Some Dance to Remember: Exploring the Psychosocial Effects of the Introduction of an Adaptive Irish Céilí Dance Group Activity with People Living with Dementia and their Carers

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Abstract

Some Dance to Remember: Exploring the Psychosocial Effects of the Introduction of an Adaptive Irish Céilí Dance Group Activity with People Living with Dementia and their Carers

Sean Donal O Shea

There are currently 64,000 people living with dementia in Ireland and this figure is expected to rise to 150,000 by 2045. To date, a biomedical approach to managing the condition has been primarily adopted however, more recently, alternative methods have gained traction. Arts-based activities, including dance, are one such alternative.

This research aimed to explore, in the context of the psychosocial effects of dance and movement, the experiences of facilitators and participants in a newly-developed adaptive Irish Céilí dance programme for people living with dementia and their care staff. Research which explores the use of this dance genre as an arts-based activity for those living with dementia or their care staff is limited. This research which included participants living with dementia attending, and care staff working in, a daycare centre in the mid-west region of Ireland, therefore provides a starting point to address this gap.

The focus of this research is on the participants' lived experience. A qualitative approach, utilising semi-structured interviews, researcher observations, and a reflexive journal, was therefore deemed the most appropriate for this research. The dance activity took place over a nine week period. Interviews were staged prior to the first dance activity, at the mid-point of the dance programme, and after the final dance activity. Participant consent was sought on an ongoing basis. In advance of any data collection, ethical approval to conduct the research was sought from, and approved by, the Limerick Institute of Technology. The data was analysed using thematic analysis.

In the context of this research, Irish Céilí dance as an arts-based activity for those living with dementia and their care staff resulted in beneficial psychosocial outcomes including an enhanced ability for people living with dementia to reminisce. Their stories and memories of attending Céilí events in their past was evoked by participation in the dance classes and interview process. In turn, enhanced reminiscence was observed to have a positive influence on the mood and psychosocial well-being of both the participants living with dementia and the care staff participants.

Declaration

The work presented in this thesis is the original work of the author, under the direction of Jennifer Moran Stritch and Carmel McKenna, and due reference has been made, where necessary, to the work of others. No part of this thesis has been previously submitted to LIT or any other institute.

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I extend a heartfelt thank you to my wife Emma and my children Conor, Kitty and Ellie, as well as our dog Alfie. Your continued support, patience, belief and love were instrumental in enabling me to complete this research.

Dedication

This thesis is dedicated to all the participants living with dementia who welcomed me into their lives and who made this experience so enjoyable and worthwhile. Your courage, determination, laughter and dancing have provided me with such inspiration as well as admiration for your wonderful individuality and personalities which will stay with me for a lifetime.

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Dissemination List

O Shea, S.D. (2019) *Interview on The Ryan Tubridy Show* (Radio), RTE Radio 1, 2nd May 2019, 09:40. Available online at: https://www.rte.ie/radio/radioplayer/html5/#/radio1/21548852

O Shea, S.D. (2019) Arts, Humanities and Social Sciences Conference, *Some Dance to Remember: Exploring the Psychosocial Effects of the Introduction of an Adaptive Irish Céilí Dance group activity for People Living with Dementia and their Care Staff*, University of Limerick, 7th May 2019.

O Shea, S.D. (2019) Postgraduate Annual Progression Review Colloquium, *Some Dance to Remember*, Limerick Institute of Technology, 8th May 2019.

O Shea, S.D. (2019) Limerick Postgraduate Research Conference, *Some Dance to Remember: Exploring the psychosocial effects of the introduction of an adaptive Irish Céilí Dance group activity for People Living with Dementia and their Care Staff*, University of Limerick, 20th May 2019.

O Shea, S.D. (2020) Transforming care and Communities- Virtual 12th International Dementia Conference, *Some Dance to Remember- The First Steps,* 2nd November 2020.

O Shea, S.D. (2020) *Interview on The Saturday Supplement'* (Radio) Radio Kerry, 7th November 2020, 09:10 Available online at: https://www.radiokerry.ie/saturday-supplement-november-7th-2020/

List of abbreviations

ADI - Alzheimer Disease International

ASI - Alzheimer Society of Ireland

BPSDs - Behavioural and psychological symptoms of dementia

DMT - Dance Movement Therapy

HSE - Health Service Executive

IHF - Irish Hospice Foundation

LIT - Limerick Institute of Technology

NDS - National Dementia Strategy

NICE - National Institute for Health and Care Excellence

QQI - Quality and Qualifications Ireland

SCU - Special Care Unit

SDOS - Sean Donal O Shea

WHO - World Health Organisation

1 Chapter 1: Introduction

The Alzheimer Society of Ireland (ASI) (2021a) estimates that there are 64,000 people currently living with dementia in Ireland and estimate that this figure will rise to 150,000 by the year 2045. The increasing prevalence of dementia has been recognised by the World Health Organisation (WHO) which has identified the condition as a global health epidemic (WHO, 2015). Medical and social care initiatives to meet the ongoing needs of people living with dementia and their caregivers are therefore required (Prince et al., 2016; WHO, 2015).

To date, the medical model of care has dominated the approach to dementia care (Karkou & Meekums, 2017; Kontos & Grigorovich, 2018). Although the medical approach has provided beneficial outcomes for those living with dementia (Borgson, 2013), it predominantly focuses on the limitations of the individual and tends to ignore the person as a whole (Canning & Blakeborough, 2019). In recent years, there is an increasing recognition of non-pharmacological approaches to dementia care (National Institute for Health and Care Excellence (NICE), 2018; Alzheimer's Association, 2020).

Research has identified the positive effects of dance for those living with dementia (Palo-Bengtsson & Ekman, 2002; Pearse, 2007; Hamill et al., 2012;

Abreu & Hartley, 2013; Foster, 2013; Lapum & Bar, 2016; Guzmán et al., 2017; Ho et al., 2018; Kontos & Grigorovich, 2018; Mabire et al., 2018; Skinner et al., 2018). To date, virtually no published literature has explored the use of Céilí dance as an arts-based activity for those living with dementia and their care staff. This thesis therefore provides a starting point to address this gap in the research by exploring, in the context of the psychosocial effects of dance and movement, the experiences of participants in a newly developed adaptive Céilí dance programme for people living with dementia and their care staff.

An adaptive Céilí dancing activity was introduced at a daycare centre which provides services, including respite services, for people in the early or middle stages of dementia. The Céilí dance activity was adapted to allow for a range of abilities that reflected participants' levels of mobility, focus, cognitive skills and interest.

The Literature Review (Chapter 2) draws on the historical and global research undertaken that lays the foundations for this study. The experiences of loss and grief, along with social death and the stigma that accompanies dementia, are explored in detail. The ways in which these concepts are intertwined, which may lead to negative perceptions of those living with dementia, is also explored. The biomedical approach to treating dementia will be challenged throughout this chapter. The benefits of arts-based interventions for dementia care are considered. Dance as an arts-based intervention is explored with a specific emphasis on Céilí dance and its influence on creating a sense of community and identity for those taking part in the research.

The Axiology chapter (Chapter 3) looks at the values embedded within this research and explores the researcher's personal, educational, and professional connection to the project. The inclusion of a reflective journal as a tool in this research, as a tool utilized by the author, is also explored. This chapter highlights the importance of recognising potential biases and explores the researcher's positioning within the research.

The Methodology chapter (Chapter 4) discusses the theoretical framework for this research and provides the rationale for a qualitative approach to this research. The ontological and epistemological approaches used within the study are highlighted to strengthen the researcher's position of investigating the lived experience of those with a diagnosis of dementia through semi-structured interviews and the dance activity. In conjunction with the researcher's observations, thematic analysis was used to identify key themes arising from the semi-structured one-to-one interviews with the participants. Ethical dilemmas experienced by the researcher are explored in this section. The need for, and obtaining of, ongoing consent throughout the research is identified.

The Results and Discussion chapter (Chapter 5) identifies the key findings from the research which are outlined below:

- **Theme 1: Reminiscence**

  Subthemes: Identity, Community and Personhood

  Access to New Knowledge

  Life Story Work

  Music and Dance - Creating a Sense of Identity

  Embodied Remembering

  The Past Informing the Present •

Theme 2: Mood

Subtheme: The Rhythm of the Dance

- **Theme 3: Mobility and Falls Risk**

  Subthemes: Opinions Altered Through Adaptive Dances

  Adapting to Inclusivity
- **Theme 4: Strengthening Bonds Between Staff and People Living with**

Dementia

Subtheme: Roles Reversed

This chapter includes direct quotes from the researcher's reflective journal, which enabled the researcher to not only capture observations made throughout the research, but also to recognise their own emotions and feelings encountered during the process. Direct quotes from the transcribed interviews (see Appendix A) that best express the themes which arose in the research are also used.

The Conclusion and Recommendations chapter (Chapter 6) highlights that there is virtually no published literature which has explored the use of Céilí dance as an arts-based activity for those living with dementia and their care staff. It advocates that the interview process, and primarily the adaptive Céilí dance activity, provided beneficial psychosocial outcomes for all participants in this research, particularly those living with dementia. Several opportunities for future research in the area of dementia care are also identified, and recommendations based on the findings of this current project are provided. Directions for future research and recommendations are outlined below:

- A link between the rhythm of the dance and embodied remembering was present in this research project. This is an area which requires further exploration and provides an opportunity for future research.
- There is a paucity of research available which has investigated the person living with dementia reflecting on past experiences as a means of expressing their present feelings. This is an area within dementia care which is overlooked and provides an opportunity for further exploration and for future research.

- Dementia specific training should be mandatory for all staff providing care to people living with dementia.
- Arts-based training should be encouraged and made available for all disciplines training in dementia care, including social care work, social work, nursing, occupational therapy and therapeutic recreation professionals (for example, the introduction of a Special Purpose Award programme at third level).
- Specialised dementia training for Irish dance teachers who may wish to introduce this programme in a variety of dementia services should also be developed and encouraged (for example, the introduction of a Special Purpose Award programme at third level).
- This adaptive Céilí dance programme should be expanded and made available in all facilities providing care for those living with dementia and could be a method of reducing the use of the medical model for treating the condition. This would include daycare centres, respite services, long term residential care as well as homecare. In light of the restrictions imposed in most services due to Covid 19, this dance activity could be facilitated online for those living at home and their professional and family carers.
- A facilitator of this dance programme should preferably be an external employee rather than one based at the facility, as this research has identified that regular staff currently do not have sufficient time to facilitate the dance activities.
- The adaptive Céilí dance programme could be utilised to better inform person-centred care plans therefore providing and maintaining a better quality of life for the individual living with dementia and their family.

2 Chapter 2: Literature Review

2.1 Introduction

> Dementia is an umbrella term for a number of progressive diseases affecting memory, cognitive abilities, and behaviour. Crucially, although dementia primarily affects older adults, it is not a normal or inevitable consequence of ageing
>
> (WHO, 2015, p.19).

This chapter draws the readers' attention to the increasing prevalence of dementia globally as well as in an Irish context. It also highlights the expectations placed on professional care staff as a result of the progressive nature of the disease. The importance of receiving a timely diagnosis as well as the challenges preventing this process are similarly highlighted. The availability of post-diagnostic supports and services in dementia care is explored. The inequality of access to these services throughout the country is examined.

In addition, the chapter focuses on previously published literature which identifies the loss and grief experienced by the person living with dementia and their family/carers. Public discourses and perceptions around dementia are explored; these can have a negative impact on the individual and their family thus creating a stigma around the condition.

The traditional bio-medical approach to treating dementia is discussed. The researcher argues that this approach does not take into consideration emotional and social factors for the individual with dementia and their family/carers. This research explores the influence that arts-based activities have on the person living with dementia and their carers. The potential benefits of an arts-based approach (such as dance) as an alternative to the bio-medical approach to treating dementia are outlined below and discussed:

- Positive therapeutic effect on the person living with dementia
- Positive effect on the social and emotional factors in their life
- Increased communication
- Increased self-expression
- Increased inclusion and socialisation
- Strengthening of bonds between the person living with dementia and care staff.

A description of what constitutes Céili dances for the purposes of this research is provided. The similarities and differences between Céilí events run under the auspices of the Gaelic League and those which are not are identified. Foley (2013) and Phelan (2015) note that the Gaelic League was founded in 1893 in an attempt to rediscover the cultural roots of Ireland, with the promotion of Irish dancing, through dance classes and competitions, seen as an important factor in this attempt. This chapter also recognises the emergence of 'modern dance' and the role which the Public Dance Hall Act 1935 played in this period in shaping the landscape for those attending Céilí events. Using the limited available research, the role which the social Céilí event and dance played in creating a sense of belonging, community and cultural identity in Ireland, and why it is significant for this research project, is also explored.

2.2 Prevalence of Dementia

Alzheimer's Disease International (ADI) (2020a) estimate that there are 46.8 million people living with dementia worldwide. The organisation predicts that this number will increase to 131.5 million by the year 2050. This figure represents a

12% -13% increase over the percentages predicted in the World Alzheimer Report 2009 (ADI, 2009). The prevalence of dementia is also increasing rapidly. It is estimated that there is a new case worldwide every 3.2 seconds (ADI, 2015).

A report published by ADI (2015) identifies that there are ten and a half million people living in Europe with dementia. The Health Service Executive (HSE) (2020a) estimates that there are eleven new cases of dementia diagnosed daily in Ireland. As previously highlighted, the ASI (2021a) estimate that the figure of 64,000 people currently living with dementia in Ireland is expected to rise to 150,000 by the year 2045.

Research conducted in the United States has highlighted that Alzheimer's disease kills more people each year than breast cancer and prostate cancer combined (World Alzheimer's Report, 2018) and it has been identified as the leading cause of death in the UK (Alzheimer's Research UK, 2020).

There has been a steadily growing recognition of the dementia epidemic which was highlighted at the first WHO global conference on dementia held in 2015 (WHO, 2021). The conference was attended by representatives from 89 countries however there was no representative from Ireland. In spite of the worldwide attention it has attracted in recent years, dementia is a complex syndrome with a wide variety of manifestations and prognoses.

2.2.1 What is Dementia?

Dementia is an umbrella term for a number of progressive diseases affecting memory, cognitive abilities, and behaviour (WHO, 2015). Alzheimer's disease is the most common form of dementia (Alzheimer Europe, 2020a; Alzheimer's Society, 2020; ASI, 2020a; HSE, 2020a). Although the majority of people living with dementia are over sixty-five years of age, it is not considered a normal part of ageing; nine out of ten people over the age of sixty-five do not have dementia (HSE, 2020a; WHO, 2020).

Dementia leads to a progressive deterioration in multiple areas of an individual's life affecting memory, physical abilities, communication skills, behaviour, problem solving as well as the ability to perform daily tasks (Irish Hospice Foundation (IHF), 2016; Alzheimer Europe, 2020b; Alzheimer's Society, 2020; ASI, 2020a; HSE, 2020a). As it is a progressive condition, those affected will eventually require care and assistance with every aspect of daily life (ADI, 2020b).

The HSE (2020a) and the WHO (2020) highlight that there is currently no cure for dementia. Every diagnosis of dementia is experienced subjectively, however people will live an average of between eight and ten years from the emergence of the first symptoms (Alzheimer's Society, 2020; WHO, 2020).

2.2.2 Stages of Dementia

This lifespan following the initial symptoms varies depending on the age of the person when a diagnosis is made (ASI, 2020a). An early diagnosis of dementia is important for both the individual as well as their family. It ensures that they have time to adequately plan for the future, which may help to relieve the psychological distress experienced by carers and may also facilitate a more person-centred approach to care (Foley et al., 2019).

In the early stages of dementia, the individual may experience slight changes such as forgetfulness, loss of interest, and low mood (Alzheimer's Society, 2020; ASI, 2020a; WHO, 2020) yet they can still function independently (Alzheimer

Association, 2020; Alzheimer's Society, 2020). The Alzheimer's Society (2020) and the WHO (2020) emphasise that, as the condition progresses to the middle stage, the symptoms become more pronounced. They also identify that the individual will need help with daily activities such as bathing and dressing during this stage. The individual may forget knowledge and personal memories completely (Alzheimer's Society, 2020; ASI, 2020a). This stage is commonly the longest stage of the disease and may last for several years (Alzheimer Association, 2020). Changes in the individual's behaviour are most common from this stage onwards and this stage is generally regarded as one of the most challenging aspects of dementia for carers (Alzheimer's Society, 2020).

Throughout the late stage of dementia, the individual will require increasing amounts of support and will gradually become dependent on others for all aspects of their daily life (Alzheimer's Society, 2020; ASI, 2020a; WHO, 2020). During this stage the individual will struggle to fight simple infections, have difficulty speaking and swallowing, and will also experience a progressive reduction in mobility (Alzheimer Association, 2020; Alzheimer's Society, 2020; ASI, 2020a). It is important to note that although the individual may struggle to communicate during the late stage, they can still respond positively to affection, touch, and other sensory stimulation such as listening to music (Alzheimer Association, 2020; Alzheimer's Society, 2020; ASI, 2020a).

2.2.3 Level of Care Required

Dementia is not only a health issue but also a social issue that requires a community response (HSE, 2020b). As previously stated in this chapter (see section 2.2.2), the level of care required for an individual is dependent on the stage of the disease they are experiencing. Equal access to the appropriate services, however, is not always possible. This disparity will be explored further in this section.

There are currently 180,000 people in Ireland who are providing, or have provided, care for a family member or partner living with dementia (Understandtogether, 2020). O' Shea et al. (2019) estimate that the cost associated with dementia in Ireland is €2 billion, with almost half of this borne directly by informal carers. This cost associated with dementia emphasises the need for the implementation of post-diagnostic supports for both the person living with dementia and their family. There is a growing body of evidence that post-diagnostic support which is provided over an extended period of time is essential for the person living with dementia, their family and their care partners (The Improvement Hub, 2017). Such supports include therapeutic treatments and activities 'that build on strengths and abilities that help to maintain and enhance quality of life' (Gibb et al., 2019, p.3).

Post-diagnostic supports are available in various forms such as homecare and daycare services as well as nursing home care. Yet the accessibility of such services is often dependent on an individual's geographical location.

Post-diagnostic supports are available in various forms such as homecare, daycare services and nursing home care. There are, however, significant gaps and inconsistencies in service provision and the availability of all dementia specific services throughout the country. This was noted in the *Dementia Specific Services in the Community: Mapping Public and Voluntary Services* project undertaken by undertaken by the ASI and the National Dementia Office in 2016. This project showed that there were significant gaps and inconsistencies in the provision of dementia-specific services throughout the country. As can be seen from Table 1 below, of the 314 services being provided throughout the country, dementia specific daycare was the most common service with sixty-three services available, followed by dementia specific homecare with thirty one services available. Dementia friendly activities had twenty nine services available and social clubs has twenty eight services available.

Table 1: Service Provision of Dementia Specific Services

Service Category	**Number of services**	**No service available**
Dementia-specific daycare	63	Wexford, Laois, Leitrim
Dementia-specific homecare	31	
Dementia friendly activities	29	Galway, Roscommon, Mayo, Donegal, Sligo, Leitrim, Cavan, Monaghan
Social clubs	28	Galway, Roscommon, Mayo

Adapted from: Alzheimer Society of Ireland and the National Dementia Office in the Health Service Executive (2016).

The project also highlighted that there are issues with regard to the frequency of dementia-specific daycare services as outlined in Table 2 overleaf:

Table 2: **Availability of Dementia Specific Daycare Services**

Days available	**Number of services**
6 days a week	1
5 days a week	26
4 days a week	2
3 days a week	8
2 days a week	9
1 day a week	13
Twice a month	3
Once a month	1
Total	**63**

Adapted from: Alzheimer Society of Ireland and the National Dementia Office in the Health Service Executive (2016).

This breakdown of the sixty-three daycare centres highlights that while the majority of these services, (twenty six), were available five days a week, thirteen were only available one day per week.

In addition, the findings identified that many post-diagnostic supports for people living with dementia were not readily available with nine dementia advisors (as of April 2021, the number of dementia advisors has increased to eighteen), seven cognitive therapists, and one dementia specific counselling services tasked with providing these services for the country. Taken together, the scarcity of services identified by the project meant that there were some counties which did not have any access to many dementia-specific resources.

2.2.4 Timely Diagnosis

The Irish National Dementia Strategy (2014) has identified the timely diagnosis of dementia as a key factor in improving dementia services for the individual and their family (Department of Health, 2014). In addition, Foley et al. (2019, p.5) state that ‘Disclosure may facilitate a more patient-centred approach, more proactive management of dementia and may end the uncertainty for patients and their families'.

General Practitioners are often the first healthcare professionals consulted by an individual or family when dementia is suspected (Department of Health, 2014; Foley et al., 2019) yet they can find disclosing a diagnosis of dementia difficult (Foley et al., 2017). The findings of a survey on Irish general practitioners undertaken by Cahill et al. in 2006, echoed in the Irish National Dementia Strategy 2014 (Department of Health, 2014), identified that the following factors impacted on a General Practitioner's decision to diagnose dementia:

- Lack of confidence
- Fear of making a wrong diagnosis
- Concerns about the impact of the diagnosis on the individual
- Confusion in distinguishing normal ageing from symptoms of dementia.

Confirmation of a diagnosis of dementia can take up to four years (Foley et al., 2019) and a connection may be drawn between this timeline and the difficulties which have been identified by Irish general practitioners.

