cluster site in the control group impacts disproportionately on the negative result for depression; if this site is dropped from the analysis, the significant effect is eliminated. Third, when the analysis is confined to per protocol sites only, significance on the depression measurement equally fades away. It may be, therefore, that while reminiscence does not impact positively on depression, it is also unlikely to have a seriously negative effect. The qualitative data support this hypothesis, as does the fact that there were no adverse effects reported during the trial.

The impact of reminiscence on the remaining secondary outcomes is clearer. There are no significant effects in relation to QoL-AD as measured by care staff, agitation in residents, or staff care burden, although all of these measures showed improvement following the intervention, i.e. the coefficient effect is correctly signed. In relation to staff burden, most of the qualitative data suggest that staff were very supportive of the intervention and saw it as having a very positive effect on their relationship with the person under their care. In face-to-face interviews staff talked about getting to know and understand the person with dementia, sometimes for the very first time, and of now finding different ways to relate to that person. Given that working with more cognitively impaired residents is usually associated with higher levels of stress in residential care staff (Brodaty et al., 2003), why did these strong positive feelings expressed by care staff not show up in reduced care burdens? It may be that the instrument used to measure care burden was not sensitive enough to capture the complexity of the various transmission mechanisms involved. In relation to the latter, higher burden cannot be ruled out as more knowledgeable and informed staff now faced more time-consuming and intense interactions with residents through the reminiscence process. Getting to know people takes time and effort and may lead to more

work, not less. Interestingly, some care trial staff referred to non-trial staff as being sceptical of the amount of time that they spent carrying out reminiscence with residents, which may, in turn, have put additional pressures on participants to be seen to be working harder, thereby adding to strain, or at least counter-balancing the pleasure of their involvement in the reminiscence programme.

The present study demonstrates that conducting a large randomised trial of a reminiscence-based intervention, although rarely done, mainly due to complexity and cost, is feasible as well as desirable. The study is, therefore, a valuable addition to the small volume of trial-based work in reminiscence available in the literature. The study contains more participants than the aggregate contained in all previous small-scale trials in this area. It follows a clear treatment protocol making it possible to estimate the range of potential benefits available from the intervention. The carefully designed protocol, allied to the clear definition of the reminiscence-based intervention, also make replication of the trial possible in other countries for similar types of residential populations. The study, therefore, meets the criteria outlined in the Cochrane review (Woods et al., 2005) for more quality research in the field.

Reminiscence is a very popular form of engagement between staff and people with dementia in residential care settings, but the international evidence on its effectiveness in relation to well-being and quality of life is weak. The study advances our knowledge of the potential effectiveness of reminiscence in enhancing quality of life, exceeding the target of a four-point minimum clinically important difference (MCID) on a per protocol analysis of data. This target is almost achieved on the basis of an intention to treat analysis. While urging caution on the interpretation of these results, the potential gains realised are not inconsequential in terms of improvements in quality of life for people with dementia in long-stay care settings in Ireland or anywhere else.

The study also provides valuable qualitative information based on face-to-face interviews with residents and staff, which supports the outcome gains evident from the analysis of the QoL-AD data. Care staff were generally enthusiastic about the intervention, even when staffing difficulties and organisational structures sometimes compromised their ability to fully implement it. The implications are clear enough for both practice and policy. Reminiscence, when implemented consistently and uniformly, has the potential to improve quality of life for people with dementia in long-stay care and impacts favourably on staff and their relationship with residents. Connections and relationships between staff and residents are enhanced through the reminiscence process, leading to a more person-centred approach to care.

The study is not without its limitations. First, undertaking a trial of this complexity is difficult and requires careful monitoring in relation to adherence to protocol. Even with that monitoring, however, staff may still have difficulties in implementing the intervention given existing care structures and processes within long-stay settings. Second, the instruments used to measure outcomes may not always be sensitive enough to pick up changes arising from the intervention. This may have been the reason, for example, for the failure of the intervention to lead to significant changes in staff burden, given the positive results emanating from the qualitative interviews with staff in regard to the reminiscence programme. Third, even with support mechanisms, we had no way of measuring the quality of the interaction between staff and residents in relation to the reminiscence sessions. Fourth, the CSDD measure

of depression may have required greater consistency in measurement than was possible in this study due to time and budget constraints, and may have contributed to the appearance of outlier results, particularly in the control arm of the trial. Fifth, there is the issue of whether there should have been much more contemporaneous measurement of benefits during the application of the programme. The qualitative evidence seems to suggest that participants, both residents and staff, enjoyed the experience of reminiscence, but these gains may have dissipated by the time formal outcome measurement was undertaken at the end of the trial. Perhaps it is time to place more emphasis on the measurement of the here and now, especially for people with dementia.