2.2.5 Social Prescribing

Tierney et al. (2020) state that social prescribing is a way of addressing 'non-medical' needs, such as loneliness, which can influence a person's health and well-being. There has been a growing recognition of the benefits of social prescribing in Ireland with, for example, the establishment of the All-Ireland Social Prescribing Network in 2018 (HSE, 2021). The availability of such resources are sporadic with

Sláintecare[1] supporting just seven Social Prescribing programmes across Ireland (Department of health, 2021). In contrast, The United Kingdom has taken a more proactive approach to Social Prescribing. The All-Party Parliamentary Group on Arts, Health and Wellbeing Annual Report (2017), for example, contains a commitment to roll out personalised care (which encompasses social prescribing) across England by 2023, potentially benefitting up to 2.5 million people. The report also highlights the importance of arts-based activities as a vital component in individual health and well-being.

McKenzie et al. (2021) emphasise that DMT (Dance Movement Therapy) is an available option which can be socially prescribed in the United Kingdom. Brauninger & Bacigalupe (2017) further note that DMT is well established as a form of complementary medicine which has become increasingly popular for such disciplines as oncology, neurology and geriatrics in dementia care.

From an Irish perspective, there are no DMT qualification programmes available at third level in Ireland; there are no Dance Movement Therapists based in Ireland who are registered with the European Association of Dance and Movement Therapy; and there is no Irish Association of Dance Movement Therapists (EADMT, 2021).

Grant (2021) reports that Dance Movement Therapists are part of a diagnostic medical team in the United Kingdom and the United States, a phenomenon that is not present in Ireland as of this writing.

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[1] *Sláintecare* is a ten-year programme aimed at transforming health and social care services in Ireland.

2.3 Post-diagnosis Supports and Services

The ASI is the leading dementia-specific service in Ireland, providing a range of supports and services throughout the country. These services include a national helpline, Alzheimer Cafes, a Dementia Advisor service, advocacy, support groups, respite centres, daycare centres as well as homecare services. In addition to the services provided by the ASI, Family Carers Ireland (www.familycarers.ie) provide a homecare service which support family carers in the home. They also facilitate support groups and provide an advocacy service for family carers (however this is not a dementia-specific service). While many people living with dementia may live at home with appropriate support and homecare services, others may require long term care and need to reside in nursing homes.

2.3.1 Long Term Care/Nursing Homes

The Irish National Dementia Strategy (2014) states that:

> While current health and social policy is focussed on caring for people with dementia in their own homes, there will come a time for many when home care may no longer be feasible or appropriate and when long-term residential care will be the best option
>
> (Department of Health, 2014, p.27).

Foley et al. (2019) identify that a lack of formal and informal supports as well as a decline in the physical and mental health of both the individual with dementia and the carer, can contribute to the need for nursing home services.

The 2020 pre-budget submission of Nursing Homes Ireland (2019) highlighted that there are 438 nursing homes in Ireland which provide a service to approximately 25,000 people.

In Ireland, Special Care Units (SCUs) are specific units tailored to provide a service to those living with dementia and their families. An Irish national survey on dementia in long-term residential care undertaken by Cahill et al. (2014) found that there were 55 SCUs in Ireland. Of these, 63% of operated privately, 30% were HSE units and only 7% represented voluntary not-for-profit facilities. The findings of the survey also revealed that those requiring such a service are often disadvantaged by geographical location. Table 3 overleaf highlights that the majority of counties have limited availability to dementia-specific SCUs, with some counties having no option for such a service.

Table 3: Geographical Breakdown of Special Care Units in Ireland

Location	**Number of Special Care Units**
Cork	13
Dublin	6
Galway + Donegal **(5 each)**	10
Cavan/Louth/Meath/Monaghan **(3 each)**	12
Clare/Roscommon **(2 each)**	4
Kerry/Limerick/Tipperary/Waterford/Wexford/ Laois/Kildare/Longford/Mayo/Leitrim **(1 each)**	10
Kilkenny/Carlow/Wicklow/Offaly/Sligo/Westmeath	0
Total	**55**

Adapted from: Cahill et al. (2014)

The survey also highlighted that only 50% of staff and a little over one-third of management had undergone dementia specific training (Cahill et al., 2014). Prior to the data provided from this survey, there was no accurate information available on dementia-specific residential care units in Ireland.

The absence of mandatory, dementia-specific training for those providing care to people living with dementia may result in staff who feel incapable of meeting the required needs of those availing of long-term care services. The authors of the survey propose that the needs of people living with dementia in long-term care are unmet, as ‘direct care workers feel incapable of meeting residents’ social, psychological and emotional needs, given that these vary considerably from people without dementia’ (Cahill et al., 2014, p.6).

Many people living with dementia may live at home with appropriate support and homecare services. In addition to the HSE, there are a number of private care service providers offering homecare services to support those living with dementia in their desire to remain in their own homes.

2.3.2 Homecare

The ASI (2020b) estimate that 63% of people with a diagnosis of dementia live at home in the community. These individuals may receive homecare, which is a set of services enabling a person to be cared for in their own home for as long as possible (HSE, 2020b; Understandtogether, 2020).

The HSE (2020b) highlights that this service provides formal carers who go into an individual’s home on a regular basis and provide care as needed. The care provided to each individual is based on their individual needs. The HSE (2020b) and Alzheimer Europe (2020c) identify that homecare may include assistance with:

- Personal care
- Maintaining skin integrity
- Continence care
- Preparing meals
- Eating/drinking
- Completing household tasks where required.

All homecare workers in Ireland are required to complete the relevant Quality & Qualifications Ireland (QQI) Level 5 training or an equivalent healthcare qualification. The QQI course is aimed at preparing learners for a career in hospitals, in the community or in residential care. The Open College (theopencollege.com) along with other training providers offers those seeking a career as a homecare worker with the opportunity to complete the required training. The course covers the following mandatory modules:

- Care Skills
- Care Support
- Personal Effectiveness
- Safety and Health at Work
- Work Experience
- Care of the Older Person

It should be noted that at the time of this writing (April, 2021) there is no requirement for dementia-specific training to become a care worker in Ireland. The lack of required dementia specific training was previously noted by Cahill et al. (2014).

While many people with dementia may live at home with appropriate support and homecare services, others may avail of a dementia specific daycare service. This service is aimed at providing person-centred care in a community setting for the person living with dementia.

2.3.3 Daycare Services

Daycare is a vital service for many people living with dementia and their carers (ASI, 2020c). Research carried out by Pierse et al. (2020) identifies that there is a total of 317 daycare centres in Ireland; however the majority of these are not dementia specific. This research suggests that the majority of daycare centres are largely generic in nature but can cater for people with dementia to various degrees.

There is a lack of available data outlining the number of dementia specific daycare centres in Ireland, however the ASI (2020c) provide 48 such centres throughout the country. These centres provide dementia specific, person-centred daycare services which are aimed at meeting the needs of the person with dementia. Services provided can include reminiscence therapy, arts and crafts, music sessions, gentle exercises as well as personal care.

Access to a daycare centre can provide the individual with an opportunity to socialise with others as well as an opportunity to access health care services (Pierse et al., 2020). Orellana et al. (2020) suggest that daycare services can benefit the relationship between the person living with dementia and their carer by providing time apart and facilitating employment for the family carer. As with the majority of services for people living with dementia, access to daycare services is largely dependent on geographic location and, for this reason, may not be an easily accessible option for many individuals and families in Ireland (Cahill et al., 2014; Pierse et al., 2020).

The lack of access to dementia specific services for the individual living with dementia and their family may provide a barrier in adjusting to the changes that dementia brings. The ASI (2021b) advocate that accessing information about the support and services available can be a vital step in the journey. They highlight the importance of building a support network for the individual and their family through services such as social clubs, daycare and homecare services as well as nursing home services. Access to such supports and services can assist in best informing those living with dementia and their family around the loss and grief which often accompanies a diagnosis (Foley et al., 2019).

2.4 Loss and Grief

> 'The test of a first-rate intelligence is the ability to hold two opposed ideas in the mind at the same time, and still retain the ability to function'
>
> (Fitzgerald, 1945, p.69).

It is common for the person living with dementia and their carer to experience feelings of loss and grief as their life is changed by dementia (ASI, 2021c).

Although loss and grief are seen as a fundamental part of the dementia experience (IHF, 2016), it can lead to confusion and feelings of helplessness for the person with dementia and their family. These losses are experienced by both the person with dementia, their family and their caregivers (Doka, 2010) and are some of the most significant and under recognised issues faced by people living with dementia and their families (IHF, 2016). Doka describes grief as:

> The constant yet hidden companion of Alzheimer's disease and other related dementias. It is ever-present for the person with dementia and accompanies their families and friends throughout the illness and after death
>
> (Doka, 2005, p. 290).

Loss and grief occur at all stages of dementia in numerous ways and supporting those experiencing is seen as an essential part of person-centred care (IHF, 2016). People living with dementia and their family can be affected by a diagnosis of dementia in several ways as outlined below:

- Emotionally

- Mentally
- Physically
- Spiritually

2.4.1 Ambiguous Loss

Dementia has been described as 'the long goodbye' (IHF, 2016) and the grief that accompanies this journey is unclear and mixed. Boss (2010) highlights that this unclear loss arises because the beloved person is physically present, yet not relationally or emotionally present. Ambiguous loss occurs when the person living with dementia remains physically present yet they are not emotionally or psychologically available (IHF, 2016). This confusing ambiguity can therefore block the processes of closure and resolution of grief as opposed to death-related grief and loss. The IHF (2016) notes that death-related loss is clearer and is located at a particular event (time of death) that occurs at a certain and objective point in time.

Dupuis (2002) argues that ambiguous loss is a loss that remains incomplete, uncertain or confusing for family members that experience it. This grief is unclear and not understood (Doka, 2002) and can be further complicated when the person with dementia has moments of clarity and lucidity (IHF, 2016) which can lead to mixed and confused feelings for family and caregivers. These feelings of grief and loss are compounded as the person with dementia may no longer recognise their family members and caregivers (Doka, 2006; Chan et al., 2012) and their personality and behaviours change.

Such losses experienced by the person living with dementia affect their past (ability to recollect/relive memories), present (self- care and independence) and future (ability to plan ahead) and are often very difficult to capture unless they are addressed with the individual early in the diagnosis. These losses can have a profound impact on the individual's social identity and can have a detrimental effect on their overall well-being. A diagnosis of dementia may influence the way in which the individual is seen and treated by others, which in turn may lead to those affected by dementia hiding or not validating the condition (IHF, 2016).

2.4.2 Disenfranchised Grief

Disenfranchised grief occurs at all stages of dementia and is experienced by the individual as well as their families and caregivers (IHF, 2016). Doka (1989) identifies disenfranchised grief as a sociological concept which arises as a result of social expectation. This is a grief which is hidden and not validated and can occur due to lack of public awareness of the nature of dementia as well as the stigma that is associated with the condition (IHF, 2016).

It is therefore suggested by this researcher that this culturally familiar dance activity can combat aspects of the ambiguity that surrounds a diagnosis of dementia as it will enable the individual to be both physically and emotionally present simultaneously. It is further suggested that the dance activity intervention highlighted in this project could challenge some of the misconceptions surrounding the condition and emphasise the capabilities of the individual as opposed to limitations.

A connection can be made between stigma and loss and grief associated with dementia and the concept of social death (Sudnow, 1967) as the personhood of the individual is challenged in both contexts.

2.5 Social Death and Dementia

Social death is used to describe the way in which an individual is treated as if they were non-existent or dead (Borgstrom, 2017). This is more prevalent for those living with dementia that those without a diagnosis (Brannelly, 2011). Sudnow (1967) first used the term 'social death' when studying the social processes surrounding death in his research in two hospitals where he observed the phasing out of attention given to dying patients. He identifies that the presumed social value of those nearing death influences how they are treated, and how much effort is invested in them by medical personnel.

Sweeting & Gilhooly (1997) explored the views of those caring for a relative with dementia. They found that over a third of their participants believed and behaved as if their relative was socially dead. Katsuno (2005) suggests that a diagnosis of dementia demotes the individual to a new lower status social group, a function that is a result of the condition itself as well as the responses to it.

2.6 Stigma Associated with Dementia

The concept of stigma stems from Goffman's (1963) study of the phenomenon and can be applied to numerous conditions and illnesses in human experience. He uses the term stigma 'to refer to an attribute that is deeply discrediting' (Goffman, 1963, p.3) with those possessing such attributes viewed as inferior in a way which makes them different from others and is undesired and shameful. Research has highlighted that stigma increases social exclusion while also having a negative influence on health and well-being (see, for example, Burgener, et al., 2015; Cuijpers & Van Lente, 2015; Kontos et al., 2020). It could be argued that the stigma that accompanies dementia is largely fuelled by the lack of public understanding around the condition and the language which is used in discourses around it.

Research undertaken by the IHF (2016) found that frontline care staff also experience the stigma and grief that is associated with dementia largely due to the lack of understanding of the general public. Goffman's theory of courtesy stigma (Goffman, 1963) identifies that stigma is also experienced by the family and carers of the individual living with dementia.

2.6.1 Person Living with Dementia and Stigma

A report published by ADI (2012) highlights that people living with dementia can be stigmatised within society. The report further emphasised that the lack of public understanding around dementia may be a cause for the stigma which is associated with the condition. Several studies have highlighted a link between stigma and social exclusion. Burgener et al. (2015) as well as Nguyen & Li (2020) argue that the stigma associated with dementia produces inequality by depriving the individual of their human rights while compromising health, well-being and quality of life. Additionally, from an Irish perspective, a study undertaken in 2008 (Cahill et al., 2008) found that stigma associated with dementia was a contributing factor in delayed diagnosis of dementia by general practitioners, a finding which is echoed in global research undertaken by Herrmann et al. (2018). In addition, Kontos et al. (2020) have identified that the discourse around dementia within the biomedical model of care contributes to the misunderstandings and prejudice which fuel the stigma attached to the condition.

2.6.2 Perceptions and Language Used

Cuijpers & Van Lente (2015) argue that within the acute care model, the person with dementia is reduced to their cognitive impairment. Gilleard & Higgs (2014) propose that the language used by health care professionals reflects a representation of those living with dementia as incapable. However, research carried out by Herrmann et al. (2018) suggests that having a personal or family connection with the person with dementia reduces the stigma associated with the condition.

Kitwood (1997) further identifies that terminology such as 'victims' and 'demented' when referring to those with a diagnosis of dementia 'devalue the person and make a unique and sensitive human being into an instance of some category devised for convenience or control' (Kitwood, 1997, p.8).

While several authors have highlighted the influence that the negative discourse surrounding dementia can have on the individual, Kontos et al. (2020) argue that it also deepens social exclusion for those who experience it.

O' Shea (2014) states that the stigma associated with dementia tends to focus on how the individuals' capabilities are limited rather than focusing on their remaining strengths. A key recommendation arising from the ADI World Alzheimer Report *Overcoming the Stigma of Dementia* (2012) highlighted the need to involve people living with dementia in their local communities. The report also recommended improving the quality of care at home and in care homes for people living with dementia as a method of challenging and negating the stigma associated with dementia.

Research such as that by ADI (2012) indicates that the family and carers of those with dementia also experience stigma which leads to inaccurate assumptions about the individual and their family.

2.6.3 Stigma Experienced by Family/carers

Family and caregivers of those living with dementia may find that the stigma experienced by the person they are supporting leaks over to their own identity (ADI, 2012; Nguyen & Li, 2020). Goffman (1963 as cited in ADI, 2012; Herrmann et al., 2018; Nguyen & Li, 2020) refers to this as courtesy stigma which is the negative impact that results from an association with the stigmatised person. This can result in the affected person delaying seeking help from others.

This section has acknowledged the impact that the stigma associated with dementia has on the individual as well as their family/carers. It is also important for this current research to identify that this stigma negatively impacts the social identity of the individual and carries with it loss and grief which is experienced by the person, their family and the carers.

2.7 Biomedical Approach to Treating Dementia

Historically a biomedical approach has been to the forefront of dementia treatment (Kitwood, 1997; Karkou & Meekums, 2014; Kontos & Grigorovich, 2018) with less acknowledgement given to the role of emotional and social factors for the individual with dementia (De Vugt & Droes, 2017). Kitwood (1997) emphasises how this approach has dominated research, policy and practice in dementia care. He states (1997, p.2) that 'the older views about the process of dementia, which were extremely negative and deterministic, were incorrect' and acknowledges the importance of a more person-centred approach. In addition, Smith et al. (2006, p.57) state that:

> Early notions that all behaviours were an inevitable component of cognitive impairment have all but disappeared in the face of evidence that diverse personal, social, and environmental factors regularly act as antecedents to behavioural and psychologic symptoms of dementia (BPSD).

2.7.1 Behavioural and Psychological Symptoms of Dementia

In the context of dementia, the term ‘challenging behaviour’ is a catch-all term which encompasses actions ranging from shouting and wandering to anger or physical attacks on individuals (Andrews, 2006). These are referred to as behavioural and psychological symptoms of dementia (BPSDs) and ‘are among the most distressing sequelae of Alzheimer’s disease and related dementias’ (Scales et al., 2018, p.88).

BPSDs can be viewed as an attempt to communicate an unmet need (Algase et al., 1996; Scales et al., 2018) and emerge as environmental demands exceed stress tolerance or coping thresholds (Hall & Buckwalter, 1987). BPSDs consist of two subgroups of symptoms namely behavioural and psychological as outlined in Table 4 overleaf:

Table 4: Behavioural and Psychological Symptoms of Dementia

Behavioural	**Psychological**
Agitation	Delusion
Aggression	Hallucination
Wandering	Depression
Disturbance in sleep	Anxiety
Disturbance in sleep-wake cycles	

Adapted from: Foley et al., 2015; Majer et al., 2019; Cloak, 2020

These symptoms are experienced by the majority of people living with dementia at some point (Foley et al., 2019; Cloak, 2020). Steinberg et al. (2008) and Cloak (2020) have argued that BPSDs are nearly universal in dementia, with 97% of people living with the condition experiencing at least one BPSD. Research undertaken by Savva et al. (2009) found that BPSDs are most likely to occur in the middle and later stages of the condition. The severity of the symptoms increases with time (Cloak, 2020).

Research undertaken by NICE (2018) recommends that non-pharmacological approaches be used primarily for treating BTSDs unless the person living with dementia is a threat to themselves or others. The report supports previous research undertaken by Schneider et al. (2005) which highlights many negative side effects of prescribed antipsychotics. These include an increased risk of falls, reduced motor function, pneumonia, increased risk of stroke and accelerated cognitive decline. McShane et al. (1997) and Douglas et al. (2004) also found that neuroleptic drugs used to treat behavioural problems in people with dementia may accelerate the decline in cognitive function.

Research by Rolland et al. (2012) identified that antipsychotics are prescribed twice as often to nursing home residents with dementia compared to those without a diagnosis. Foley et al. (2019) suggest that those with advanced dementia are at an increased risk of inappropriate prescribing and adverse outcomes.

It is important to acknowledge that the medical model has been successful in addressing many aspects of dementia, including making significant advances in the improvement of early disease detection through cognitive impairment screening (Borson et al., 2013). Additionally, research conducted by Walsh et al. (2018) emphasised that the use of antipsychotics for people living with dementia is often needed as a means of protecting staff, family members and other residents from potentially dangerous and aggressive situations.

A consideration of the literature suggests that the biomedical approach to dementia may have inadvertently influenced public perception of the disease. De Vugt & Droes (2017) note that this approach focuses on the limitations of the individual, which in turn contributes to a negative discourse around dementia. A recent review of non-pharmacological treatments for behaviours such as agitation and aggression in people living with dementia concluded that this approach appeared to be more effective than pharmacological treatments (Alzheimer's Association, 2020).

2.8 **Dementia: Valuing the Person**

> Personhood is a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust. Both the according of personhood, and the failure to do so, have consequences that are empirically testable
>
> (Kitwood, 1997, p.8).

Dementia is associated with many challenging behaviours and nonpharmacological approaches to treating the illness require implementation in all care settings (NICE, 2018). While accepting that there have been advances in dementia care through the biomedical model, it should also be acknowledged that the overemphasis on this approach, which predominantly focuses on the limitations of the individual, tends to ignore the person as a whole (Canning & Blakeborough, 2019). It is important, therefore, that interventions for managing dementia should also focus on the quality of life of the individual.

Kitwood emphasised the need for a shift from ‘person with **DEMENTIA** to **PERSON** with dementia’ therefore recognising people who are living with dementia in their full humanity (Kitwood, 1997, p.7). Sabat (2005) has noted the importance of including the person with dementia in decision-making, yet also notes that receiving a diagnosis can negatively position the individual within this decision-making process. Further research, such as that undertaken by Øksnebjerg et al. (2018) has highlighted that a person with dementia may take part in studies around the disease in order to gain something personally. Øksnebjerg et al. (2018) argue that they also do so as an altruistic means of educating others about dementia and contributing towards changing perceptions around the condition.

Kitwood’s (1997) emphasis on how social interactions in a caring environment profoundly affect the person with dementia reinforces the need to recognise self-identity in dementia care and encourages further implementation of a more person-centred approach. In addition, he argues that the needs of people living with dementia must be balanced with respect for the well-being and personhood of the care staff as a means of ensuring that those living with dementia receive effective care. The following section explores the lead role which care staff play in dementia care.

2.8.1 Care Staff in Dementia Care

Research carried out by Kadri et al. (2018) emphasised that care staff play a lead role in delivering programmes of person-centred care to those living with dementia. Previous research undertaken by Kim & Park (2017) highlights that investment in the learning and skills development of care staff is pivotal in the successful implementation of such programmes.

Close professional care relationships are a key component in maintaining the personhood of people living with dementia as well as improving care quality (Smebye & Kirkevold, 2013; Milte et al., 2016). Programmes and interventions aimed at assisting those living with dementia are less likely to be implemented or to be successful when staff feel undervalued, morale is low, a service is understaffed or when insufficient time is allocated to the programme (Boyden, 2015; Lawrence et al., 2016; Rapaport et al., 2017; Kadri et al., 2018). Previous research conducted by Testad et al. (2010) and Franklin (2014) identified that many care staff are poorly trained, low paid, and work in high pressure situations where staff shortages and high staff turnover are common.

Melhuish et al. (2017) found that collaboration between care staff and those delivering arts-based activities has the potential to enhance relationships between client and staff while simultaneously increasing staff well-being. The research indicated that participation in a dance activity enables the person living with dementia to become more talkative and engaged in their social environment. This research emphasised that staff who participated in DMT sessions with people living with dementia discovered capabilities and emotional responses as well as an increased sense of connection with people in their care.

Psychosocial effects from arts-based activities have the potential to enhance relationships between care staff and those living with dementia. This is explored in more detail in the next section.

2.9 **Psychosocial Effects**

There is a paucity within health research literature which provides a definition of the term 'psychosocial' as noted by Martikainen et al. (2002) and Vizzotto et al. (2013). For the purposes of this research, the definition of 'psychosocial' provided by the Oxford English Dictionary (2021) was deemed the most appropriate for this project by the researcher. It states that 'psychosocial' means 'pertaining to the influence of social factors on an individual's mind or behaviour, and to the interrelation of behavioural and social factors' (OED, 2021).

Dunkel & Harbke (2017) and Volkmar (2020) discuss Erikson's (1963) theory of psychosocial development and how social interaction and relationships play a role in the development and growth of human beings. Providing for the psychosocial needs of the individual facilitates the provision of high-quality dementia care (Edvardsson et al., 2008; Cook & Manthorpe, 2009; Hansen et al., 2017) as it allows care plans to be developed which take care needs outside of the medical sphere into consideration (Hansen et al., 2017).

Kitwood (1997) emphasised that psychosocial interventions are key to maintaining the personhood of the individual living with dementia while also identifying that such approaches can build positive relationships between those with dementia and their care staff. Vernooij-Dassen et al. (2010) and Hansen et al. (2017) identified that such interventions have the potential to enhance the quality of care as well as the quality of life of those living with dementia.

Hunter et al. (2016) identify that psychosocial interventions include a variety of non-pharmacological approaches when working with people with dementia. The National Dementia Strategy (NDS) (2014) echoes the viewpoint put forward by Kitwood (1997) which recognises the importance of maintaining the personhood and citizenship of the individual with dementia:

> The Irish National Dementia Strategy seeks to progress the dual and overarching principles of personhood and citizenship by enabling people with dementia to maintain their identity, resilience and dignity and by recognising that they remain valued, independent citizens who, along with their carers, have the right to be fully included as active citizens in society
>
> (Department of Health, 2014, p.12).

The NDS (2014) was designed to improve the lives of people living with dementia and their carers in Ireland (Department of Health, 2014). The strategy directs specific attention to integrated services, supports and care for the individual and their carers, as well as on appropriate training for those assisting people with dementia. The recognition of these supports and services in the strategy can be viewed as an acknowledgement of the importance of the psychosocial needs for those living with dementia in Ireland.

2.10 **Reminiscence Therapy**

One type of intervention that may contribute psychosocial benefits to those living with dementia is reminiscence therapy. The development of reminiscence work can be traced back to Butler (1963). Norris (1986) as cited in Woods et al. (2018) suggests that reminiscence therapy was first introduced into dementia care in the late 1970's. McKeown et al. (2006) and VandenBos (2006) describe reminiscence as the use of written or oral life histories to improve an individual's psychological well-being and note that this technique is often used with people living with dementia.

Brooker & Duce (2000, p.354) state that reminiscence therapy ‘involves the sharing of memories often evoked through the use of stimulating material such as old pictures, songs, household items and newspapers’. Scales et al. (2018) and Woods et al. (2018) further propose that reminiscence therapy involves the discussion of past events and experiences with another person or group.

The Social Care Institute for Excellence (2021) suggests that life story work and reminiscence are inextricably connected. McKeown et al. (2010) found that life story work has the potential to enable the person living with dementia to be heard both verbally and non-verbally as well as enabling care staff to see the person behind the dementia. Life story books are increasingly popular in dementia care (Subramanian & Woods, 2016) and can help the individual ‘recount and evaluate his or her life story in chronological order’ (Subramaniam et al., 2014, p.363).

The creation of a life story book (either by the person with dementia or a relative) can produce psychosocial benefits for the person with dementia living in a care home setting, such as improvements in mood and positive effects on communication and interaction, (Haight et al., 2006; Woods et al. 2018) and ‘appears to be a valuable therapeutic approach to aid a person living with dementia’ (Subramaniam et al., 2014, p.374).

Testad et al. (2014) and Woods et al. (2018) noted that reminiscence therapy has had a positive influence on improving the mood of the person with dementia while also decreasing levels of agitation for the individual. Blake (2013) and Keating et al. (2018) advocate for reminiscence activities as a means of improving the mental health and quality of life of the person with dementia. Woods et al. (2018) suggest that reminiscence therapy may be suitable for people living with dementia because their long term memory is often more accessible than their short term memory.

In this current study, the adaptive Céilí dance activity may enable the person living with dementia to reminisce on past experiences of attending Céilí events, thus aligning with reminiscence activities. In addition, it is anticipated that information obtained from observing and recording this information via this project may enable care staff to better tailor person-centred care plans for those living with dementia.

Arts-based interventions may provide an opportunity for the person living with dementia to reminisce. The arts-based approach has been shown to provide positive outcomes for the person with dementia (Moss & O' Neill, 2017). This will be explored further in the next section.

2.11 **Arts-based Interventions**

Arts-based interventions are becoming increasingly popular in dementia care with several studies demonstrating the positive effects of such interventions for people living with dementia and their carers (Gerdner, 2000; Rylatt, 2012; Sole, 2014; Zeilig, 2014; Wu, 2015; Brooker, 2016; Young, 2016; Robertson & McCall, 2018). Douglas et al. (2004) recommend arts-based interventions for people living with dementia as a means of providing meaningful stimulation, social interactions and improvements in self-esteem.

Bedard et al. (2011) found that psychosocial interventions, such as arts-based activities, have been shown to have the potential to improve both the quality of life of people with dementia as well as the quality of care of people with dementia. Regier et al. (2017) identify that participation in meaningful activities (e.g. arts-based activities) have been shown to improve the quality of life of the person living with dementia while showing a reduction in behavioural symptoms. In addition, Kontos & Grigorovich (2018) highlight that arts-based programmes offer an alternative approach to dementia care and have been shown to reduce BPSD. This strengthens the argument that a focus on non-pharmacological approaches can be a successful alternative for treating the disease, while prioritising the individual and their needs throughout the whole process.

An arts-based approach can take many forms such as song, music (Sole et al., 2014; Cheung et al., 2018; Scales et al., 2018), and animal assisted therapy (Ashley et al., 2016) to name just a few. For the purposes of this research, this section will concentrate on dance, and more specifically Irish dance and Irish Céilí dance, as an arts-based intervention.

2.11.1 Dance as an Arts-based Intervention

This study does not look at the effects of Céilí dance on cognition for people living with dementia. Other arts-based activities have, however, shown positive cognitive effects for people living with dementia. These arts-based activities include music therapy (Moreno-Morales et al., 2020), storytelling (Lin et al., 2020), participatory visual arts (Cavalcanti Barroso et al., 2020) and dance interventions (Chan et al., 2020; Charras et al., 2020).

There has also been a large volume of research which identifies other benefits of dance as an arts-based intervention for people living with dementia. As shown in Table 5 below, the potential benefits arising from an arts-based intervention for people living with dementia vary according to the perspective from which they are studied. The benefits from a clinical psychologist's perspective can include decreased agitation and an improvement in mood and memory. From a DMT perspective, the potential therapeutic benefits can include an increase in reminiscent emotional responses, enhanced use of breath, heart-beat regulation and an improvement in mobility, agility and balance.

Table 5: Potential therapeutic and clinical benefits of Dance as an Arts-based Intervention for people living with dementia:

Potential Therapeutic and Clinical benefits
Stimulates different areas of the brain
Improved memory and mood
Evokes reminiscent emotional responses
Decreased agitation
Improved mobility and balance
Improved cognition

Adapted from: Palo-Bengtsson & Ekman, 2002; Pearse, 2007; Hamill et al., 2012; Abreu & Hartley, 2013; Foster, 2013; Lapum & Bar, 2016; Guzmán et al., 2017; Ho et al., 2018; Kontos & Grigorovich, 2018; Mabire et al., 2018; Skinner et al., 2018; Fong et al., 2020.

Many dance interventions are therapeutic in nature and have reported numerous positive outcomes for those living with dementia (Pearce, 2007; Foster, 2013; Ho et al., 2018). Ho et al. (2018, p.561) highlight that DMT 'is a mind-body intervention that integrates physical elements of exercise and psychosocial therapeutic components'.

Pearce (2007) advocates that DMT is beneficial for mood and memory among older people with a cognitive impairment as it creates an enhanced rhythmic movement. Hayes & Povey (2010, p.82) propose that 'rhythmic music wakes us up and helps us feel ourselves inside our bodies'. Brennan (1999, p.14) suggests that the rhythm of the dance is 'the most insistent beat of Irish life'.

Foster (2013) found that DMT stimulates different brain areas which are associated with memory and motor skills while Ho et al. (2018) propose that participation in DMT may evoke reminiscent emotional responses for the individual.

DMT has also provided positive outcomes for care staff in dementia care. Kowarzik (2006) found that DMT had the potential to create a new avenue of communication between staff and people living with dementia. Guzman-Garcia et al. (2012) linked participation in a dance activity to an increase in staff care skills and the enhanced facilitation of social interactions in a care facility

Kontos & Grigorovich (2018) argue that research on dance in the context of dementia care focuses primarily on its therapeutic and clinical benefits. Their research strengthens the findings of previous studies undertaken by Hamill et al. (2012) and Abreu & Hartley (2013) which also propose that research on dance in dementia care focuses primarily on its therapeutic and clinical benefits. They also propose that secondary consideration is given to other benefits such as empowerment, communication, self-expression, enjoyable experience and sociability (Palo-Bengtsson & Ekman, 2002; Guzmán et al., 2017).

Kontos & Grigorovich (2018) argue that the enrichment that dancing brings to the human life is overlooked in research and practice as it is viewed exclusively as a ‘therapeutic aid’ (Kontos & Grigorovich, 2018, p.719). In addition, Lapum & Bar (2016) identify dance activities as a complementary approach which provides people living with dementia with opportunities to connect with others irrespective of cognitive and social challenges associated with dementia. Skinner et al. (2018) identify that dance activities can provide opportunities for physical touch and connection. Dupis et al. (2016) state that arts-based activities, such as dance, can challenge the dominant ideas which surround dementia and ‘support the development of new forms of mutual support, caring and relating between persons living with dementia and others’ (cited in Skinner et al., 2018, p.3).

Dance activities are inherently interactive (Coaten & Newman-Bluestein, 2013), and can increase movement and mobility in people living with dementia (Smith et al., 2012). Dance interventions are often used with people living with dementia in care settings as they are viewed as a pleasant social activity (Mabire et al., 2018). Such interventions embrace non-verbal communication, affect and embodied expression (Kontos & Grigorovich, 2018).

Table 6: Potential Social benefits of Dance as an Arts-based Intervention for people living with dementia:

Potential Social benefits
Pleasant social activity
Embraces non-verbal communication
Embraces affect and embodied expression
Improved memory and mood
Improved mobility and balance

Empowerment
Self-expression
Sociability
Connection with others

Adapted from: Palo-Bengtsson & Ekman, 2002; Pearse, 2007; Hamill et al., 2012; Abreu & Hartley, 2013; Foster, 2013; Lapum & Bar, 2016; Guzmán et al., 2017; Ho et al., 2018; Kontos & Grigorovich, 2018; Mabire et al., 2018; Skinner et al., 2018; Fong et al., 2020.

Studies have identified that participation in arts-based activities such as dance, which includes those with dementia and care staff, can enhance communication, social interaction and enjoyment for all involved (Guzmán-García, 2012; Young et al., 2016). Skinner (2018) further highlights that research into the experiences and effectiveness of arts-based programmes for social inclusion for people living with dementia and their carers is largely absent, which this current study hopes to address.

2.11.2 Irish Dance as an Arts-based Intervention

Parkinson's disease is a progressive neurodegenerative condition affecting movement and gait functions in the early stages of the condition, and cognitive function in the later years (Armstrong & Weiner, 2014). Similarities may therefore be drawn between Parkinson's disease and dementia in that they are both progressive conditions which can affect an individual's cognitive function, movement and balance. In addition, Lewy Body dementia is a type of dementia that shares characteristics with Parkinson's disease and Alzheimer's disease (ASI, 2021d).

Research has shown that Irish dance has provided positive outcomes when used with people living with Parkinson's disease. The research undertaken by Volpe et al. (2013) and Shanahan et al. (2015; 2016), for example, concluded that community-based Irish dance was a feasible form of exercise that reported improvements in balance and improved the quality of life of the participants living with Parkinson's disease.

Silvester & Frampton (2014) highlight that elderly people enjoy traditional folk dancing and that it provides a valuable opportunity for reminiscence work. Kelly (2017) identified Irish dance as a vehicle used by older people for self-discovery, to heal, and to reminisce. Research undertaken by Allen (2003) which focused on Irish Céilí Dance and elderly dancers concluded that:

> Irish Céilí dance has rich and varied meanings for elderly dancers, ranging from its perceived health benefits, its stimulus to reminiscence, its connection to culture, and its usefulness as a vehicle of socialisation
>
> (Allen, 2003, p.121).

The research centred on Parkinson's disease and older dancers suggests that an Irish dance activity with people living with dementia may also result in similar positive outcomes, and thus providing a rationale for the selection of Irish Céilí dance as the vehicle for field work in the current project.

2.12 **Irish Céilí Dance and the Céilí Event**

There is a paucity of literature available which provides a definition of Céilí dance. For the purposes of this research, Céilí dance refers to vernacular, noncodified, couple dances performed in the social and recreational context of an event known as an Irish Céilí.

The Irish Céilí holds an important place in forming a sense of identity, community and belonging for many Irish people. Research undertaken by Allen (2003) has shown that the Céilí is seen as a method of socialising, a connection to one's culture as well as providing a stimulus for reminiscence among older people.

There are two different types of social Céilí which the participants living with dementia in this research are likely to have experienced, given their age profile and ethnicity (see Section 4.7). These are events run under the auspices of the Gaelic League, and those which are not. Both of these Céilí event types encompass a fun element centred around social Céilí dancing for those in attendance. While the Gaelic League Céilí event involved codified Céilí dances only, the social Céilí event was viewed as a more fluid and recreational event which welcomed a range of differing dance styles.

2.12.1 The Social Céilí

O hAllmhurain (2005) notes that social dances were part of Irish culture before the Gaelic League was founded in 1893 and that people danced at a myriad of locations such as in households, at crossroads and in unlicensed dancehalls throughout the towns and villages of Ireland. He further emphasises that house dances were a means of connection and support within a community as they were often used to raise money for 'destitute families' (O hAllmhurain, 2005, p.10). The social Céilí included differing dancing styles (Phelan, 2015), which included, but were not limited to set dancing, waltzing, and sean-nós dancing.

2.12.2 Public Dance Hall Act 1935

The Public Dance Hall Act 1935 was introduced by the Irish government and restricted public dances to legally approved dance halls which required a licence to be sanctioned by local district judges (Phelan, 2015; Porter, 2018). The act is viewed as a significant factor in the decline in house dances and crossroad dances across Ireland and resulted in public dances moving to licensed dance halls.

2.12.3 Sense of Community

The influence of Céilí dance in instilling a sense of community and cultural identity is, according to Allen, (2003) and Foley (2011), evident in the titles of dances such as *The Siege of Ennis* and *The Walls of Limerick.*

Given the age profile of the people living with dementia who participated in this research, the period of the 1950s and 1960s coincides with their formative years. Around this time, one of the main sources of entertainment in Irish households was listening to the radio. Radio Éireann, the only Irish radio station at the time, prioritised Irish music over other types of music at the time (McKenna, 2015). One particular programme, namely *Take the Floor* (RTÉ Archives, 2020), gave the listening audience the opportunity to listen to the tapping feet of Irish dancer Rory O Connor. During a conversation held between the researcher and his dance teacher, the researcher was informed that Rory O Connor became a household name across Ireland largely as a result of his participation in this show. McKenna identifies that this programme provided families and communities with an opportunity to gather together and listen to the dancing feet of Rory O Connor who became known as the ‘Man who Danced on the Radio’ (McKenna, 2015).

The popularity of *Take the Floor* was such that it was extended to an hour long show as opposed to the regular time limit for programmes of between fifteen and twenty minutes. The programme featured Irish dance music, with the bands, singers and dancers performing in the traditional style (RTÉ Archives, 2020).

Shanagher (2014) highlights that due to the lack of mobility and cars in Ireland in the 1940's and 1950's, entertainment tended to be localised, with concerts and plays taking place in local halls. Rory O Connor, the 'Man who Danced on the Radio', regularly topped the bill at these concerts (McKenna, 2015). Shanagher (2014) noted that social dances were community events which 'even when it took place on a frequent basis, retained the character of a 'special occasion' (Shanagher, 2014, p.73).

Céilí dances have provided opportunities for Irish people to interact socially and culturally (Leonard, 2005; Foley, 2011) and 'express their identity and cohesion' (Foley, 2013, p.135). The Céilí event also played an integral part in instilling the Irish identity, not just for those living in Ireland but for Irish emigrants attending Céilí events abroad in such locations as the United States, Great Britain, Australia and so on (Foley, 2011). Of note is that the popularity of ballrooms in Ireland was mirrored by the popularity of the Céilí in America which was the new home of many Irish immigrants (Phelan, 2015).

2.12.4 Sense of Identity

Foley (2011) asserts that the Céilí event was a tool used by individuals to shape their identities. The Public Dance Hall Act of 1935 contributed to a new sense of freedom and identity for the youth of Ireland at this time. Young people saw this restriction placed on licensed dancehalls as an opportunity to explore new experiences which were previously beyond their reach. Many of the youth living in rural Ireland deserted the traditional dances which they were accustomed to in exchange for the 'Ballrooms of Romance' and modern dance which were becoming increasingly popular (Phelan, 2015). After numerous attempts by the Gaelic League, jazz was eventually banned from the national airwaves by the early 1940's (O'

Fearail, 1975) which meant that the only way to experience this style of dance was by attending the ballrooms. These dancehalls facilitated all types of dances which offered those attending the opportunity to dress up, drink and ‘court’ unsupervised (Phelan, 2015), something which was not conceivable for those attending Céilí events under the conditions imposed by the Gaelic League.

Young people were no longer confined to attending dances which were governed by the Gaelic League and as a result were in a position to participate in other styles of dance. The popularity of dancehalls spread throughout the country.

2.13 **Conclusion**

This chapter has identified the increasing prevalence of dementia from a global and Irish perspective. It provided an exploration of published literature which identified the expectations placed on professionals involved in dementia care at different stages of the condition. The importance of receiving a timely diagnosis and addressing the challenges faced by those tasked with confirming a diagnosis were highlighted.

The availability of post-diagnostic supports and services was examined, including the inequality of access to these services throughout the country. This disparity of access to such dementia specific services provides a barrier for the Irish person living with dementia and their family in adjusting to the changes which dementia brings. The loss and grief experienced by the person living with dementia as well as that experienced by their family was also explored. The losses experienced within dementia are some of the most significant and unrecognised issues faced by people living with the condition and their families. The stigma experienced by a diagnosis of dementia which suggested that this is largely a result of a lack of public understanding, the prevalence of stigmatising language and general misconceptions around dementia, was highlighted.

The bio-medical approach to dementia care has been the dominant force in caregiving for dementia; however this chapter noted that the non-pharmacological approach to dementia care is becoming increasingly popular. This shift in thinking and practice to person-centred care and less medicalised approaches was discussed. These social and environmental therapies can improve the quality of life experienced, as well as the quality of care received, by the person living with dementia.

This literature review noted that arts-based interventions when properly conceived and implemented can provide positive experiences for people living with dementia and their families and carers. Arts-based interventions can provide the person living with dementia with meaningful stimulation, positive social interactions, improvements in self-esteem and an opportunity to reminisce. In particular, dance as an arts-based intervention had significant benefits to the person living with dementia and spanned across the social, clinical and therapeutic areas of the condition.

Irish Céilí dance as an art-based intervention for people living with Parkinson’s Disease and older dancers has resulted in positive outcomes. It was noted that similarities can be drawn between Parkinson’s and dementia in that they are both progressive conditions which can affect the cognitive function of the individual as well as movement and balance. The research on Parkinson’s disease and older dancers suggests that an Irish dance activity with people living with dementia may also yield positive outcomes.