Finally, setting an MCID of four points, although reasonable and rational in terms of estimating sample size and power, may have set the bar too high in relation to acceptable and unacceptable gains from the intervention. This is a formidable target which was achieved on a per protocol basis and almost achieved on an intention to treat basis but, for example, would half that figure be any less welcome by residents and staff in residential care settings? The answer to that question is probably not, given the absence of much focus on the dynamics of quality of life among people with dementia in long-stay care. We know that the day-to-day experience of long-term care within residential care settings needs to be improved for people with dementia. On the basis of the DARES study, more research is justified into exploring how reminiscence can play an important role in improving the quality of care provided to people with dementia in long-stay care settings. ■

# References

- Alexopoulos GS, Abrams RC, Young RC. (1988). Cornell scale for depression in dementia. *Biological Psychiatry* 23: 271-284.
- American Psychiatric Association (1995). *Diagnostic and Statistical Manual of Mental Disorders* (4th edition). Washington DC: American Psychiatric Association.
- Ball M, Whittington F, Perkins M, Patterson V, Hollingsworth C, King S et al. (2000). Quality of life in assisted living facilities: Viewpoints of residents. *Journal of Applied Gerontology* 19(3): 304-325.
- Bates J, Boote J, Beverley C. (2004). Psychosocial interventions for people with a milder dementing illness: A systematic review. *Journal of Advanced Nursing* 45(6): 1-15.
- Bohlmeijer E, Roemer M, Cuijpers P, Smit F. (2007). The effects of reminiscence on psychological well-being in older adults: A meta-analysis. *Ageing & Mental Health* 11(3): 291-300.
- Bradt J, Dileo C. (2011). Music therapy for end-of-life care. *Cochrane Database of Systematic Reviews* 2010 1: Art. No.: CD007169.
- Brodsky H, Green A, Koschera A. (2003). Meta-analysis of psychosocial interventions for caregivers with dementia. *Journal of the American Geriatrics Society* 51: 1-8.
- Burnside I, Haight BK. (1992). Reminiscence and life review: Analyzing each concept. *Journal of Advanced Nursing* 17(6): 855-862.
- Burnside I, Haight BK. (1994). Reminiscence and life review: therapeutic interventions for older people. *Nurse Practitioner* 19(4): 55-61.
- Butler RN. (1963). The life review: An interpretation of reminiscence in the aged. *Psychiatry* 26(1): 65-76.
- Cahill S, Diaz-Ponce A. (2010). The underdetection of cognitive impairment in nursing homes in the Dublin area: The need for on-going cognitive assessment. *Age and Ageing* 39(1): 128-131.
- Cahill S, O'Shea E, Pierce M. (2012). *Creating Excellence in Dementia Care: A Research Review for Ireland's National Dementia Strategy*. School of Social Work and Social Policy, Trinity College Dublin and Irish Centre for Social Gerontology, National University of Ireland, Galway.
- Cappeliez P, Guindon M, Robitaille A. (2008). Functions of reminiscence and emotional regulation among older adults. *Journal of Aging Studies* 22: 266-272.
- Cappeliez P, O'Rourke N, Chaudhury H. (2005). Functions of reminiscence and mental health in later life. *Ageing and Mental Health* 9(4): 295-301.
- Chapman SB, Weiner MF, Rackley A, et al. (2004). Effects of cognitive communication stimulation for Alzheimer's disease patients treated with donepezil. *Journal of Speech, Language and Hearing Research*, 47: 1149-1163.
- Chaudhury H, Rowles G. (2005). Between the shores of recollection and imagination: Self, aging, and home. In Rowles G, Chaudhury H. (eds) *Home and Identity in Later Life: International Perspectives*, 3-20. Berlin: Springer Publishing Company.
- Clare L, Woods B. (2003). Cognitive rehabilitation and cognitive training for early-stage Alzheimer's disease and vascular dementia. *Cochrane Database of Systematic Reviews* 2003, Issue 4.
- Cohen G, Taylor S. (1998). Reminiscence and ageing. *Ageing and Society* 18: 601-610.
- Cohen-Mansfield J, Billig N. (1986). Agitated behaviour in the elderly: A conceptual review. *Journal of the American Geriatric Society* 34: 711-721.

- Coleman P. (2005). Uses of reminiscence: functions and benefits. *Ageing and Mental Health* 9(4): 291-294.
- Connolly S, Gillespie P, O'Shea E, Cahill S, Pierce M. (2012). Estimating the economic and social costs of dementia in Ireland. *Dementia: the International Journal of Social Research and Practice*. DOI: 10.1177/1471301212442453.
- Corbin J, Strauss A. (2008). *Basics of Qualitative Research: Grounded Theory Procedures and Techniques*. London: Sage.
- Department of Health and Children (2009). *Long Stay Activity Statistics 2008*. Dublin: Department of Health and Children.
- Devane D, Begley CM, Clarke M. (2004). How many do I need? Basic principles of sample size estimation. *Journal of Advanced Nursing* 47: 297-302.
- Dewing J. (2002). From ritual to relationship. A person-centred approach to consent with persons who have a dementia. *Dementia* 1(2): 157-171.
- Edelman P, Fulton BR, Kuhn D, Chang CH. (2005). A comparison of three methods of measuring dementia-specific quality of life: Perspectives of residents, staff, and observers. *Gerontologist* 45 (Spec No 1): 27-36.
- Edwards H, Courtney M, O'Reilly M. (2003). Involving older people in research to examine quality of life in residential aged care. *Quality in Ageing and Older Adults* 4(4): 38-44.
- Egan M, Munroe S, Hubert C, Rossiter T, Gauthier A, Eisner M, et al. (2007). Caring for residents with dementia and aggressive behaviour: Impact of life history knowledge. *Journal of Gerontology Nursing* 33(2): 24-30.
- Finnema E, Drees RM, Ribbe M, Tilburg WV. (2000). The effects of emotion-oriented approaches in the care for persons suffering from dementia: A review of the literature. *International Journal of Geriatric Psychiatry* 15(1): 141-161.
- Fisk J, Beattie B, Donnelly M. (2007). Ethical considerations for decision making for treatment and research participation. *Alzheimer's & Dementia* 3(4): 411-417.
- Folstein MF, Folstein SE, McHugh PR. (1975). Mini Mental State. A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research* 12:189-198.
- Goldwasser AN, Auerbach SM, Harkins SW. (1987). Cognitive, affective and behavioural effects of reminiscence group therapy on demented elderly. *International Journal of Aging and Human Development* 25(3): 209-222.
- Groger L. (1995). Nursing home can be a home. *Journal of Aging Studies* 9: 137-153.
- Group for the Advancement of Psychiatry (1984). *The Psychiatric Treatment of Alzheimer's Disease*. Report Group for the Advancement of Psychiatry 125: 1-160.
- Gubrium J. (1975). *Living and Dying at Murray Manor*. New York: St Martin's Press.
- Hancock G, Woods B, Challis D, Orrell M. (2006). The needs of older people with dementia in residential care. *International Journal of Geriatric Psychiatry* 21: 43-49.
- Haslam C, Haslam SA, Jetten J, Bevins A, Ravenscroft S, Tonks J. (2010). The social treatment: The benefits of group interventions in residential care settings. *Psychology and Aging* 25(1):157-167.