A definition of Irish Céilí dance for the purposes of this research was provided. The role of the Irish Céilí event in creating a sense of identity and community for those who attended was explored. It can be argued that a dance intervention connected to Céilí dance could be culturally relevant for people living with dementia in Ireland.

In summary, there is a dearth of research exploring the psychosocial effects of the introduction of an adaptive Irish Céilí group dance activity with people living with dementia and their care staff. It is intended that this research project, will provide new knowledge in this area and partially serve to address this gap.

3 Chapter 3: Axiology

3.1 Introduction

Given (2008) identifies axiology as a term used to cover a philosophy of values and represents an attempt to bring the varied and contrasting discussions of values under a single heading. The author recognizes that this viewpoint covers ‘a wide area of critical analysis and debate that includes truth, utility, goodness, beauty, right conduct and obligation’ (Given, 2008, p.2).

This chapter looks at the axiological concerns within this research which explore my personal, educational and professional connections to the project. The use of a reflective journal as discussed in this chapter enabled me to document and reflect on prominent and emotional areas of the research. It highlights the importance of recognizing my potential biases and positioning as a social sciences researcher within the project. This chapter also alludes to ethical arguments and tension I encountered at various stages of this research. These ethical challenges are explored in more detail in the Methodology chapter (Chapter 4).

3.2 Researcher Profile

I have a personal, educational and professional connection to this research project. To accurately capture my educational and professional connections, it is important that I first identify my personal connection to this research.

3.2.1 Personal Connection to the Research

My knowledge of dementia was non-existent until early August 2004. This is when my Mother received a diagnosis of early-onset dementia. She was 50 years of age. Overnight, the dynamics of our relationship changed forever. I became my

Mothers' primary carer and remained in that role for more than 10 years until her death in July 2016. While the diagnosis changed the dynamics in our relationship, it brought us closer together than ever before. A bond was created which is difficult to describe. I learned to be more patient, kind, caring, and to love someone unconditionally. Many of these skills were instrumental in enabling me to complete this research.

As a carer for my Mother, I was lost. It was not a role I had chosen. It was something about which I knew little. In fact, I did not recognize myself as a carer until many years later. I was her son. I will always identify as her son.

My Mother always loved to dance. Some of my earliest memories are going to dances with my Mother. I remember the joy and social connection that took place at these events; I was part of it. These dances were social Céilí dances and although I did not know it in my youth, dance would play an important role in our relationship and our journey through dementia.

My Mother was a regular visitor to my primary school as she taught Irish dancing to each class. This embarrassed me somewhat and I never committed to these classes or to learning the steps and dances which she taught. This would be something I would later regret as I had to attend dance classes in order to facilitate the dance activity within this research:

> ***I should have paid more attention to Mom when she was teaching me how to dance. She would be laughing at me now and telling me how she is always right***
>
> (O Shea, Reflective Journal, 12th September 2019).

After my Mother's diagnosis of dementia, my reluctance to take part in dancing disappeared when I was with her. We would regularly dance around the sitting room at home. She would correct my steps and the positioning of my feet, while praising me when she could. These memories are some of the most powerful that I have of my Mother and me. They are personal and filled with emotion. As my Mother's dementia progressed, her mobility and cognition deteriorated. The dancing remained. We danced when we could, and we learned to chair dance. These experiences instilled in me an appreciation that participation was not solely about dancing around the floor but could be achieved by being present, seizing the moment.

As our journey with dementia progressed, I became more interested in dementia care and the services available to those affected by the condition. I took a lead role in advocacy as a volunteer with the ASI and committed myself to raising public awareness around dementia. I also wanted to educate myself in the area of social care, which I believed would proactively enable me to become a better, more informed advocate for those living with dementia and their carers.

3.2.2 Educational and Professional Connection to the Research

My academic connection to this research began in 2010 at LIT where I commenced my undergraduate degree in Applied Social Studies in Social Care. This was a challenging but rewarding experience. I was challenged with attempting to be my Mother's primary carer while simultaneously pursuing my educational goals. I learned that I had to accept help from others if this was to be achieved, for which I will always be grateful. The experience helped me to grow academically but also personally. My focus remained primarily on dementia, both personally and academically. My final year thesis was titled*: An Exploration of the Lived Experience of those Caring for a Family Member with Early-Onset*

Alzheimer's Disease. I was rewarded in 2014 when I obtained a first class honours degree. This achievement is special as it belongs to my Mother and me.

We danced together when I received the results.

My educational achievements enabled me to achieve a career in the social care arena and I am currently working as a Dementia Advisor with the ASI. My primary responsibility in this role is to be a point of contact on an outreach basis for people who are concerned about their cognitive health and/or have a diagnosis of dementia, and for their families and friends. My journey from my Mother's diagnosis in 2004 to this present point has challenged me more than I could have ever imagined, but it has rewarded me all the more.

3.3 **Reflexivity, Bias and Positionality**

While conducting the research, I was grappled with some dilemmas, namely researcher bias and positionality. Throughout the research process, these dilemmas crossed paths. This led me to challenge my own biases and positioning within the research. My personal, educational and professional experiences have undoubtedly influenced this research project. It was important for the integrity of this research that I was transparent throughout the entirety of it. This was achieved by keeping a reflective journal which I used throughout the research project. The reflective journal provided me space and opportunity to write down my feelings and emotions which were prominent during the research.

3.3.1 Reflexivity

> Through reflexivity, researchers acknowledge the changes brought about in themselves as a result of the research process and how these changes have affected the research process
>
> (Palaganas et al., 2017, p. 426).

Berger (2015) argues that researchers need to be self-aware and monitor the impact of their biases, beliefs and personal experiences on their research. Although reflexivity is viewed as a continuous process applied throughout the entirety of the research, it should be acknowledged that researcher positionality may influence the research process. This emphasises the requirement to be open and transparent form the beginning of the process. Throughout my research, I kept a reflective diary which enabled me to remain aware of the impact that the research was having on me, that I was having on the research, and potentially on any conclusions drawn.

In addition, I met regularly with my supervisors which gave me an outlet to reflect on any issues I encountered. I had access to a counselling service in LIT if required as well as support from the ASI through my association with the organisation. These supports were important for me to be able to offload stress and emotional difficulties I encountered and to be able to look at my potential biases across this very personal project.

3.3.2 Capturing, Reflecting and Acknowledging Feelings Evoked

I supported the use of a reflective journal form the beginning of the research but I was surprised with the reflections I captured in it. The reflective journal provided an outlet which enabled me to capture, reflect and acknowledge the impact which the research was having on me, in areas which I did not predict:

> ***While dancing with Mary today, I found myself being transported back to when I was dancing with my Mother. Mary has a resemblance to my Mother and a similar smile. And as we danced, we made eye contact and I found myself back in our living room waltzing with my Mother. I was left with mixed emotions because the experience unearthed some feelings of happiness and some of sadness***
>
> (O Shea, Reflective Journal, 29th November, 2020).

> ***I was dancing with Sheila today and I noticed a white vest that she was wearing. It had a little bow on the centre of the neck piece. In that moment I found myself very vulnerable as it reminded me of the vests which my Mother always wore***
>
> (O Shea, Reflective Journal, 20th December 2019).

Acknowledging these feelings enabled me to recognise my emotions and the influence which the research was having on me.

During the process of transcribing the interviews, my reflective journal highlights my previously unconscious feelings around this process. It reflects my commitment to immersing myself in this process as a means of respecting those who agreed to participate in this project:

> ***Transcribing the interviews is proving extremely time consuming. Some of the interviews with those living with dementia are difficult to comprehend and I find myself replaying sections to attempt to capture their voices correctly. My wife advised me that I should get a professional to transcribe the interviews. To be honest, I think to do so could mean missing out on some important tones and feelings which I believe can only be captured by immersing myself in these conversations. I also think to get someone else to do so would be disrespectful to those who allowed me to interview them***
>
> (O Shea, Reflective Journal, 20th March 2020).

The reflective journal also made me recognise areas which reflect my stubborn nature. Throughout the research, when referring to a person living with dementia, I used exactly that title **person living with dementia**. I believed that to use the acronym PLWD (a term used when referring to people living with dementia) would be disrespectful and contradict my belief that the person needs to be highlighted before the dementia. This simple act made me recognise something very similar that I have done since writing about my Mother. I use a capital M whenever I write Mother. This was something which I had done subconsciously until I became aware of it in the process of this research. It is something which I continue to do as I see it as a sign of the respect and honour which I have for my Mother.

3.3.3 Acknowledging Potential Biases within the Research

When conducting qualitative research, the researcher is most often the key person obtaining information from those being interviewed. This may potentially increase the possibility of bias within the data collection. For example, I found that both Irish music and dance positively influenced my Mother's journey with dementia therefore steering my outlook on these activities as primarily positive ones. However, I am also aware that each person living with dementia may have different experiences, and activities such as dance may have the potential to elicit contrasting emotions from each participant.

While my position as the researcher was clear that this process may elicit potential biases, I was confident that this bias could be utilised, enabling more transparent and honest conclusions to be drawn form the data analysis, a position suggested by Poggenpoel & Myburgh (2003). This is a position shared by Chenail (2011, p. 255) who states that 'interviewees can contribute their insiders' perspective with little or no limitations imposed'. Mehra (2002) acknowledges that bias in qualitative research is important and requires special attention. Research undertaken by Galdas (2017), argues that the researcher is an integral part of the overall qualitative research process and any attempt to remove this bias from the research is not possible or desirable. Semi-structured interviews were instrumental in enabling me to probe, where needed, as well as enabling the interviewee to expand where required or desired.

3.3.4 Positionality within the Research

> 'Despite the influence of one's theoretical and cultural viewpoints and the importance of acknowledging ones biases, researchers rarely address their position in their research'
>
> (Greene, 2014, p. 1).

As the researcher, I encountered a conundrum during this research. Naples (2003) has argued that insider research can be defined as the study of one's own social group or society. Asselin (2003) proposes that insider research can be viewed where the researcher shares an identity and experiential base with the study participants. Having previously cared for my Mother who had a diagnosis of early-onset Alzheimer's disease, my research position could be seen as that of an insider. However, as this specific research involves conducting interviews with people with a diagnosis of dementia, I can also be seen as an outsider as I do not have a diagnosis of dementia. While there are benefits and challenges to both positions, there is a third position, which Dwyer & Buckle (2009) refer to as 'the space between' which 'challenges the dichotomy of insider versus outsider status' (Dwyer & Buckle, 2009, p. 60). This was the stance I tried to adopt throughout this work. Milligan (2016) argues researchers are never entirely an insider or outsider as they take on different positioning throughout the research process.

3.4 **Conclusion**

This chapter explored the axiological concerns within this research which identified my personal, educational and professional connections to the project. Keeping a reflective journal regularly enabled me to document and reflect on prominent and emotional areas of the research and to begin to note potential biases and positioning within the research. The next chapter explores how the research was designed and implemented, including the ethical dilemmas that arose across the span of the project.

4 Chapter 4: Methodology Chapter

4.1 Introduction

This chapter outlines the design of the research project and particular methods chosen. The ontological and epistemological approaches used within the study are highlighted to strengthen the researcher's position of investigating the lived experience of those with a diagnosis of mild to moderate dementia. Additionally this chapter will take into consideration alternative approaches which could have been utilised for this research. It outlines why the epistemological position taken was an interpretivist one which was achieved through a qualitative approach, namely semi-structured interviews and the dance activity. The profile of the research participants in this research is identified in this chapter. The dance activity and the adapted dance formations are explored in this chapter, with the Céilí dance of 'Shoe the Donkey' utilised to emphasise the need for, and process required in, making the necessary adaptations. This section identifies the nature of the ethics and ongoing consent processes involved in the research and highlights how they were addressed and negotiated. The limitations of the research are also identified in this chapter.

4.2 Ontology

According to Blaikie (2007), ontology is a branch of philosophy that is concerned with the nature of what exists. Similarly, Killam (2013), notes that ontology 'refers to the study of our existence and the fundamental nature of reality or being' (Killam, 2013, p.7).

Ritchie et al. (2014) highlight that there are two overarching ontological positions in relation to social science, namely realism and idealism. These two positions differ significantly. Realism proposes that there is an external reality which exists independently of people's understanding of it (see, for example, Ritchie et al., 2014; O' Leary, 2017; King et al., 2019). Idealism proposes that reality can only be understood via the human mind and socially constructed meanings, and that no reality exists independently of these (Blaikie, 2007, Ritchie et al., 2014). The researcher supports the latter approach namely idealism, and therefore this research was guided by the position that no external reality exists independently of our beliefs and understandings.

4.3 **Epistemology**

Epistemology is concerned with the nature of knowledge and how it can be acquired (Ritchie et al., 2014). It can be further defined as a theory of how human beings come to have knowledge of the world around them (O' Leary, 2017). Furthermore, Blaikie (2007), argues that epistemology offers an answer to the question: 'How can social reality be known?' (Blaikie, 2007, p.18), and is central in any methodological approach (King et al., 2019).

The epistemological position taken within this research was that of interpretivism. Ritchie et al. (2014), propose that there are ways of learning about individuals rather than through direct observation. They emphasised the importance of understanding and studying peoples lived experiences. In contrast to this approach, positivism asserts that human beings are part of nature and therefore can be studied in the same way as other objects in the physical world (King et al., 2019). This approach assumes that human behaviour can be reduced to variables and measured via statistical analysis (King et al., 2019). As this research topic is concerned with exploring the lived experience of participants, an interpretivist approach is of more significant value to the researcher than that of the positivist approach.

4.3.1 Quantitative Research

> The quantitative tradition is based on a belief that the study of society is no different than the scientific study of any other element of the world- from particles to animals
>
> (O'Leary, 2017, p. 134).

A quantitative approach will usually have one or more hypotheses prior to conducting the research (Alzheimer Europe, 2019), a position with which this researcher did not agree.

A quantitative approach to research, such as that undertaken by Clare et al. (2014), uses methods such as questionnaires and surveys to capture data. Its use would have enabled this researcher to reach a larger group of participants over a wider geographical area. While online questionnaires and/or surveys could have provided statistical information on the psychosocial effects arising from this research, this would not capture the information that can only be achieved through a qualitative approach, such as speaking with and exploring the lived experiences shared by the research participants. As the quantitative approach is considered more objective in nature and does not take into consideration the subjective nature of this research, the researcher concluded that this approach was not suitable for this particular topic.

It was the view of this researcher therefore that a qualitative approach was the more appropriate approach to pursue as it enabled both the researcher and research participants to provide clarity where possible around any areas of ambiguity, while also enabling the researcher to gain a more accurate insight in to how each participant interpreted and viewed the world which in which they live.

4.3.2 Qualitative Research

O' Leary (2017) defines a qualitative approach to research as one which is highly reliant on data which are not quantified and may include words, images, experiences and observations. Auerbach & Silverstein (2003) suggest that a qualitative approach which uses interviewing is beneficial as it focuses more on stories than numbers. King et al. (2019) propose that this approach enables the researcher to observe and explore the chosen research topic. They argue that the best way to learn about the subjective experience of people is to ask them about it and listen carefully to what they have to say. This approach gives the researcher a better understanding of human behaviour and, in the context of this research, how people with dementia and their care staff view and interpret the world in which they live and experience:

> The qualitative tradition…strongly argues the value of depth over quantity and works at delving into social complexities in order to truly explore and understand the interactions, processes, lived experiences and belief system that are part of individuals, institutions, cultural groups and even the everyday
>
> (O'Leary, 2017, p. 142).

It should be noted that this specific research topic is not taking part in the participants' natural setting. Instead, it is taking part in a daycare centre which the participants attend. One of the benefits of a qualitative approach to research is that it is a flexible method which allowed the researcher to carry out the interviews at a time and in a setting that suited each participant. Furthermore, a key strength of qualitative research is its ability to provide complex textual descriptions of the individuals' experience of the chosen phenomena (Aspers & Corte, 2019).

Within a qualitative approach, the researcher can be viewed as an instrument for collecting data. The use of interviews enabled flexibility throughout the interview process. This flexibility could not have been achieved using a quantitative approach.

4.3.3 Observation as a research tool

The researcher's observations were utilised in conjunction with the emerging themes from the interviews as a means of strengthening the findings from this project. Observation is a method that is commonly used in anthropology, ethnography, social psychology and sociological research (Spradley, 1980; Kosso, 1998; Outhwaite, 1998; Kawulich, 2005), and is regularly used in dance research (Sims et al., 2019; Bläsing et al., 2018; Woolhouse & Lai, 2014; Spradley, 1980). McKechnie (2008, p.573) proposes that observation in qualitative research "is one of the oldest and most fundamental research methods approaches. This approach involves collecting data using one's senses, especially looking and listening in a systematic and meaningful way". While observed actions in qualitative research can be seen as problematic (May, 2011), Ritchie et al. (2014) advocate the importance of the researchers' observations stating that 'The researcher's experience of what they observe, their response to it, the physical and emotional feelings it evokes, are all part of where the value of observation lies' (2014, p.246).

The researcher concluded that the qualitative approach was appropriate for this research as it is an approach utilised to explore the chosen phenomena as opposed to the quantitative approach which seeks to confirm previously selected hypotheses.

4.4 **Phenomenology**

> ‘The person who opens her eyes and sees the world, sees it and has knowledge of it consciously’
>
> (Gallagher, 2012, p. 8).

Phenomenology is a qualitative approach to research that focuses on the lived experience of the research participants (O’ Leary, 2017). Its roots can be traced back to the German philosopher Edmund Husserl (1859-1938). Denzin & Lincoln (2005, p. 106) note that ‘A phenomenological study usually involves identifying and locating participants who have experienced or are experiencing the phenomenon that is being explored’ (Denzin & Lincoln, 2005, p. 106).

Previous research has highlighted that interviews are a popular data collection tool in phenomenological research (King et al., 2019; O’ Leary, 2017). This has cemented the researcher’s belief that this approach would yield the most accurate representations of the research participants’ lived experiences.

4.5 **Research Methods**

Kothari (2004) suggests that there are two basic approaches to research, namely the quantitative approach and the qualitative approach. While the former focuses on measuring the quantity of a phenomena, the latter focuses on investigating the reasons for human behaviour (Kothari, 2004).

4.5.1 Recruiting Research Participants

The researcher identified people willing to take part in the study by sourcing a daycare centre in the mid- west region which provides services, including respite services, for people in the early or middle stages of dementia. The host organisation was provided with an information sheet in relation to the nature of the research. The researcher also met with the management, service users and care staff of the centre on several occasions prior to the commencement of the study. The host organisation disseminated information sheets (see Appendix B, pp. 39092) to service users and their family members/primary carers as a means of sourcing those willing to take part in the study. The researcher was assisted with this process by the ASI which offered its full support for this study. Care staff in the host organisation were also recruited to participate in this research.

Alzheimer Europe (2019) suggest that participation in research around dementia should not be restricted to people with a mild to moderate diagnosis of dementia. The decision to only include participants with a mild to moderate diagnosis of dementia in this research was made following consultation with the host organisation particularly with respect to safety concerns. In particular, the fear that the dance activity may prove too dangerous due to, for example, reduced mobility for those with advanced dementia was discussed with the host organisation.

4.6 Interview Types

Selecting the most appropriate type of qualitative interview for this research process would ultimately dictate the type and depth of data achieved through the research process. There are, however, several different types of qualitative interviews which the researcher could have chosen for this research, such as focus groups, structured interviews, and semi-structured interviews.

4.6.1 Face-to-face Interviews

> The face-to-face interview is an excellent way to actively engage with the informant in a manner that narrows the gap between researcher and researched and maximises the efficacy and quality of data collection enterprise
>
> (Klenke, 2008, p. 120).

Research undertaken by Klenke (2008) and Lavrakas (2008) argue that the face-to-face interview enables the researcher to actively engage with the participant therefore maximising the quality of data collected. There are several approaches to undertaking face-to-face interviews when conducting an interview. These are outlined in the following section.

4.6.2 Focus Groups

Focus groups can be an excellent method of collecting data in relation to the lived experience of individuals, highlighting the differences in perspective between individuals and groups (Rabiee, 2004). It is also as a quicker method of interviewing. There is, however, limited published research available on the use of focus group interviews involving people with a diagnosis of dementia, and the nature of the disease may be an influencing factor in this trend.

While acknowledging that focus groups can work particularly well in determining the feelings, perceptions and thinking of people (Krueger & Casey, 2000), Pesonen et al. (2013) highlight that joint interviews may prevent participants from expressing their thoughts and concerns. Ritchie et al. (2003) propose that focus groups offer less opportunity for the individual to give a detailed perspective of their lived experience.

The researcher believed that focus group interviews may cause confusion for the person with a diagnosis of dementia therefore acting as a barrier to capturing the type and depth of data of the lived experience of each participant. As a result, individual interviews were seen as a more effective approach for this project.

4.6.3 Structured Interviews

Stuckey (2016) and O' Leary (2017) outline that this type of interview uses preestablished questions which are delivered in a predetermined order. This type of interview can resemble that of a job interview (Stuckey, 2016) or that of a questionnaire (Mathers et al., 2002). Stuckey (2016) suggests that the questions asked during these interviews tightly control the data produced by the interviewee. King et al. (2019) emphasise that a key component in successful qualitative interviewing is building rapport with your participants, which this researcher believed was not possible using this approach.

4.6.4 Semi-Structured Interviews

Alzheimer Europe (2019) propose that a semi-structured approach to interviewing enables the participant to speak freely while also allowing the researcher to ensure that certain aspects of the interview are covered. O' Leary (2017) highlights that this type of interview enables the researcher to collect data which was intended through the interview process as well as interesting and unexpected data. It was concluded that semi-structured interviews were the appropriate data collection tool for this topic.