- Health Information and Quality Authority (2009). National Quality Standards for Residential Care Settings for Older People. Cork: HIQA.
- Helmer C, Peres K, Letenneur L, et al. (2006). Dementia in subjects aged 75 years or over within the PAQUID cohort: Prevalence and burden by severity. *Dementia and Geriatric Cognitive Disorders* 22: 87-94.
- Hoe J, Hancock G, Livingston G, Orrell M. (2006). Quality of life of people with dementia in residential care homes. *British Journal of Psychiatry* 188: 460-464.
- Hoe J, Hancock G, Livingston G, Woods B, Challis D, Orrell M. (2009). Changes in the quality of life of people with dementia living in care homes. *Alzheimer's Disease and Associated Disorders* 23: 285-290.
- Hoe J, Katona C, Orrell M, et al. (2007). Quality of life in dementia: Care recipient and caregiver perceptions of quality of life in dementia: the LASER-AD study. *International Journal of Geriatric Psychiatry* 22:1031-1036.
- Hoe J, Katona C, Roche B, et al. (2005). Use of the QOL-AD for measuring quality of life in people with severe dementia - The LASER-AD study. *Age and Ageing* 34:130-135.
- Ito T, Meguro K, Akanuma K, Ishii H, Mori E. (2007). A randomised controlled trial of the group reminiscence approach in patients with vascular dementia. *Dementia and Geriatric Cognitive Disorders* 24 (1): 48-54.
- Jones GM. (1985). Validation therapy: A companion to reality orientation. *The Canadian Nurse* 81(3): 20-23.
- Kane R. (2001). Long-term care and a good quality of life. *The Gerontologist* 41(3): 293-304.
- Kane R. (2003). Definition, measurement, and correlates of quality of life in nursing homes: Towards a reasonable practice, research, and policy agenda. *The Gerontologist* 43 (special Edition II): 28-36.
- King W, Lashley R. (2000). A quantifiable alternative to double data entry. *Controlled Clinical Trials* 13:183-197.
- Kitwood T. (1997). *Dementia reconsidered: The person comes first*. Buckingham, UK: Open University Press.
- Kitwood, T. (1998). Towards a theory of dementia care: Personhood and well-being. *Journal of Clinical Ethics* 9(1): 23-34.
- Knapp M, Thorgrimsen L, Patel A, Spector A, Hallam A, Woods B, Orrell M. (2006). Cognitive stimulation therapy for people with dementia: Cost-effectiveness analysis. *British Journal of Psychiatry* 183: 248-254.
- Knapp M, Prince M. (2007). *Dementia UK Full Report*. London: Alzheimer's Society.
- Kontos PC. (1998). Resisting institutionalization: Constructing old age and negotiating home. *Journal of Aging Studies* 12(2): 167-184.
- Lai CK, Chi I, Kayser-Jones J. (2004). A randomized controlled trial of a specific reminiscence approach to promote the well being of nursing home residents with dementia. *International Psychogeriatrics* 16(1): 33-49.
- Lin YC, Dai YT, Hwang SL. (2003). The effect of reminiscence on the elderly population: A systematic review. *Public Health Nursing* 20(4): 297-306.
- Logsdon R, Gibbons LE, McCurry SM, Teri L. (1999). Quality of life in Alzheimer's disease: patient and caregiver reports. *Journal of Mental Health and Aging* 5: 21-32.

- Logsdon RG, Gibbons LE, McCurry SM, Teri L. (2002). Assessing quality of life in older adults with cognitive impairment. *Psychosomatic Medicine* 64: 510–519.
- Merchant A, Ford J. (2008). Nostalgia and giving to charity: A conceptual framework for discussion and research. *International Journal of Nonprofit and Voluntary Sector Marketing* 13(1): 13–30.
- Moise P, Schwarzingler M, Um M. (2004). *Dementia Care in 9 OECD Countries: A Comparative Analysis*. OECD Health Working Papers no 13. Paris: OECD.
- Moniz-Cook E, Vernooij-Dassen M, Woods R, et al. (2008). A European consensus on outcome measures for psychosocial intervention research in dementia care. *Aging & Mental Health* 12: 14–29.
- Murphy K, O'Shea E, Cooney A, Shiel A, Hodgins M. (2006). *Quality of Life in Long-Stay Settings in Ireland*. Dublin: NCAOP.
- Neal M, Barton Wright P. (2003). Validation therapy for dementia. *Cochrane Database of Systematic Reviews* 2003 (3): Art. No.: CD001394.
- O'Connor DW, Ames D, Gardner B, King M. (2009). Psychosocial treatments of behavior symptoms in dementia: A systematic review of reports meeting quality standards. *International Psychogeriatrics* 21(2): 225-240.
- Onder G, Zanetti O, Giacobini E, et al. (2005). Reality orientation therapy combined with cholinesterase inhibitors in Alzheimer's disease: Randomised controlled trial. *The British Journal of Psychiatry* 187: 450–455.
- O'Shea E, Devane D, Murphy K, Cooney A, Casey D, Jordan F, et al. (2011). Effectiveness of a structured education reminiscence-based programme for staff on the quality of resident with dementia in long-stay units: A study protocol for a cluster randomised trial. *Trials* 12: 41.
- Prince M, Jackson J. (2009). *World Alzheimer Report 2009*. London: Alzheimer's Disease International.
- Robichaud L, Hebert R, Desrosiers J. (1994). Efficacy of a sensory integration program on behaviors of inpatients with dementia. *American Journal of Occupational Therapy* 48(4): 355-360.
- Rodgers B. (2000). Concept analysis: An evolutionary view. In Rogers BL, Knafk KA. (eds) *Concept Development in Nursing: Foundations, Techniques and Applications*. 2nd ed. pp. 77–102. Philadelphia, PA: WB Saunders.
- Rowles GD. (1983). Place and personal identity in old age: Observations from Appalachia. *Journal of Environmental Psychology* 3: 299-313.
- Sansoni J, Marosszeky N, Jeon Y-H, Chenoweth L, Hawthorne G, King M, Budge M, Zapart S, Sansoni E, Senior K, Kenny P, Low L. (2007) *Final Report: Dementia Outcomes Measurement Suite Project*. Centre for Health Service Development, University of Wollongong.
- Schweitzer P, Bruce E. (2008). *Remembering yesterday, caring today: Reminiscence in dementia care, a guide to good practice*. London: Jessica Kingsley Publications.
- Shield RR. (1988). *Uneasy Endings: Daily Life in an American Nursing Home*. Ithaca: Cornell University Press.
- Slaughter S, Cole D, Jennings E, Reimer MA. (2007). Consent and assent to participate in research by people with dementia. *Nursing Ethics* 14(1): 27-40.
- Spector A, Thorgrimsen L, Woods B, Royan L, Davies S, Butterworth M, Orrell M. (2003). Efficacy of an evidence-based cognitive stimulation therapy programme for people with dementia: Randomised controlled trial. *British Journal of Psychiatry* 183: 248-254.