4.6.5 Location of Interviews

The location of the interviews can have a strong influence on how it proceeds (O' Leary, 2017; King et al., 2019). The researcher therefore took guidance from the management of the host organisation regarding the physical space in which they would be conducted. It was decided that the interviews would take place in a comfortable, private and quiet room within the centre as each participant was familiar with this space. The chosen setting also allowed for little or no disruption to the audio recording process.

4.7 Profile of the Research Community

A total of twenty-five interviews were conducted over a ten-week period. All participants interviewed were Irish. Ten of the interviews were with participants living with dementia. Two participants living with dementia interviewed were male and four were female. These participants were aged between 75-91 years of age. The demographic profile of this research cohort is outlined in Table 7 below.

Table 7: Demographic of participants living with dementia

Name	**Gender**	**Age**	**Ethnicity**
Eileen	Female	80-85	Irish
Ted	Male	75-80	Irish
Theresa	Female	75-80	Irish
Vera	Female	75-80	Irish
Mary	Female	80-85	Irish
Mickey	Male	90+	Irish

A total of fifteen interviews were conducted with care staff at the centre. Of the ten staff interviewed, nine were female. The demographic profile of this research cohort is outlined in Table 8 overleaf.

Table 8: Demographic of Care Staff Participants

Name	**Gender**	**Ethnicity**
Ciara	Female	Irish
John	Male	Irish
Julie	Female	Irish
Kate	Female	Irish
Lisa	Female	Irish
Maura	Female	Irish
Niamh	Female	Irish
Rebecca	Female	Irish
Susan	Female	Irish

The care staff participants were interviewed prior to the first dance activity, at the midway point of the project and after the final dance activity was completed. The participants living with dementia, however, were not interviewed at the midpoint stage.

It is important to highlight that many of the findings in this project were of the researchers' observations of people who participated in the dance activity and not necessarily in conjunction with the interview process.

4.8 <u>Dance Activity</u>

There was a total of six adaptive Irish Céilí dance sessions. The overall aim of the dance programme was to provide a meaningful activity in which the participants could engage and which may improve the health and well-being of all participants. Zeilig et al. (2014) argue that there is a growing body of research highlighting the potential of the participative arts, such as dance, to influence the health and well-being of those living with dementia. For the purposes of this research, participation in the dance activity includes dancing, tapping feet, clapping, singing, and observing the activity.

The researcher facilitated the dance activity in the host organisation; however it should be noted that the researcher himself is not a trained dance teacher. In order to guide the necessary steps and movements for the dance activity, the researcher first had to learn them. This was achieved by attending Irish Céilí dance classes with Munster Academy of Dance. These classes enabled the researcher to learn a number of dances from which the participants living with dementia could then choose. Attendance at these classes also enabled the researcher to learn dances which could be adapted to best suit the physical and cognitive function of each participant living with dementia.

4.8.1 Shoe the Donkey

'Shoe the Donkey' is danced to in polka (3/4 timing) to the tune *Varsovienne*. This dance is regularly performed as a two-hand dance. Couples stand side-by-side, with men on the left and women on the right.

Figure 1: Formation of dancers for 'Shoe the Donkey'

OX
OX
OX

Front of room

Each O represents a participant living with dementia, X a care staff participant.

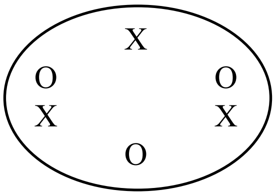
There are a number of potential ways in which partners hold hands for this dance. One such way is to cross hands (right hand in right, left hand in left underneath). Men start by raising the left foot, women with the right.

1st part: Hop a 1, 2, hop a 1, 2, hop a 1, 2 and turn (inwards to face the opposite direction) stamp; repeat this 3 more times.

2nd part: Hop a 1, 2, turn (inwards) stamp; repeat this 7 more times, forward and back.

4.8.2 Adapting the Formations

The researcher attempted to facilitate the dance activity using the formation outlined in Figure 1 during the first dance session. This proved to be an unsuccessful approach and was not suitable for the participants living with dementia due to their varying levels of mobility and cognition. This approach proved particularly difficult when each couple were required to turn inwards to face the opposite direction. This resulted in couples facing each other rather than facing the same direction and led to confusion. The researcher also observed that some of the participants appeared to be nervous attempting this approach and he concluded that this indicated a safety concern for all participants. The formation of this dance was therefore adapted into a circular formation which proved successful.



4.8.3 Adapted Formation

The researcher adapted this dance into a circular formation as shown in Figure 2 below:

Figure 2: Formation of adapted dance

Each O represents a participant living with dementia, X represents a care staff participant. This adapted formation ensured that each participant was holding hands with another participant, which formed the circle. The formation of the adapted dance ensured that each participant living with dementia (O) was holding hands with a care staff participant (X) either side of them. This enabled each participant to advance and retire together and provided an extra layer of safety to the dance.

1st part: Advance together - hop a 1, 2, hop a 1, 2, hop a 1, 2 and stamp; retire together- back a 1, 2, back a 1, 2, back a 1, 2 and stamp; repeat this 3 more times

2nd part: Advance together- hop a 1, 2 and stamp; retire together- back a 1, 2 and stamp; repeat this 7 more times.

Note taking, participating in and facilitating dance classes, as well as observing the group dynamic of an inclusive dance activity were key in preparing the researcher to facilitate dance classes with the research participants. The researcher used a speaker which was connected via Bluetooth to their mobile phone to control the music. This enabled the researcher to control the volume of the music as well as starting and stopping the music when/if required.

4.9 Thematic Analysis

> 'In order to generate findings that transform raw data into new knowledge, a qualitative researcher must engage in active and demanding analytic processes throughout all phases of the research'
>
> (Thorne, 2000, p. 68).

Braun & Clarke (2006) identify thematic analysis as 'a flexible and useful tool, which can potentially provide a rich and detailed, yet complex, account of data' (Braun & Clarke, 2006, p. 78). Nowell et al. (2017) state that although thematic analysis is widely used and can produce trustworthy and insightful findings, it is not without its criticisms. Braun & Clarke (2006, p.87) highlight that thematic analysis is time consuming as it requires repeated 'repeated reading of the data' (Braun & Clarke, 2006, p.87).

The researchers familiarity of Braun & Clarke's (2006) six guideline steps to thematic analysis (see table 9 overleaf), along with the researcher's previous use of thematic analysis as an undergraduate (O Shea, 2014) provided familiarity and confidence that thematic analysis was the appropriate approach to analysing the data.

Table 9: Braun & Clarke's six guideline steps to thematic analysis

Phase 1: Familiarising yourself with the data
Phase 2: Generating initial codes
Phase 3: Searching for themes
Phase 4: Reviewing themes
Phase 5: Defining and naming themes
Phase 6: Producing the report

Adapted from: Braun & Clarke (2006)

The purpose of thematic analysis is not only to identify common themes throughout the research, rather it is to identify those relevant to answering the chosen research question (Liamputtong, 2019). While the repeated reading of the data may be viewed as a limitation of this approach to analysing data, the researcher found it beneficial as it enabled him to be aware of any potential biases and his positioning throughout the research.

Thematic analysis was the tool chosen to analyse all text from the transcribed interviews (see Appendix A). This enabled the researcher to find and explore themes that emerged throughout the research.

4.10 Ethical Considerations

Consideration of ethical issues was of the utmost importance to the researcher throughout the entirety of the research project. Ethical approval was sought and obtained from LIT prior to the commencement of any research (see Appendix B).

This research posed an ethical dilemma for negotiation in relation to obtaining consent as the individuals with a dementia diagnosis had a range of capacities to give consent. The researcher, however, believed that not involving people living with dementia would further stigmatise this vulnerable group. This ethical dilemma was addressed by legislative provision under the *Assisted Decision Making (Capacity) Act 2015* (as cited in Kelly, 2016). The Act provides a statutory framework for individuals who lack, or may lack, the capacity to make legally-binding decisions unaided. It allows for such individuals to be assisted and supported in making decisions about their welfare, property and affairs.

The overall decision to involve people with dementia was guided by the values of enablement, inclusiveness, minimum harm and integration in a holistic framework of positive collaboration with families, management and staff members of the host organisation. Additionally, throughout the research process the researcher made every possible effort to ensure ethical research protocols were adhered to in line with the provisions of Alzheimer Europe, ASI, Health Research regulations as well as LIT's Research Ethics, Research Integrity and General Data Protection Regulation policies.

4.10.1 Data Collection and Data Privacy

Data was collected using a Dictaphone device as well as using a mobile phone recording device as back up. All data collected was pseudonymised ensuring that the identity of all participants remained confidential throughout the research process. The researcher and the Principal Supervisor had access to and custody of the data which was stored on a password encrypted device. Additionally, all hard copies of transcripts were kept in a locked, fireproof cabinet in LIT until the completion of the project. It will be held securely for seven years after the research is completed in accordance with LIT policies on Research Ethics, Research Integrity, and General Data Protection Regulation policies. All audio files were transferred from the original source and were stored, password encrypted, on a computer file.

4.10.2 Ongoing Consent

> ‘Informed consent should be seen as a process rather than simply a document to be signed’
>
> (Alzheimer Europe, 2019).

Due to the sensitive nature of the research project, as advocated by Alzheimer Europe (2019), ongoing consent was viewed as a process rather than simply signing a document. Consent was sought at regular intervals throughout the project. Prior to the commencement of the research, the researcher ensured that all participants were fully informed of what would be involved in the research to enable them to give their full consent to participate in it.

The researcher was aware that participants with dementia may have difficulties with memory, attention span, communication and understanding. Extra care was taken when providing these participants with information relating to the research. To this end, the researcher provided each participant (both those living with dementia and care staff) with an information sheet (Appendix B, pp.390-92) and consent form (Appendix B, pp. 394-96) prior to the commencement of data collection. The information sheet informed and reminded each participant that the research would include a dance activity as well as several interviews which would be audio recorded. It also stated that participants may still take part in the research if they did not wish for the interviews to be recorded. The researcher chose to record the interviews, as taking notes could disturb the flow of the interview while also distracting the participants in line with the recommendations of Alzheimer Europe (2019).

The information sheet highlighted to each participant that their identity would be kept anonymous throughout the whole process. It also informed participants of their right to withdraw from the research up to one month after the final dance activity had concluded as well at any point throughout the process.

All information on the information sheet and consent forms provided to the participants living with dementia was in large bold font which made it easier to read. The information was worded in plain language in accordance with the National Adult Literacy Agency (2021) guidelines. The information sheet and consent form were re-issued to the participants throughout the research. This proved particularly helpful for the participants who had challenges with short term memory and therefore may have had difficulty remembering previous conversations by the time they were asked to sign the consent form.

The participant information sheet (see Appendix B) also served as a reminder throughout the course of the data collection phase as to the purpose of the study and what was involved in it. A family carer/primary carer was also included in the process as a witness when obtaining consent. Obtaining consent was an ongoing process throughout the research and these forms were made available to participants regularly across the duration of the project.

4.1 **Limitations of the Research**

A number of limitations were experienced throughout the research process. The primary limitation was the sporadic availability of staff for the interview process as well as for the dance activity. Staff availability in the centre during a dance session occasionally impacted on the number of staff who could participate in the dance activity. Examples of the factors impacting staff availability include staff rotas, staff lunch breaks as well as staff on leave. Previous research has found that staff who work in care homes generally work in conditions where staff shortages are common (Kadri et al., 2018). This was observed by the researcher throughout the project, and it was also identified by the staff during the interview process.

Furthermore, this research found that the continuation of this activity in the centre after the cessation of the research was at risk due to other staff commitments within the centre. It was found that while staff universally advocated for the continuation of the dance activity, without the presence of an outside facilitator they felt that this could not be achieved.

Another limitation experienced was the inability to accurately capture and comprehend some sentiments expressed by the participants living with dementia during the interview process. A diagnosis of dementia and the progression of the disease can mean that communication and conversations are often put at risk (Schweitzer & Bruce, 2008). As identified in the literature review (see section 2.2.1), dementia leads to a progressive deterioration in multiple areas of an individual's life which includes their communication skills (IHF, 2016; Alzheimer Europe, 2020b; Alzheimer's Society, 2020; ASI, 2020d; HSE, 2020b). It is therefore important to highlight that while the best efforts were made to accurately capture the meanings of some segments of interviews, this was not always possible.

4.2 **Conclusion**

This chapter outlined the design of the research project and identified the rationale for choosing the specific approaches adopted for this research project. The ontological and epistemological approaches used within the study were identified to strengthen the researcher's position of investigating the lived experience of those with a diagnosis of mild to moderate dementia. The dance activity and the adapted dance formations were explored in this chapter, with the Céilí dance of 'Shoe the Donkey' utilised to emphasise the need and process required in making the necessary adaptations. This chapter identified the delicate and fluid nature of the ethics and ongoing consent processes involved in this research while highlighting how they were addressed and negotiated. The interests of the participants with dementia were of paramount importance throughout the entirety of the research. This chapter also identified the limitations experienced during the research.

5 Chapter 5: Results and Discussion

5.1 Introduction

This research project explored the psychosocial effects of the introduction of an adaptive Irish Céilí dance group activity with people living with dementia and their carers in a care facility. This chapter briefly revisits the methodology used in this research which takes into consideration the demographic profile of the participants living with dementia. It also gives a brief overview of the quantity of interviews and dance sessions completed with all participants in this research.

The themes found throughout this research are also accompanied by subthemes which are listed below. Reminiscence was the most common theme found in this research which is reflective of previous literature around dance and people living with dementia. The impact the dance activity and interview process had on the mood of all participants was evident in this research and is again reflective of the previous literature on dance for people living with dementia and their care staff. This research also identifies that the Céilí dance activity provided an opportunity for the participants living with dementia to take part in exercise which they usually would not have. The final theme in this research emphasises the role the dance activity had on strengthening bonds between the participants living with dementia and the care staff in the daycare centre. These themes and subsequent subthemes are listed overleaf:

- **Theme 1: Reminiscence**

  Subthemes: Identity, Community and Personhood
  Access to New Knowledge
  Life Story Work
  Music and Dance - Creating a Sense of Identity
  Embodied Remembering
  The Past Informing the Present •

Theme 2: Mood

  Subtheme: The Rhythm of the Dance

- **Theme 3: Mobility and Falls Risk**

  Subthemes: Opinions Altered Through Adaptive Dances
  Adapting to Inclusivity

- **Theme 4: Strengthening Bonds Between Staff and People Living with Dementia**

  Subtheme: Roles Reversed

It is important to highlight that this research project explores the use of Irish Céilí dance as an activity and not as a therapy.

5.2 Methodology Used

The epistemological position taken in this research was an interpretivist approach. This was achieved through a qualitative method, namely semi-structured interviews and the dance activity. All text collected from the transcribed interviews (see Appendix A) was analysed using thematic analysis. The researcher’s observations were utilised in conjunction with the themes found from the interviews as a means of strengthening the findings from this project.

5.2.1 **Demographic of Participants**

A total of twenty-five interviews were conducted over a ten-week period. Ten of these were with participants living with dementia while fifteen were with care staff at the centre. All interviews took place at the centre and were conducted prior to the first dance activity, at the midway point of the project and after the final dance activity was completed. The care staff participants were interviewed at all three stages of the research; however the participants living with dementia were not interviewed at the midpoint stage. There was a total of six adaptive Irish Céilí dance sessions which were accompanied at various intervals with the interview process. Two participants living with dementia interviewed were male and four were female. These participants were aged between 75-91 years of age. Of the ten staff interviewed, nine were female. It is also important to highlight that many of the findings presented in this chapter result from the researchers' observations of people who participated in the dance activity and not necessarily in conjunction with the interview process.

All participants in this project were born in Ireland and resided here for most of their adult lives. This is significant to the findings of this research as it explores the psychosocial effects of the introduction of a Céilí dance activity with people living with dementia who may have a personal and cultural history with Céilí. It also gives an insight into the role that dancing played in the lives of each participant and the social sphere in which they grew up. By taking into account the age profile of the participants living with dementia, this research provides us with a more in-depth understanding on the role of dance and the lived experience of each participant. This theme will be explored later in this chapter in greater detail as the researcher explores the instruments and influences which helped shape each individual's sense of identity and community.

5.3 <u>Reminiscence</u>

Reminiscence was the primary theme found in this research. It was observed through the dance activity as well as the interview process:

> ***'Isn't it magic'***
>
> (Eileen, first interview, line 172).

> ***'I have lovely memories of dancing. I used to work, I used to rush home from work, and, am, tell my Mother, I'm going out now tonight'***
>
> (Theresa, first interview, lines 1209-1210).

No single definition of reminiscence exists in healthcare literature (Dempsey et al., 2012). However as highlighted in the literature review (section 2.10) Brooker & Duce (2000) state that reminiscence therapy involves the sharing of memories which are often evoked through the use of stimulating material. In addition, McKeown et al. (2006) and VandenBos (2006) describe reminiscence as the use of written or oral life histories to improve an individual's psychological wellbeing and this technique is often used with people living with dementia. Although this research does not propose that the dance activity is a therapy, it is aligned with the views put forward by Brooker & Duce (2000), McKeown et al. (2006) and VandenBos (2006) which suggest that reminiscence therapy, employing the sharing of memories through the use of stimulating material and through the use of written or oral histories of the person may improve an individual's psychological well-being.

The review of the literature for this study (section 2.10) suggests that reminiscence techniques have had positive effects, such as improving the mood and decreasing levels of agitation for the person living with dementia (Haight et al. 2006; Subramaniam et al., 2014; Testad et al., 2014; Woods et al. 2018). It also notes that reminiscence activities can contribute to both the mental health and the quality of life of those living with dementia (Blake, 2013; Keating et al., 2018). Brooker & Duce (2000) and Keating et al. (2018) propose that these benefits may be achieved by discussions of past experiences and can be evoked through the use of stimulating material.

This research can be interpreted as a reminiscence technique which can be used with people living with dementia. The semi-structured interviews in this project explored participants' past experiences of dancing and other areas of interest which arose during the process. It used a culturally familiar dance activity which enabled the participants living with dementia to not only speak about their previous experiences of dancing, but to also relive past experiences of dancing. The researcher's reflective journal captured some of the views expressed throughout the research which illustrate the benefit that the dance activity was having on the mood and well-being of all participants. The journal also captured reflections on conversations which suggest that the dance activity provided stimulation and an opportunity for reminiscence:

> ***All staff have commented on the positive influence which the dance activity is having on everyone in the centre. In particular, staff have said that the participants living with dementia are in a great mood during and after the dancing. I have observed this on many occasions and have witnessed how relaxed everyone appears after the activity***
>
> (O Shea, Reflective Journal, 15th of December 2019).

> ***The dance activity has sparked so many conversations about dancing and appears to assist in reminiscing. Theresa has mentioned the dancehall in Limerick on several occasions and how she loved to dance there. She often tells me that she will go there tonight***
>
> (O Shea, Reflective Journal, 23rd of December 2019).

The stimulating influence of the dance activity not only apparently contributed to the mood and well-being of the participants living with dementia, but also to the sense of identity and community of the participants. This is explored further in the following section.

5.3.1 Identity, Community and Personhood

In contemporary Ireland, the internet and the growing popularity of social media platforms has given global access to a vast array of music and dance, therefore expanding the global community with relative ease. This is a resource which people use to shape their identity and the community in which they belong, and which may be taken for granted today for younger individuals. In contrast, the research participants in this study who are currently living with dementia were restricted in their access to alternative forms of dance and music during their youth. It is likely that their identity was largely shaped by the immediate community in which they lived and the resources which were available to them in rural Ireland.

When considering the age profile of the participants living with dementia, it is possible that they would have heard Céilí dance on the radio, attended local concerts, and participated in social dances in their local community halls. Below are examples taken from the interview process with the participants living with dementia reminiscing on dancing and the feelings which were evoked from these activities:

> ***'I went to, I went to dances all the time. I was always dancing in the. What's the place in Limerick? The ballroom in Limerick'***
>
> (Theresa, first interview, lines 1155-1156).

> ***'Oh, I danced all my life…but with that it was magic…magic out of the sea'***
>
> (Eileen, first interview, lines 19-34).

The dance activity and interview process gave an insight into the role that dance played in the lives of each participant and the social sphere in which they grew up. Allen (2003) and Foley (2011), as noted in section (2.10.3) of the literature review, suggest that the Céilí can be interpreted in the context of this research as a tool for facilitating reminiscence. This is reflected in the statement below taken from the first interview with Mickey as he reminisces on how dances were intertwined with other social activities in his community:

> ***'You'd dance when you were 16, 17, 18 and you were playing tennis and playing soccer and the club you were in maybe had dances'***
>
> (Mickey, first interview, lines 459-461).

Though all the participants living with dementia reminisced on past experiences, the majority linked their memories of dancing to close relationships with their spouses as well as immediate family members:

> ***SDOS: …And, ah your boyfriend, would you ever have gone dancing with your boyfriend? Mary: Ya***
>
> ***SDOS: And ye'd go dancing and ye'd listen to music and that was nice I suppose wasn't it? Mary: I loved it.***
>
> ***SDOS: Did you?***
>
> ***Mary: Mmm.***
>
> ***SDOS: You loved it. And what did you love about it?***
>
> ***Mary: The happiness***

(Mary, first interview, lines 385-403).