- Tadaka E, Kanagawa K. (2007). Effects of reminiscence group in elderly people with Alzheimer disease and vascular dementia in a community setting. *Geriatrics & Gerontology International* 7(2): 167–173.
- Tester S, Hubbard G, Downs M, MacDonald C, Murphy J. (2004). Frailty and institutional life. In Walker A, Hennessy Hagan C. (eds) *Growing Older: Quality of Life in Old Age*. Berkshire: Open University Press.
- Thorgrimsen L, Schweitzer P, Orrell, M. (2002). Evaluating reminiscence for people with dementia: A pilot study. *The Arts in Psychotherapy* 29(2): 93-97.
- Thorgrimsen L, Selwood A, Spector A, Royan L, de Madariaga Lopez, M, Woods RT, Orrell M. (2003). Whose quality of life is it anyway? The validity and reliability of the quality of life - Alzheimer's Disease (QoL-AD) scale. *Alzheimer's Disease and Associated Disorders* 17: 201-208.
- Verkaik R, van Weert JC, Francke AL. (2005). The effects of psychosocial methods on depressed, aggressive and apathetic behaviours of people with dementia: A systematic review. *International Journal of Geriatric Psychiatry* 20 (4): 301-314.
- Wang JJ. (2007). Group reminiscence therapy for cognitive and affective function of demented elderly in Taiwan. *International Journal of Geriatric Psychiatry* 22(12): 1235–1240.
- World Health Organization (1992). *The ICD-10 Classification of Mental and Behavioural Disorders: Clinical Descriptions and Diagnostic Guidelines*. Geneva: WHO.
- Wildschut T, Sedikides C, Arndt J, Routledge C. (2006). Nostalgia: Content, triggers, functions. *Journal of Personality and Social Psychology* 91(5): 975–993.
- Wimo A, Jönsson L, Gustavsson A, et al. (2011). The economic impact of dementia in Europe in 2008 - cost estimates from the EuroCoDe project. *International Journal of Geriatric Psychiatry* 26: 825-832.
- Wimo A, Prince P. (2010). *World Alzheimer Report 2010. The Global Economic Impact of Dementia*. London: Alzheimer's Disease International.
- Woods P, Ashley J. (1995). Simulated presence therapy: Using selected memories to manage problem behaviors in Alzheimer's disease patients. *Geriatric Nursing* 16(1): 9-14.
- Woods RT, Bruce E, Edwards RT, Hounscome B, Keady J, Moniz-Cook ED, et al. (2009). Reminiscence groups for people with dementia and their family carers: Pragmatic eight-centre randomised trial of joint reminiscence and maintenance versus usual treatment: A protocol. *Trials* 10: 64.
- Woods RT, Portnoy S, Head D, Jones G. (1992). Reminiscence and life review with persons with dementia: Which way forward? In Jones G, Miesen B. (eds) *Care-Giving in Dementia*. pp. 137-161. London: Routledge.
- Woods B, Spector A, Jones C, Orrell M, Davies S. (2005). Reminiscence therapy for dementia (review). *Cochrane database of systematic Reviews* 2: CD001120.
- Yamagami T, Oosawa M, Ito S, Yamaguchi H. (2007). Effect of activity reminiscence therapy as brain-activating rehabilitation for elderly people with and without dementia. *Psychogeriatrics* 7(2): 69–75.
- Zarit SH, Reever KE, Bach-Peterson J. (1980). Relatives of the impaired elderly: Correlated feelings of burden. *Gerontologist*, 20: 649-655.



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