> ***'Every one of us would be up dancing and that sure. And our parents threw us out you know because they knew where we were'***
>
> (Mickey, first interview, lines 576-577).

Below is an extract taken from the first interview with Theresa where she reminisces about her experience of meeting her husband at a dancehall:

> ***'Well, I can remember the first time I went in there (dancehall), I made a bee line for ladies choice…and I married him…I can't believe it'***
>
> (Theresa, first interview, lines 1165-1174).

The findings of this research suggest that the Céilí dance activity can provide opportunities for the person living with dementia to reminisce on previous experiences of dance. It can also enable them to speak and reminisce about other areas of, and interests in, their life which helped to shape their identity. This suggests that the positive psychosocial effects of the dance intervention had the potential to radiate to other aspects of their daily lives, including interactions with carers and others.

5.3.2 Access to New Knowledge

The interview process acted as a means for the participants living with dementia to speak not only about their previous experience of dance but also about other areas of interest. This proved invaluable as it enabled the researcher to connect and build trust with the participants. It provided the researcher with information about the individual which was utilised to engage conversation around other areas of interest prior to, during and after each dance session in the centre. The below extract is taken from the first interview with Ted, and while he did not have any great interest in dancing he did express his love for soccer:

> ***SDOS: Would you have gone to dance halls?***
> ***Ted: Ah… hardly.***
> ***SDOS: What were, what were your hobbies?***
> ***Ted: Ah…Football.***
> ***SDOS: Football, oh sure can talk all day so. Ya, ya.***
> ***TED: Soccer if you like.***

(Ted, first interview, lines 854-861).

Ted actively participated in each dance activity and appeared to enjoy each session as highlighted in the researcher's journal entry:

> ***I had a good chat with Ted today about Stoke City and football. He loves to chat about them and football in general. I was surprised that he danced as much as he did but he got up, interacted with others and appeared to enjoy the activity***

(O Shea, Reflective Journal, 13th of December 2019).

Although the journal entry above highlights that Ted participated in the dance activity, the dance activity combined with the interview process enabled the researcher to become familiar with other aspects of Ted's life. The new knowledge gained throughout the research propose that learning about the individual experiences of the person living with dementia can facilitate the development of person-centred activities. This knowledge provides an evidence base for the use of person-centred activities, an approach advocated by Kitwood (1997) as discussed in section (2.8). This approach takes a holistic approach of the person living with dementia. This research reflects the benefits of adaptive Céilí dance as an activity which can be used with people living with dementia to develop authentic person-centred care within organisations. One such person-centred activity which could be informed by the generation of new knowledge is life-story work.

5.3.3 Life Story Work

The Social Care Institute for Excellence (2021) identifies *Life Story Work* as the focus on a person's past while bringing their life history into the present. As highlighted in the literature review (section 2.10), research has suggested that life story books are a valuable means of recounting past events which can produce psychosocial benefits for the person living with dementia (Haight et al., 2006; Subramaniam et al., 2014; Woods et al., 2018).

A diagnosis of dementia and the progression of the disease often means that communication and conversations are often put at risk (Schweitzer & Bruce 2008). In spite of this apparent barrier, life story books are often used as a reminiscence tool in supporting the recollection of real-life memories for people living with dementia (Elfrink et al., 2018). The findings of this research project illustrate that reminiscence activities, such as the interview process with the individual as well as participation in a familiar dance activity, can provide a stimulus for the person living with dementia to verbalise these memories in conversations with staff, family members and others. These activities can provide important knowledge about an individual which could uniquely inform the care they receive. The below extract from the researcher's journal is an example of how the researcher's knowledge of the participants living with dementia influenced some of the music chosen for the dance activities. It pinpoints how the knowledge gained through these activities enabled the researcher to choose music which the people living with dementia could identify with:

> ***I play about 6 minutes of waltz music at the end of each session which I think is a good way to wind down. What I find interesting is that the participants living with dementia who lived in different areas of the country can relate to the music specific to their own region. Mary sings the words of the Boys of County Armagh as we waltz and Mickey taps his feet while listening to the Homes of Donegal***
>
> (O Shea, Reflective Journal, 6th of December 2019).

5.3.4 Music and Dance - Creating a Sense of Identity

Music has been shown to play an important role (see for example Brooker & Duce, 2000; Scales et al., 2018; Woods et al., 2018) in enabling people living with dementia to reminisce on previous experiences. As part of the adaptive dance activity, the researcher played traditional Céilí music in the background prior to the commencement of the activity. This was done in an attempt to replicate the normal practice of musicians preparing for a Céilí session to begin.

The extract below taken from the researcher's reflective journal details the influence which the Céilí music had on the participants living with dementia and their participation in the dance activity:

> ***The whole atmosphere in the room changed once the Céilí music was turned on. Everybody joined in and it was amazing. Some people were up and dancing, some people were in wheelchairs and some were sitting down and clapping, it was amazing. The smiles on each participant's face was amazing and uplifting. It went better than I ever imagined***
>
> (O Shea, Reflective Journal, 15th of November 2019).

Staff taking part in the dance activity also benefitted from this interaction. The below extract is taken from the final stage interviews with a staff member. In it, they speak about their interaction with a participant living with dementia prior to and after participation in the dance activity. In particular, they refer to the influence that the dance activity had on their relationship with this service user.

Melhuish et al. (2017) suggest that participation in a dance activity enables those living with dementia to become more talkative and engaged in their social environment:

> ***Am, well just, just there was one particular man anyway that I never, I never heard him speaking or taking part in anything. And he danced and he sang as he was going out the door and he sang, I think it was "The town I loved so well", that was on and they were waltzing around the floor to it***
>
> (Niamh, final stage interview, lines 4287-4292).

While it is generally acknowledged that dementia involves major losses in short term cognitive ability, the individual's long-term memory often remains intact (Kitwood, 1997). This is also evident in the aforementioned interview passage as the person with dementia, subsequent to their involvement in the dance activities and interviews, appears to be accessing long term memories.

The participants living with dementia in this research primarily identified positive memories of attending dances in their youth. While this was voiced in the interview process, the researcher observed that the dance activity promoted social inclusion, communication, self-expression, connection and participation within the day programme setting. It is possible that these same feelings were experienced by the participants when attending dances in their youth and the dance activity may have triggered such memories in the present.

5.3.5 Embodied Remembering

Reminiscence is a key theme in this research and it is appropriate to reflect on the role of embodied remembering when focusing on this theme. Although Bernsten (2009) argues that unintentional activation of memories is primarily triggered by smells and tastes, Sutton & Williamson (2014, p.1) state that embodied remembering emphasises that ‘hearing a particular song can viscerally bring back the urge to dance’. Similarly, the findings of this research provide further evidence that participation in a familiar dance activity can elicit memories and feelings. Examples from this research varied from participants engaging in conversation about attending dances in their local areas, to the female participants sitting together while waiting to be asked to dance, a scene reminiscent of the Irish dance halls of their youth. These observations gave the researcher a sense of what life must have been like for the people living with dementia while attending dance events in their youth.

> ***The dance activity seems to bring the participants living with dementia to life. They initiate conversation during the dance activity and dance with a conviction and confidence that I imagine can only come from years of experience***
>
> (O Shea, Reflective Journal, 22nd of November 2019).

Although previous research has shown that touch using dance and movement ‘can counteract isolation by offering bodies the opportunity to interact safely’ (Silvester & Frampton 2014, p. 21) there is limited research highlighting the link between touch and reminiscing. Therefore, this research project proposes that touch, when used in a familiar dance activity, is a valuable link to past memories and may challenge the notion of ‘social death’ (Borgstrom, 2017). Katsuno (2005) proposes that public responses to a diagnosis of dementia demote the individual to a new lower status, while more recent research undertaken by Canning & Blakeborough (2019) highlights that people living with dementia are viewed through a reductionist lens. Classen (2005, p.12) argues that ‘our hands and bodies learn to speak a certain language of touch, a language shaped by culture and inflicted by individuals’.

The use of touch as a means of communication was particularly important for the participants living with dementia who, while unable to communicate effectively through verbal means, were able to do so physically through the dance activity. This was observed by the researcher on several occasions throughout the dance activity sessions and is highlighted in the below extract from the researcher's journal:

> ***Today I danced with Mary and it was amazing. She usually says very little if anything at all. However as we were waltzing towards the end of the session, it was so very clear that we were communicating. She squeezed my hand, smiled and held eye contact with me. It was quite emotional for me but absolutely amazing***
>
> (O Shea, Reflective Journal, 20th of December 2019).

While this research proposes that participation in the dance activity can elicit positive memories for those living with dementia, it also suggests that the physical act of touch involved in the dance activity can combat the idea of social death as well as challenging the stigma which is associated with a diagnosis of dementia.

5.3.6 The Past Informing the Present

Throughout the interviews, a minority of the participants living with dementia indicated that they felt they would not be any good at the dancing activity and that they never were any good at dancing. This may be an attempt to communicate present emotions by reflecting on their feelings of past events. Schweitzer & Bruce (2008) argue that what a person chooses to share their past life it has the potential not just to provide information about their past experiences, but to also tell others how they are feeling in the present. The below passage is taken from the first interview with Mickey:

> ***SDOS: Would you like to listen to it on the radio?***

> ***Mickey: Ah, a, well I wouldn't know whether if I was a good singer or a bad singer or anything else like that (both laughing) that's to be honest with you, you know. And, and they were always quoting at home to me "He who had no music in his soul is fit for treason and terrorism and all that".***
>
> ***SDOS: My God, so music was a big thing at home was it?***
>
> ***Mickey: Ya, well everybody, it is in every house you know but I was the one sucker that didn't know what they were talking about you know… I won't be able to contribute, I, I, I can't sing the scales even now.***
>
> (Mickey, first interview, lines 496-506).

There is a paucity of research available which has investigated how the person living with dementia reflects on past experiences as a means of expressing their present feelings. This is an area within dementia care which is overlooked in the literature and provides an opportunity for further exploration and research.

5.4 **Mood**

> ***'You could see the old sparkle in them you know. And they got a good laugh out of it'***
>
> (John, final stage interview, line 3803-3804).

This research project highlights the positive impact that the dance activity had on the mood of all participants. The research also highlighted the sense of joy in the daycare centre as a whole. Silvester & Frampton (2013) have previously advocated for the use of dance and movement as a means of stimulating individuals and highlight that dance has the capability of transforming an atmosphere while enhancing people's moods. More recent research has suggested that social relationships are enhanced when people dance together which can enrich one's self-confidence (Charras et al., 2020) with creative dance interventions having a positive effect on the quality of life of those taking part (Koh et al., 2019). It is important to acknowledge that music has the ability to reduce agitation in people living with dementia as well as having a profound effect on people's mood and well-being (Cheung et al., 2018; Scales et al., 2018; Sherrat et al., 2004; Sole et al., 2014). It is particularly pertinent to this research project that Sakamoto et al. (2013) found that an interactive music intervention led to greater improvement in the individual's emotional state as opposed to passive music interventions. While this was observed throughout the dance activities by the researcher; staff commented that this theme continued long after the activity had finished:

> ***'Not even like for the clients, for the staff, for the managers, there was a buzz around the place that wasn't here before'***
>
> (Ciara, final stage interview, lines 3690-3691).

As evidenced in the review of the literature in Chapter Two, previous research suggests that a dance activity which includes both people with dementia and care staff can lift the spirits of those involved while also creating a therapeutic bond (Duignan et al., 2009; Silvester & Frampton, 2013). While this was observed on numerous occasions throughout the project by the researcher, this following interview extract illustrates staff opinion of the dance activity:

> ***'Oh, I think it's great, it's great … I think it's marvellous. I think it should be mandatory'***
>
> (Julie, final stage interview, lines 3962-3963).

The research participants living with dementia had varying levels of mobility and cognitive function. Despite this, the dance activity promoted inclusion through adaptive dance formations. This enabled everyone to have an equal opportunity to participate. The below extract is taken from the final interview stage. The researcher queried staff members on their observations of mood or behaviour in people living with dementia resulting from participation in the dance activity:

> ***'SDOS: What changes in mood or behaviour, if any, did you notice after people took part in the dance activity?***
> ***Lisa: Am, elation really'***
>
> (Lisa, final stage interview, lines 4158-4160).

Given that all participants in this research project were Irish, a culturally familiar dance activity proved to be an effective means of engaging each person within the centre. Previous research has illustrated that a culturally specific dance activity can increase positive emotional states as well as satisfaction levels of people with dementia and care staff (Guzmán-García et al., 2012). Again, this theme was observed by the researcher throughout the dance activity as well as through the interviews with all participants. While earlier research has acknowledged that music and dance are powerful instruments for the expression of emotion for people living with dementia, it is of particular relevance to this research that Innes et al. (2004) write that 'music in particular has the ability to impact on mood, tapping into deep memories. An Irish jig, an uplifting melody, can transform the atmosphere' (2004, p.188).

5.4.1 The Rhythm of the Dance

As identified in the literature review (section 2.10.2) music and dance can provide a rhythm which encourages one to want to dance (Brennan, 1999; Hayes & Povey 2010). The researcher observed throughout the dance activity that the participants living with dementia responded to the rhythm of the dance. In turn, this was reflected in their dancing:

> ***The rhythm of the dances and the reactions to them are great to observe and take part in. While the waltz is a slower and gentler dance, the polka and hornpipe dances create a more excited and energetic response with stamping of the feet accompanied by laughter and the odd roar***
>
> (O Shea, Reflective Journal, 13th of December 2019).

Brennan's (1999) reference to the tapping, stamping and drumming feet highlights that the link between the rhythm of the dance and embodied remembering was present in this research project. This is an area which requires further exploration and provides an opportunity for future research.

In this research, the circular dance activity provided participants with the most joy. It enabled the participants living with dementia the best opportunity to express themselves through dance, and to the rhythm of the music in comparison with individual or 'couples' dance arrangements. For example, the tune and rhythm of *'Shoe the Donkey'* was used as all participants advanced and retired in unison while stamping their feet to the rhythm of the music. The dance formations were adapted (see section 4.8.3) by the researcher as the original approach created safety concerns while also leading to confusion.

This adaptive dance formation provided an extra layer of safety for all participants and enabled those with reduced mobility to participate. It also enabled staff to observe the benefits of a fully inclusive activity:

> ***'And it (circular dance) seemed to work better because, you could even see, see the light lighting up in people's eyes like they're not just dancing with one person'***
>
> (Ciara, final stage interview, lines 3644-3645).

While it was clear to the researcher that the adaptive dance formations brought joy to all who participated in the activity, the dances also provided everyone with exercise which they would not have had otherwise. This was evident during the interview process when the researcher interviewed Lisa (staff):

> ***SDOS: Do you think that the dance activity is or isn't benefitting participants?***
>
> ***Lisa: Ya it is, absolutely. Firstly, with their mood, secondly I suppose with movement, with exercise that kind of thing***
>
> (Lisa, final stage interview, lines 4172-4173).

This section highlighted that the participants living with dementia responded to the rhythm of the dance within the dance activity. It also highlighted that the adaptations made to the dance formations enabled those with reduced mobility to actively participate in the dance activity. The following section identifies the risk of falls that is present for people living with dementia and the possibility that participation in a dance activity may help to alleviate some of these risks.

5.5 Mobility and Falls Risk

> ***'Noel was out there today like and no bother dancing you know. I was like Oh my God. Because there's days that he can't actually walk'***
>
> (Kate, second stage interview, lines 3362-3364).

Shaw (2002) suggests that people living with dementia are less likely to participate in regular physical exercise when compared to those living without dementia. This may be a reason for the increased risk in falls for people living with dementia (Lam et al., 2018). The mobility or lack of mobility of participants living with dementia was highlighted by the majority of staff during the first interview stage and was seen as a possible challenge to their participation in the activity:

> ***‘I suppose the physical side of it would be a, a, a big issue with them you know’***
>
> (John, first stage interview, line 2620-2621).

Falls for older people can have a detrimental effect on the individual, possibly resulting in injury and increased fear of future falls which can in turn restrict the person’s movement (Moniz-Cook & Manthorpe, 2020). It is therefore worth noting that Charras et al. (2020) have highlighted that dance for people with dementia can have a positive influence on balance and the risk of falling. This research has identified that the adaptative nature of the dance activity can provide an opportunity for those with mobility issues to actively take part in the activity. The outcomes of the adaptations made to the dance routines are explored further in the following section.

5.5.1 Opinions Altered Through Adaptive Dances

There is always a falls risk while participating in a dance activity. The initial concerns raised by staff around individual mobility had subsided once the dance activities commenced:

> ***‘Kind of surprised really at a lot of them that I thought wouldn’t be that mobile, got up and did it you know’***
>
> (John, second stage interview, line 2997-2998).

Irish Céilí dance formations such as *‘The Stack of Barley’* and *‘Shoe the Donkey’,* which are usually performed by couples, were adapted into a circular dance formations. This adaptation ensured that each participant living with dementia was linked to a care staff participant, thus decreasing the risk of a fall. In the main this was achieved by the researcher discussing, practicing and facilitating such dance formations while attending weekly dance lessons. The researcher's growing intimate knowledge of each participant was also a key influence in any adaptations considered.

The researcher, as far as possible, tailored each session to imitate Céilí events which the participants living with dementia would have attended. To this end, each session concluded with several waltzes which Shanagher (2014) emphasizes was a regular dance at Céilí events.

Cheung et al. (2018) argue that music activities tailored to the personal preferences of a specific group of people is safer than pharmaceutical therapies, with fewer side effects being reported. The adaptive nature of the dance activity in this project enabled the researcher to create a safer space for all participants taking into consideration the varying levels of mobility of each participant. This appeared to instil more confidence in all participants which was reflected in the volume of people taking part in the circular dance activity:

> ***'I think the circle worked quite well because there was a sense of being held up'***
>
> (Julie, second stage interview, lines 3138-3140).

While holding hands added an extra layer of safety to the activity, Silvester & Frampton (2014) suggest that it boosts confidence and also 'bridges distance, enabling connection between people often isolated by their age or disability' (2014, p.45). The adaptive dance formations also enabled those in wheelchairs to fully participate in the dance activity:

> ***'Yes, it's for everybody, it's not just, that's why I was saying, it's not just for the able bodied it's like for the wheelchairs and stuff as well'***
>
> (Kate, second stage interview, lines 3347-3348).

Previous research has shown that participation in a dance activity enabled those living with dementia, who may usually appear frail and unmotivated, to actively participate in the activity while showcasing their talent at dancing (Melhuish et al., 2017):

> ***When he's getting on and off the bus, he's very slow and ah, ah you know but very immobile at times. But it just goes to show you when he got into the swing maybe it brought back something***
>
> (John, second stage interview, lines 3008-3010).

5.5.2 Adapting to Inclusivity

The researcher's observations and participation in the dance activity have strengthened his hypothesis that an Irish Céilí dance activity can be adapted to enable those with varying levels of mobility safely participate in the activity. This research found that the circular formation dance acted as a conduit enabling the person living with dementia to be acknowledged as a **person** taking part in a dance activity and not a person with **dementia** taking part in a dance activity.

Kitwood (1997) states 'one of the profoundest acts of recognition is simply the direct contact of the eyes' (p.90) which this research found is enhanced during the circular dance activity.

Previous research has shown that dance movement therapy is 'highly accessible for those with a cognitive impairment, even at an advanced stage, owing to the emphasis on non-verbal forms of expression and interaction' (Melhuish et al., p.283). The below extract taken from the researcher's reflective journal highlights how the challenge around mobility concerns was overcome:

> ***Everyone appears to be enjoying the dance activity. The adapted circular dance is proving more popular for everyone and seems to be more fun. The circle linked us all together allowing every member of staff to hold***

> ***hands with two people living with dementia. It also increases eye contact, participation and the safety of all involved***
>
> *(*O Shea, Reflective Journal, 22nd of November 2019).

This research has also illustrated the importance of care staff involvement in the dance sessions and therefore suggests that an adaptive dance activity can strengthen the bond between staff and those for whom they care. Moreover, the effectiveness of a person-centred approach is significantly influenced by investments made in the learning and skill development of those staff delivering the care (Kadri et al., 2018).

5.6 Strengthening Bonds between Staff and People Living with Dementia

> ***If it's giving you some technique that you're able to make a connection … you know it's not all about the physical caring and washing and the personal care and all that***
>
> (Susan, first stage interview, lines 2886-2895).

Person-centred care is widely viewed as the best approach to provide care for people living with dementia (Kitwood, 1997; Lorentzon & Bryan, 2007). The care staff play a pivotal role in this approach (Kitwood, 1997; Melhuish et al., 2017). The person-centred approach gravitates around the needs of the person living with dementia. The findings of this research highlight that staff themselves have needs which they strive to meet during their interactions with those living with dementia. As highlighted in the literature review (section 2.8.1) Kadri et al. (2018) argue that the personhood of the care staff is often neglected when implementing person-centred care.

Care staff have needs which must be met when working in dementia care.

Research suggests that when these needs are unmet, staff morale is low which can influence the effectiveness of person-centred interventions (Franklin, 2014;

Boyden, 2015; Lawrence et al., 2016; Rapaport et al., 2017; Kadri et al., 2018).

Throughout the first interview stage of the research, the majority of care staff participants highlighted that they enjoy watching and participating in activities with the participants living with dementia (such as playing pool, hand massage, listening to music). The staff hoped that the dance activity would enable them to make more of a connection with those for whom they care. As identified in the literature review (see section 2.11.1) previous research has highlighted the benefits of dance activities for care staff and those for whom they provide care. These benefits include providing a new avenue of communication between staff and those they provide care to, an increase in staff care skills as well as providing a means which facilitates social interactions with those living with dementia (Kowarzik, 2006; Guzman- Garcia et al,. 2012).

Kowarzik (2006) found that DMT had the potential to create a new avenue of communication between staff and people living with dementia. When taking into consideration the cognitive changes and social challenges associated with dementia, dance activities can provide a great opportunity for people living with dementia to connect with others (Lapum & Bar, 2016). More recent evidence provided by Skinner et al. (2018) proposes that arts-based activities benefit person-centred care and emphasise that these activities 'can enliven the individual living with dementia' (2018, p.2). This research suggests that the dance activity affords the care staff the opportunity to forge a deeper connection with those for whom they are caring. It may also increase their own feelings of worth within the caring role.

Overall, staff participants viewed the Céilí dance activity as an enjoyable and uplifting activity which can trigger conversations with the people living with dementia and enhance the connection between the staff and those for whom they care. Data from this research suggest that staff participation in the dance activity has enabled them to interact more with the participants living with dementia:

> ***'Even if you were in bad humour that morning, by the time you were finished a session you were in, your spirits were raised'***
>
> (Ciara, final stage interview, lines 3611-3612).

> ***'Do you know they like chatting about it before you get here … Because we were chatting on the bus now about it this morning'***
>
> (Susan, second stage interview, lines 3494-3495).

Melhuish et al. (2017) emphasise that staff interaction with people living with dementia through the medium of dance and music enabled them to connect in a more fulfilling way while simultaneously increasing their own self-awareness. This aligns with findings from the current project. Results here suggest that the inclusion of a familiar dance activity enables those participating to experience a deeper connection than that which is afforded by only listening to music. This was captured through the researcher's observations which is highlighted in his reflective journal:

> ***The joy and smiles on the faces of everyone taking part is great to see. As one staff member said to me today "it can't help but put you in a good mood". It is clear that the people living with dementia are enjoying the dance activity and they are dancing and tapping along with the music***
>
> (O Shea, Reflective Journal, 29th of November 2019).

5.6.1 Roles Reversed

Kitwood (1997) suggests that the majority of interactions between a person living with dementia and care staff 'represents a form of care' (Kitwood, 1997, p.92). He proposes that this interaction is primarily led by the staff drawing the person living with dementia into the social world. He further suggests that another type of interaction occurs where the interaction between the person living with dementia and care staff is reversed, and the person with dementia takes the leading role. This role reversal was evident throughout the dance activities. On several occasions, the participants living with dementia showed the care staff the correct method of dancing as well as initiating conversation with their dance partners:

> ***'And the staff are also learning, learning the correct dance steps from those with dementia, especially when doing the waltz'***
>
> (O Shea, Reflective Journal, 6th of December 2019).

This research again suggests that participation in the Céilí dance activity may provide opportunities to counteract the rhetoric of social death and the stigma associated with a dementia diagnosis as highlighted in the literature review (see section 2.5, 2.6). The psychosocial effects of social inclusion, connection and belonging achieved in the dance activity may serve to challenge negative public perceptions (ADI, 2012; Burgener et al., 2015; Nguyen & Li, 2020) of those living with dementia.

5.7 Conclusion

The aim of this qualitative research project was to explore the psychosocial effects of the introduction of an adaptive Irish Céilí dance group activity with people living with dementia and their carers in a care facility. The themes found throughout this research were identified and explored in detail in this chapter, with reminiscence being the most prominent theme found for the participants living with dementia.

The findings in this research advocate for the use of an adaptative Céilí dance activity as an arts-based activity which can be used with people living with dementia. The findings suggest that this research can advance a practitioner's knowledge of Céilí dance as a meaningful activity which can benefit the quality of care which the individual receives as well as improving the quality of life of the person living with dementia. This research has illustrated that the Céilí dance activity focuses on the strengths on the individual rather than their limitations, which may help to reduce the concept of social death and stigma that surrounds dementia.

This research aligns itself with previous studies which have shown the benefits of non-pharmacological approaches to dementia care. The culturally appropriate Céilí dance activity used in this research took the emotional and social factors of all participants into consideration throughout the entirety of the project. The findings in this research have shown that the Céilí dance activity provided the participants living with dementia with a meaningful activity which promoted social inclusion, participation, and which enabled them to reminisce on previous experiences of attending Céilí events. This research has also identified that the arts-based approach provided positive psychosocial outcomes for all the participants in this research and strengthened the bond between those living with dementia and the care staff.

The findings in this research are aligned with Kitwood's (1997) position in dementia care which recognises people living with dementia in their full humanity and which places the **PERSON** before the dementia.

Chapter 6: Conclusion and Recommendations

6.1 Introduction

This research project aimed to explore, in the context of the psychosocial effects of dance and movement, the experiences of participants in a newly-developed adaptive Céilí dance programme for people living with dementia and their care staff. To date, virtually no published literature has explored the use of Céilí dance as an arts-based activity for those living with dementia and their care staff. This thesis therefore provides a starting point to address this gap.

An adaptive Céilí dancing activity was piloted at a daycare centre which provided services including, for example, respite services, for people in the early or middle stages of dementia. The Céilí dance activity was adapted to allow for a range of abilities that reflected participants' levels of mobility, focus, and cognitive skills.

The Literature Review (Chapter Two) identified previous research which laid the foundations for this study. This research exposed specific challenges impeding care professionals in disclosing a diagnosis of dementia. Post-diagnostic supports, or lack thereof , which the person living with dementia and their caregivers may face were identified. The experiences of loss and grief, along with social death and the stigma that accompanies dementia were explored. The research identified how these concepts are intertwined, which may lead to negative perceptions of those living with dementia.

The biomedical approach to treating dementia was challenged in this chapter. The benefits of arts-based interventions in dementia care were highlighted. The use of dance as one such arts-based intervention was explored. Céilí dance as an arts-based activity was explored with a specific emphasis on its influence on creating a sense of community and identity for those taking part in the research.

Chapter Three explored the axiological concerns within this research and identified the researchers personal, educational and professional connection to the project. The researcher's use of a reflective journal to document and reflect on prominent and emotional areas of the research was discussed. This chapter also highlighted the importance of recognising the researcher's potential biases and explored the researcher's positioning within the research.

The Methodology Chapter (Chapter Four) discussed the theoretical framework for this research and provided the rationale for the use of a qualitative approach. The ontological and epistemological approaches used within the study were highlighted to strengthen the researcher's position of investigating the lived experience of those with a diagnosis of dementia, namely through semi-structured interviews and the dance activity. In addition to the researcher's observations, thematic analysis was used to identify key themes arising from the semi-structured one-to-one interviews with the participants. Ethical dilemmas experienced by the researcher were explored in this chapter. The process of the need for, and obtaining of, ongoing consent throughout the research was identified.

The Results and Discussion chapter (Chapter Five) identified the key findings from the research. Direct quotes from the researcher's reflective journal were included in this section which captured observations made throughout the research as well as the researcher's reflections on those observations. Direct quotes from the transcribed interviews that best express the themes which arose in the research (see Appendix A) were also used in this chapter.

6.1 **Covid-19**

Since the conclusion of the adaptive Irish Céilí dance programme, the world has witnessed the emergence of Covid-19 and its global impact. In Ireland, those with dementia, their families, and care staff are also experiencing the effects of the restrictions put in place to curtail the progression of this disease. Daycare centres, for example, have been closed. At the time of this writing (April, 2021), it is unclear as to when services for people living with dementia will return to normal. There is also ambiguity as to when arts-based activities will be made available to those for whom they have become the norm.

The emergence of Covid 19 has highlighted the importance of daycare centres and the opportunities for socialisation that they provide for the service users, their families and the staff. A report produced by the ASI (2020) focused on the impact of Covid 19 on those living with dementia and their families. The report emphasised that loneliness, due to social distancing guidelines, was directly linked to individuals being unable to attend daycare services and the socialisation associated with it (ASI, 2020). It could be argued, therefore, that the psychosocial effects of inclusion and participation such as those reflected in this research, may help to combat the loneliness experienced by those living with dementia as a result of Covid 19.

The ASI (2021e) are currently providing a service in the home to those who used to attend their daycare centres prior to the emergence of Covid 19. This is an attempt to continue to provide a service to those living with dementia and may be an opportunity to combat the loneliness experienced during Covid 19. This service focuses on providing social activity-based care which can include reminiscence activities, companionship and recreational activities.

6.2 Synopsis of the Research

This research sought to explore the psychosocial effects of the introduction of an adaptive Irish Céilí dance group activity with people living with dementia and their carers in a care setting. Themes were collated using a thematic analysis approach to twenty-five semi-structured interviews with both the participants living with dementia and care staff in the daycare centre. The researcher’s observations throughout the dance activity and during the interview process were also an integral part of identifying the themes highlighted in this chapter.

A dominant finding borne out in this research highlights that both the interview process and predominately the dance activity enabled the person living with dementia to reminisce on and relive past experiences through participation in a familiar dance activity. While the researcher utilised both the interview process and the dance activity to engage the person living with dementia, it was the latter which appeared to provide the most joy to each individual. Although the researcher observed that listening to familiar music provided the participants with pleasure, it was a more enjoyable and inclusive occasion when the dance activity was also present. A discussion on the preferred dance formation was presented. It noted that the circular formation enhanced feelings of safety, confidence, inclusion and participation.

This research also provides an understanding of the role which culturally-relevant and familiar dance and music can play in the lived experience of each person and how their experiences helped to shape their identity and sense of community. Participants highlighted how, in the past, they would meet their friends at dances as well as one lady meeting her husband at a dance.

The semi-structured interview process provided the researcher with some invaluable insights into the lives and experiences of each individual which otherwise may not have come to light during the dance activity. The information gathered emphasises that exploration of the person's past experiences with the individual themselves, can uncover aspects of their lives which may not have been previously known to staff in the care setting. This information can then be utilised to provide information about the person which could best inform the care they receive.

All staff interviewed emphasised that the dance activity was a positive experience with the majority stating that it enhanced their mood. Staff participants highlighted that they believed that the people living with dementia were also in a better mood after each activity and that it provided a source of conversation within the centre each week. It was found during the project that a circular dance formation provided each participant with the most enjoyment as it instilled a sense of safety as well an inclusion.

The researcher kept a reflective journal throughout the project to document his observations. This also enabled him to acknowledge his own feelings and struggles during the research process. As mentioned in the Axiology chapter (Chapter Three), the researcher has a personal attachment to the research topic. The journal allowed the researcher to reflect on emotional moments which occurred during the research, specifically during the dance activity. It also enabled the researcher to acknowledge that he was also reminiscing throughout the dance activity.

While the majority of the themes focused on those living with dementia, a significant finding which emerged from the research was the need for the staff to feel more connected to those for whom they provide care. The dance activity provided staff with the opportunity to engage in an activity which centred around enjoyment and connection and away from the role of providing personal care to the individual. This research found that the dance enabled staff to gain a deeper, more fulfilled connection with those living with dementia.

In conclusion, this research provides evidence of the positive psychosocial effects that the introduction of an adaptive Irish Céilí dance group activity can have for the person living with dementia and their care staff. The following section will discuss recommendations arising from this study and identify opportunities for further research.

6.3 **Recommendations**

As a result of the findings of this research, the researcher recommends the following:

- More research should be undertaken to explore the psychosocial effects of the introduction of an adaptive Céilí Dance activity with people living with dementia and their care staff. The results highlighted in this research provide a possible framework for further exploration in this area. As identified in the literature review (Chapter Two), there is a paucity of research in this area in Ireland and internationally.
- A link between the rhythm of the dance and embodied remembering was present in this research project. This is an area which requires further exploration and provides an opportunity for future research.

- Ongoing dementia specific training should be mandatory for all staff providing care in all settings to people living with dementia. There should also be an emphasis on person-centred care for staff in this training.
- Arts-based training should be encouraged and made available for all disciplines training in dementia care, including social care work, social work, nursing, medicine, occupational therapy and therapeutic and recreation professionals (for example, the introduction of a Special Purpose Aware programme at third level).
- Specialised dementia training for dance instructors who may wish to implement this dance programme for a variety of dementia services should also be developed and encouraged (for example, the introduction of a Special Purpose Aware programme at third level).
- The adaptative Céilí dance programme should be expanded and made available in all facilities providing care for those living with dementia as it could be a method of reducing the medical model surrounding the condition. This would include daycare centres, respite services, long-term residential care as well as homecare. In light of the restrictions imposed in most services due to Covid 19, this dance activity could be facilitated online for those living at home and their carers, or for those in residential care or nursing homes. This would also provide an opportunity for further research to investigate the experiences of those participating in online classes.
- An adaptive Irish Céilí dance activity should be included as part of a regular treatment programme alongside other medications for people living with dementia.

- A facilitator of the adaptive Céilí dance programme should not be a permanent employee of any one facility as this research has identified that regular staff who have other paid roles in the organisation may not have sufficient training and expertise, as well as sufficient time, to facilitate the dance activities. This would acknowledge the 'professionalism' of the independent dance artist/movement practitioner working with those living with dementia in a care setting.
- The adaptive Céilí dance programme could be utilised to better inform person-centred care plans therefore providing and maintaining a better quality of life for the individual and their family.
- There is a paucity of research available which has investigated the person living with dementia reflecting on past experiences as a means of expressing their present feelings. This is an area within dementia care which is overlooked and provides an opportunity for further exploration and for future research.

The recommendations above are based on the researcher's observations as well as the data collected in the research. It is recommended that adaptive Céilí dance programmes be made available to all those living with dementia in Ireland, regardless of location. The psychosocial benefits of activities such as the one considered in this research will allow people living with dementia to both dance and remember.

Bibliography

Abreu, M., & Hartley, G. (2013) The effects of Salsa dance on balance, gait, and fall risk in a sedentary patient with Alzheimer's dementia, multiple comorbidities, and recurrent falls. *Journal of Geriatric Physical Therapy (2001),* 36(2), 100–108.

Algase, D.L., Beck, C., Kolanowski, A., Whall, A., Berent, S., & Richards, K. (1996) Need-driven dementia-compromised behavior: An alternative view of disruptive behavior. *American Journal of Alzheimer's Disease and Other Dementias,* 11, 10–19.

All-Party Parliamentary Group on Arts, Health and Wellbeing (APPGAHW) (2017). *Creative Health: The Arts for Health and Wellbeing - Second Edition* Available at: https://www.culturehealthandwellbeing.org.uk/appg-inquiry/ [Accessed on 14 August 2021].

Allen, C., (2003*)* Irish Céilí Dance and Elderly Dancers. *American Journal of Dance Therapy,* 25(2), pp.111-122.

Alzheimer's Association (2020). *Stages of Alzheimer's*. [online] Available at: https://www.alz.org/alzheimers-dementia/stages [Accessed 27 September 2020].

Alzheimer's Disease International (ADI) (2020a). *Dementia Statistics | Alzheimer's Disease International*. [online] Available at: https://www.alz.co.uk/research/statistics [Accessed 18 October 2020].

Alzheimer's Disease International (ADI) (2020b). *About Dementia | Alzheimer's Disease International*. [online] Available at: https://www.alz.co.uk/aboutdementia [Accessed 27 September 2020].

Alzheimer's Disease International (ADI) (2012), *World Alzheimer report 2012: Overcoming the stigma of dementia,* London: Alzheimer's Disease International.

Alzheimer's Disease International (ADI) (2015). *World Alzheimer report 2015: The global impact of dementia,* London: Alzheimer's Disease International.

Alzheimer Europe. (2019a). *Ethical issues*. [online] Available at: https://www.alzheimer-europe.org/Research/Understanding-dementiaresearch/Participating-in-research/Ethical-issues [Accessed 4 Jul. 2019].

Alzheimer Europe. (2019b). *Participating in research*. [online] Available at: https://www.alzheimer-europe.org/Research/Understanding-dementiaresearch/Participating-in-research/Who-can-take-part-in-research [Accessed 5 Jul. 2019].

Alzheimer Europe. (2019c). *Research methods*. [online] Available at: https://www.alzheimer-europe.org/Research/Understanding-dementiaresearch/Types-of-research/Research-methods [Accessed 4 Jul. 2019].

Alzheimer Europe. (2019d). *Types of research*. [online] Available at: https://www.alzheimer-europe.org/Research/Understanding-dementiaresearch/Types-of-research/Research-methods [Accessed 5 Jul. 2019].

Alzheimer Europe. (2020a). *Alzheimer's disease and Alzheimer's dementia*. [online] Available at: https://www.alzheimer-europe.org/Dementia/Alzheimer-sdisease-and-Alzheimer-s-dementia [Accessed 26 Sep. 2020].

Alzheimer-Europe. (2020b). *Alzheimer Europe - Living with Dementia - Caring for someone with Dementia - Memory and Communication - Memory Loss*. [online] Available at: https://www.alzheimer-europe.org/Living-withdementia/Caring-for-someone-with-dementia/Memory-andCommunication/Memory-loss [Accessed 18 October 2020].

Alzheimer Europe. (2020c). *Alzheimer Europe - Research - European Collaboration on Dementia - Social Support Systems - Specific Services and Support for people with Dementia and Carers*. [online] Available at: https://www.alzheimer-europe.org/Research/European-Collaboration-onDementia/Social-Support-Systems/Specific-services-and-support-for-people-withdementia-and-carers [Accessed 20 November 2020].

Alzheimer's Research UK. (2020). *Deaths due to Dementia | Dementia Statistics Hub*. [online] Available at: https://www.dementiastatistics.org/statistics/deathsdue-to-dementia/ [Accessed 30 October 2020].

Alzheimer's Society. (2020). *How Dementia Progresses*. [online] Available at: https://www.alzheimers.org.uk/about-dementia/symptoms-and-diagnosis/howdementia-progresses [Accessed 18 October 2020].

Alzheimer Society of Ireland (ASI) (2021a). *Dementia in the Media - Alzheimer*. [online] Available at: https://alzheimer.ie/creating-change/awarenessraising/dementia-in-the-media/ [Accessed 7 February 2021].

Alzheimer Society of Ireland (ASI) (2021b). *About our Services and Support - Alzheimer*. [online] Available at: https://alzheimer.ie/get-support/our-servicesand-support/ [Accessed 9 February 2021].

Alzheimer Society of Ireland (ASI) (2021c). [online] Available at: https://alzheimer.ie/wp-content/uploads/2018/11/ASI_Grieving-Loss_SectionE2_final.pdf [Accessed 10 March 2021].

Alzheimer Society of Ireland (ASI) (2021d). *What is Dementia and Alzheimer's - Alzheimer*. [online] Available at: https://alzheimer.ie/about-dementia/what-isdementia-and-alzheimers/ [Accessed 13 March 2021].

Alzheimer Society of Ireland (ASI) (2021e). *Day Care at Home Archives - Alzheimer*. [online] Available at: https://alzheimer.ie/service/day-care-at-home/ [Accessed 15 February 2021].

Alzheimer Society of Ireland (ASI) (2020a). *What is dementia and Alzheimer's - Alzheimer*. [online] Available at: https://alzheimer.ie/about-dementia/what-isdementia-and-alzheimers/ [Accessed 27 September 2020].

Alzheimer Society of Ireland (ASI) (2020b). *Dementia in the Media - Alzheimer*. [online] Available at: https://alzheimer.ie/creating-change/awarenessraising/dementia-in-the-media/ [Accessed 16 March 2021].

Alzheimer Society of Ireland (ASI) (2020c). *Day Care Services Archives - Alzheimer*. [online] Available at: https://alzheimer.ie/service/day-care-services/ [Accessed 27 October 2020].

Alzheimer Society of Ireland and the National Dementia Office in the Health Service Executive, (2016). *Dementia Specific Services in the Community: Mapping Public and Voluntary Services*. Dublin: Health Service Executive.

Andrews, G. (2006). *Managing Challenging Behaviour in Dementia*. BMJ, 332 (7544), p.741.

Ashley, P., Eriksson, J. and Jeon, A., (2016). Animal Assisted Therapy: An Effective Solution for Symptoms of Dementia in Institutionalized Elderly Patients.

Aspers, P. and Corte, U., (2019). What is Qualitative in Qualitative Research. *Qualitative Sociology*, 42(2), pp.139-160.

Auerbach, C. F., & Silverstein, L. B. (2003). *Qualitative Studies in Psychology.* Qualitative data: An introduction to coding and analysis. New York, New York University Press.

Berntsen, D. (2009) *Involuntary Autobiographical Memories: An introduction to the unbidden past*. Cambridge. Cambridge University Press.

Blaikie, N. (2007). *Approaches to social enquiry: Advancing knowledge*. 2nd ed. Malden: Polity.

Blake M. (2013). Group reminiscence therapy for adults with dementia: a review. *British journal of community nursing*, *18*(5), 228–233. Available online at: https://doi.org/10.12968/bjcn.2013.18.5.228 [Accessed 18 October 2020].

Bläsing, B., Coogan, J., Biondi, J. and Schack, T., (2018). Watching or Listening: How Visual and Verbal Information Contribute to Learning a Complex Dance Phrase. *Frontiers in Psychology*, 9.

Borgstrom, E. (2017) *Social Death. QJM* : monthly journal of the Association of Physicians, 110 (1), 5–7.

Borson, S., Frank, L., Bayley, P. J., Boustani, M., Dean, M., Lin, P. J., McCarten, J. R., Morris, J. C., Salmon, D. P., Schmitt, F. A., Stefanacci, R. G., Mendiondo, M. S., Peschin, S., Hall, E. J., Fillit, H., & Ashford, J. W. (2013). Improving dementia care: the role of screening and detection of cognitive impairment. *Alzheimer's & dementia : the Journal of the Alzheimer's Association*, *9*(2), 151–159. Available online at: https://doi.org/10.1016/j.jalz.2012.08.008 [Accessed 28 October 2020]

Boss, P. (2010). The trauma and complicated grief of ambiguous loss. *Pastoral Psychology*, 59(2), pp.137-145.

Boyden, S. (2015). Perceptions of care home staff on the effect of the care home environment for individuals living with dementia. *Working with Older People*. 19. 69-76. 10.1108/WWOP-03-2015-0007.

Brannelly, T., (2011). Sustaining citizenship: People with dementia and the phenomenon of social death. *Nursing Ethics*, 18(5), pp.662-671.

Braun, V. & Clarke, V., (2006). Using thematic analysis in Psychology. *Qualitative research in Psychology,* Volume 3, pp. 77-101.

Braun, V. and Clarke, V., (2019). Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health*, 11(4), pp.589-597.

Braun, V., & Clarke, V. (2021). Conceptual and design thinking for thematic analysis. *Qualitative Psychology.* Advance online publication. https://doi.org/10.1037/qup0000196

Brauninger & Bacigalupe (2017). The Oxford Handbook for Dance and Wellbeing (pp.739-756) *Chapter: Dance movement therapy in health care: Should we dance across the floor of the ward?* Oxford University Press.

Brennan, H. (1999). *The Story of Irish Dance*. Lanham: Roberts Rinehart Publishers.

Brooker, D. & Duce, L. (2000) 'Wellbeing and activity in dementia: a comparison of group reminiscence therapy, structured goal-directed group activity and unstructured time', *Aging & Mental Health*, 4 (4), pp. 354-358. doi: 10.1080/13607860020010510.

Burgener, S. C., Buckwalter, K., Perkhounkova, Y., & Liu, M. F. (2015). The effects of perceived stigma on quality of life outcomes in persons with early-stage dementia: Longitudinal findings: Part 2. Dementia: *The International Journal of Social Research and Practice*, 14 (5), 609–632.

Butler, R., (1963). The Life Review: An Interpretation of Reminiscence in the Aged. *Psychiatry*, 26 (1), pp.65-76.

Cahill, S., Clark, M., Walsh, C., O'Connell, H., & Lawlor, B. (2006). Dementia in Primary Care: the first survey of Irish general practitioners. *International Journal of Geriatric Psychiatry*, *21* (4), 319–324. Available on: https://doi.org/10.1002/gps.1464 [Accessed 18 November 2020].

Cahill, S., Clark, M., O'Connell, H., Lawlor, B., Coen, R. and Walsh, C. (2008). The attitudes and practices of general practitioners regarding dementia diagnosis in Ireland. *International Journal of Geriatric Psychiatry*, 23 (7), pp.663-669.

Cahill, S., O’ Nolan, C., O’ Caheny, D. and Bobersky, A. (2014) *An Irish National Survey of Dementia in Long-stay Residential Care*, Dublin: Dementia Services Information and Development Centre.

Canning, S., & Blakeborough, D. (2019). Intergenerational dance in long-term residential care: Social Citizenship in Dementia Care. *BC Studies*, 202, 167-168.

Cavalcanti Barroso, A., Rai, H., Sousa, L., Orrell, M. and Schneider, J., (2020). Participatory visual arts activities for people with dementia: a review. *Perspectives in Public Health*, p.175791392094891.

Chan, J., Wu, J., Deng, K. and Yan, J., (2020). The effectiveness of dance interventions on cognition in patients with mild cognitive impairment: A meta-analysis of randomized controlled trials. *Neuroscience & Biobehavioral Reviews*, 118, pp.80-88.

Chan, D., Livingston, G., Jones, L. and Sampson, E., (2012). Grief reactions in dementia carers: a systematic review. *International Journal of Geriatric Psychiatry*, 28(1), pp.1-17.

Charras, K., Mabire, J., Bouaziz, N., Deschamps, P., Froget, B., de Malherbe, A., Rosa, S. and Aquino, J., (2020). Dance intervention for people with dementia: Lessons learned from a small-sample crossover explorative study. *The Arts in Psychotherapy*, 70, p.101676.

Chenail, R. (2011). Interviewing the investigator: Strategies for addressing instrumentation and researcher bias concerns in qualitative research. *Qualitative Report*. 16. 255-262.

Cheung, D., Lai, C., Wong, F. and Leung, M., (2018). The effects of the music with-movement intervention on the cognitive functions of people with moderate dementia: a randomized controlled trial. *Aging & Mental Health*, 22(3), pp.306315.

Clare, L., Nelis, S. M., Quinn, C., Martyr, A., Henderson, C., Hindle. (2014). Improving the experience of dementia and enhancing active life--living well with dementia: study protocol for the IDEAL study. *Health and Quality of Life Outcomes*, *12*, 164. doi:10.1186/s12955-014-0164-6.

Classen, C. (2005), *The Book of Touch*, Oxford: Berg.

Cloak, N., & Al Khalili, Y. (2020). Behavioural and Psychological Symptoms In Dementia. *In StatPearls*. StatPearls Publishing.

Coaten, R. (2001). Exploring Reminiscence through Dance and Movement, *Journal of Dementia Care*, 9, 5: 19-22.

Coaten, R. & Newman-Bluestein, D. (2013). Embodiment and dementia- Dance and movement psychotherapists respond. *Dementia* 12(6): 677-681.

Creswell, J. and Poth, C. (2018). *Qualitative inquiry and research Design: Choosing among Five Approaches*. 4th ed. Singapore: Sage Publications.

Cuijpers, Y., & van Lente, H. (2015). Early diagnostics and Alzheimer’s disease: Beyond ‘cure’ and ‘care’. *Technological Forecasting and Social Change*, 93, 54–67.

Dempsey, L., Murphy, K., Cooney, A., Casey, D., O'Shea, E., Devane, D., Jordan, F., & Hunter, A. (2014). Reminiscence in dementia: A concept analysis. *Dementia*, 13(2), 176–192. https://doi.org/10.1177/1471301212456277

Denzin, N. K. & Lincoln, Y. S. (eds) (2005). *The Sage Handbook of Qualitative Research.* 4th ed. Thousand Oaks: Sage Publications.

Department of Health (2014). *The Irish National Dementia Strategy*. Dublin: Department of Health. Available at: https://www.gov.ie/en/publication/62d6a5national-dementia-strategy/?referrer=http://www.health.gov.ie/wpcontent/uploads/2014/12/30115-National-Dementia-Strategy-Eng.pdf [Accessed 1 February 2021].

Department of Health (2021). *Sláintecare in Action 2019*. [online] Available at: https://www.gov.ie/en/publication/cf284-slaintecare-in-action-2019/# [Accessed 7 August 2021].

De Vugt, M., Droes, R (2017) 'Social health in dementia. Towards a positive discourse', *Aging and Mental health*, 21(1), 1-3, Available online at: http://dx.doi.org/10.1080/13607863.2016.1262822 [Accessed 8 October 2020].

Doka, K. J. (Ed.). (1989). *Disenfranchised grief: Recognizing hidden sorrow.* Lexington Books/D. C. Heath and Com.

Doka, K., (2002). *Disenfranchised Grief.* Champaign: Research Press.

Doka, K., (2005). *Living with Grief: Alzheimer's Disease*. Washington: Hospice Foundation of America.

Doka, K., (2006). Caring for the carer: The lessons of research. *Grief Matters*, 9(1), pp.4-7.

Doka, K., (2010). Grief, multiple loss and dementia. *Bereavement Care*, 29(3), pp.15-20.

Douglas, S., James, I., & Ballard, C. (2004). Non-pharmacological interventions in dementia. *Advances in Psychiatric Treatment,*10, pp.171-179. doi: 10.1192/apt.10.3.171

Duignan, D, Hedley, L. & Milverton, R. (2009) 'Exploring dance as a therapy for symptoms and social interaction in a dementia care unit'. *Nursing Times*, 16 (1), pp.9-28.

Dunkel, C. and Harbke, C. (2017) A Review of Measures of Erikson's Stages of Psychological Development: Evidence for a General Factor, *Journal of Adult Development,* 24(1), pp. 58-76. doi: 10.1007/s10804-016-9247-4.

Dupuis, S. L., (2002). Understanding ambiguous loss in the context of Dementia care. *Journal of Gerontological Social work,* 2(37), pp. 93-115.

Dwyer, C. S., & Buckle, J. L. (2009). The space between: On being an insider/outsider in qualitative research. *International Journal of Qualitative Methods*, 8(1), 54-63.

Edvardsson, D., Winblad, B., & Sandman, P. O. (2008). Person-centred care of people with severe Alzheimer's disease: current status and ways forward. *The Lancet. Neurology*, *7*(4), 362–367. Available online at: https://doi.org/10.1016/S1474-4422(08)70063-2 [Accessed 9 October 2019].

Elfrink, T., Zuidema, S., Kunz, M., & Westerhof, G. (2018). Life story books for people with dementia: a systematic review. *International Psychogeriatrics*. 30. 1-15. 10.1017/S1041610218000376.

Erikson, E. H. (1963). *Youth: Change and challenge*. New York: Basic books.

European Association of Dance Movement Therapy (EADMT). (2021). *eadmt map - EADMT*. [online] Available at: https://eadmt.com/eadmt-members/eadmt-map/ [Accessed 6 August 2021].

Family Carers Ireland. (2021). *Family Carers Ireland*. [online] Available at: https://familycarers.ie/ [Accessed 9 March 2021].

Fitzgerald, F. (1945). *The Crack-Up*. New York: New Directions.

Flanagan, K. (2009). *Steps in Time: The history of Irish dance in Chicago*. Wisconsin: Macater Press.

Foley, C. (2011). The Irish Céilí: A Site for Constructing, Experiencing, and Negotiating a Sense of Community and Identity. *The Journal of the Society for Dance Research*, 29(1), pp.43-60.

Foley, C. (2013). *Step Dancing in Ireland: Culture and History*. Surrey: Ashgate Publishing Limited.

Foley, T., Jennings, A., & Swanwick, G. (2019). Dementia Diagnosis & Management in General Practice Quick Reference Guide. *Quality and Safety in Practice Committee. Irish College of General Practitioners.*

Foley, T., Boyle, S., Jennings, A., Smithson WH. (2017) “We’re certainly not in our comfort zone”: a qualitative study of GPs’ dementia-care educational needs. *BMC Fam Pract* 18, 66. Available at: https://doi.org/10.1186/s12875-0170639-8 [Accessed 23 December 2019].

Fong, Z., Tan, S., Mahendran, R., Kua, E. and Chee, T., (2020). Arts-based interventions to improve cognition in older persons with mild cognitive impairment: A systematic review of randomized controlled trials. *Aging & Mental Health*, pp.1-13.

Foster P. P. (2013). How does dancing promote brain reconditioning in the elderly?. *Frontiers in aging neuroscience*, *5*, 4. Available at: https://doi.org/10.3389/fnagi.2013.00004 [Accessed 18 December 2019].

Franklin, B. (2014). *The future care workforce*. London: ILC-UK.

Galdas, P. (2017) ‘Revisiting Bias in Qualitative Research: Reflections on Its Relationship with Funding and Impact’, *International Journal of Qualitative Methods*. doi: 10.1177/1609406917748992.

Gallagher, S. (2012). *What is Phenomenology*? 1st ed. London: Palgrave Macmillan.

Gerdner, L., (2000). Music, Art, and Recreational Therapies in the Treatment of Behavioral and Psychological Symptoms of Dementia. *International Psychogeriatrics*, 12(S1), pp.359-366.

Gilleard, C. J. & Higgs, P. (2014) *Ageing, corporeality and embodiment* . London: Anthem Press.

Goffman, E. (1963) *Stigma: Notes on the Management of Spoiled Identity*. Englewood Cliffs, New Jersey: Prentice Hall.

Grant, D. (2021) Email to Sean Donal O'Shea, 21 June.

Greene, M. J. (2014). On the Inside Looking in: Methodological insights and challenges in conducting qualitative insider research. *The Qualitative Report*, 19(29), 1-13.

Guzmán, A., Robinson, L., Rochester, L., James, I. A., & Hughes, J. C. (2017). A process evaluation of a Psychomotor Dance Therapy Intervention (DANCIN) for behaviour change in dementia: attitudes and beliefs of participating residents and staff. *International psychogeriatrics*, *29*(2), 313–322. Available at: https://doi.org/10.1017/S104161021600171X [Accessed 4 January 2020].

Guzmán-García, A., Hughes, J., James, I. and Rochester, L., (2012). Dancing as a psychosocial intervention in care homes: a systematic review of the literature. *International Journal of Geriatric Psychiatry*, 28(9), pp.914-924.

Guzmán-García, A., Mukaetova-Ladinska, E. and James, I., (2012). Introducing a Latin ballroom dance class to people with dementia living in care homes, benefits and concerns: A pilot study. *Dementia*, 12(5), pp.523-535.

Haight, B. K., Gibson, F., and Michel, Y. (2006). The Northern Ireland life review/life storybook project for people with dementia. *Alzheimer's & Dementia*, 2, 56–58. doi: 10.1016/j.jalz.2005.12.003.

Hall, G.R., & Buckwalter K.C. (1987). Progressively lowered stress threshold: A conceptual model for care of adults with Alzheimer's disease. *Archives of Psychiatric Nursing*, 1, pp. 399-406.

Hamill, M., Smith, L., & Röhricht, F. (2012). 'Dancing down memory lane': Circle dancing as a psychotherapeutic intervention in dementia—a pilot study. *Dementia*, 11(6), 709–724. doi.org/10.1177/1471301211420509.

Hansen, S. (2017). Dementia and music therapy. *Alzheimer's & Dementia*, 13(7), P1411–P1411. doi.org/10.1016/j.jalz.2017.06.2188

Hansen, A., Hauge, S., & Bergland, Å. (2017). Meeting psychosocial needs for persons with dementia in home care services - a qualitative study of different perceptions and practices among health care providers. *BMC geriatrics*, *17*(1), 211. Available at: https://doi.org/10.1186/s12877-017-0612-3 [Accessed 27 March 2020].

Harrison, B., Son, G., Kim, J. and Whall, A., (2007). Preserved Implicit Memory in Dementia: A Potential Model for Care. *American Journal of Alzheimer's Disease & Other Dementias*, 22(4), pp.286-293.

Hawley, J., Armstrong, M., & Weiner, W. (2014). *Parkinson's disease : improving patient care*. Oxford University Press.

Hayes, J., & Povey, S. (2010). *The Creative arts in Dementia Care: Practical person-centred approaches and ideas*. Jessica Kingsley Publishers: London.

Health Service Executive (HSE) (2020a). *Facts And Figures - HSE.ie*. [online] Available at:

https://www.hse.ie/eng/services/list/4/olderpeople/dementia/aboutdementia/dementia-stats/ [Accessed 18 October 2020].

Health Service Executive (HSE) (2020b). *Home Support Services - HSE.ie*. [online] Available at: https://www.hse.ie/eng/home-support-services/ [Accessed 27 October 2020].

Health Service Executive (HSE) (2021). HSE Social Prescribing Framework: Mainstreaming social prescribing in partnership with community & voluntary organisations. [online] Available at: https://www.hse.ie/eng/about/who/healthwellbeing/our-priority-programmes/mental-health-and-wellbeing/hse-social-prescribing-framework.pdf [Accessed 10 August 2021].

Herrmann, L., Welter, E., Leverenz, J., Lerner, A., Udelson, N., Kanetsky, C. and Sajatovic, M., (2018). A Systematic Review of Dementia-related Stigma Research: Can We Move the Stigma Dial?. *The American Journal of Geriatric Psychiatry*, 26(3), pp.316-331.

Ho, R., Fong, T., Chan, W., Kwan, J., Chiu, P., Yau, J. and Lam, L., (2018). Psychophysiological Effects of Dance Movement Therapy and Physical Exercise on Older Adults With Mild Dementia: A Randomized Controlled Trial. *The Journals of Gerontology: Series B*.

Hulme, C., Wright, J., Crocker, T., Oluboyede, Y., & House, A. (2010). Nonpharmacological approaches for dementia that informal carers might try or access: a systematic review. *International journal of geriatric psychiatry*, *25*(7), 756–763.

Available at: https://doi.org/10.1002/gps.2429 [Accessed 18 October 2020]

Hunter, A., Keady, J., Casey, D., Grealish, A., & Murphy, K. (2016). Psychosocial Intervention Use in Long-Stay Dementia Care: A Classic Grounded Theory. *Qualitative Health Research*, 26(14), 2024–2034. Available at: https://doi.org/10.1177/1049732316632194 [Accessed 13 January 2020].

Innes, A., Archibald, C. and Murphy, C., (2004). *Dementia and social inclusion*. London: Jessica Kingsley.

Irish Hospice Foundation (IHF) (2016). *Guidance document 3: Loss and grief in dementia*. Retrieved from: https://dementiapathways.ie/_filecache/ded/a3f/1155irish-hospice-foundation-guidance-document-3-loss-and-grief-in-dementia-2016.pdf [Accessed 14 October 2020].

Jacobsen, S., Thompson, G., & Stine, B. (2017). *Music Therapy with Families : Therapeutic Approaches and Theoretical Perspectives*. London: Jessica Kingsley Publishers.

Kadri, A., Rapaport, P., Livingston, G., Cooper, C., Robertson, S. and Higgs, P., (2018). Care workers, the unacknowledged persons in person-centred care: A secondary qualitative analysis of UK care home staff interviews. *PLOS ONE*, 13(7), pp.1-20.

Karkou, V. & Meekums, B., (2017). Dance movement therapy for dementia. *Cochrane Database of Systematic Reviews 2017*, Issue 2.

Kavanagh, D., Kuhling, C., Keohane, K., (2008). Dance-work: Images of Organization in Irish Dance. *Organization* (London), 15 (5), pp.725-742.

Katsuno, T. (2005). Dementia from the inside: how people with early-stage dementia evaluate their quality of life. *Ageing and Society*, 25(2), pp.197-214.

Kawulich, B., (2005. Participant Observation as a Data Collection Method. *Forun Qualitative Social Research*, 6(2), pp. 145-180.

Keating, F., Cole, L. and Grant, R., (2018). An evaluation of group reminiscence arts sessions for people with dementia living in care homes. *Dementia*, 19(3), pp.805-821.

Kelly, B. (2016). The Assisted Decision-Making (Capacity) Act 2015: what it is and why it matters. *Irish Journal of Medical Science*, 186(2), pp.351-356.

Kharicha, K., Iliffe, S., Harari, D., Swift, C., Gillmann, G., & Stuck, A. E. (2007). Health risk appraisal in older people 1: are older people living alone an "at-risk" group? *The British journal of general practice: the journal of the Royal College of General Practitioners*, *57*(537), 271–276.

Killam, L. (2013). *Research terminology simplified: Paradigms, axiology, ontology, epistemology and methodology*. Sudbury, ON: Author.

Kim, S. K., & Park, M. (2017). Effectiveness of person-centered care on people with dementia: a systematic review and meta-analysis. *Clinical interventions in aging*, *12*, 381–397. Available at: https://doi.org/10.2147/CIA.S117637 [Accessed 18 October 2020].

King, N. (2010). *Interviews in Qualitative research.* London: Sage publications.

King, N., Horrocks, C. and Brooks, J. (2019). *Interviews in Qualitative Research*. 2nd ed. London: Sage Publications.

Kitwood, T. (1997). *Dementia Reconsidered: The person comes first.* Buckingham:

Open University Press.

Klenke, K. (2008). *Qualitative research in the study of leadership.* Bingley: Emerald Group Publishing Limited.

Kontos, P. & Grigorovich, A. (2018). Intergrating Citizenship, Embodiment, and Relationality: Towards a reconceptualization of Dance and Dementia in Long-term Care. *The Journal of Law, Medicine and Ethics*, 46, pp.717-723.

Kontos, P., Grigorovich, A., Dupuis, S., Jonas-Simpson, C., Mitchell, G. and Gray, J. (2020). Raising the curtain on stigma associated with dementia: fostering a new cultural imaginary for a more inclusive society. *Critical Public Health*, 30(1), pp.91-102.

Kosso, P. (1998), 'Observation' In: Routledge Encyclopedia of Philosophy, Taylor and Francis, Available at: https://www.rep.routledge.com/articles/thematic/observation/v-1 [Accessed 22 August 2021].

Koh, E., Low, Felicia & Kam, Jia & Rahim, Sahnan & Ng, Wei & Ng, Li. (2019). Person-centred creative dance intervention for persons with dementia living in the community in Singapore. *Dementia.* doi:10.1177/1471301218823439.

Kothari, C. (2004). *Research methodology Methods and Techniques*. 2nd ed. New Delhi: New Age International (P) Ltd.

Kowarzik, U. (2006). Opening doors: Dance movement therapy with people with dementia. In H. Payne (Ed.), *Dance movement therapy: Theory, research and practice* (2ed). London: Routledge.

Králová, J. (2015). What is social death? *Contemporary Social Science*, 10(3), pp.235-248.

Krueger, R. and Casey, M. (2000). *Focus Groups: A practical guide for applied research*. 3rd ed. London: Sage Publications, Inc.

Laland, W. (2016). The evolution of dance. *Current Biology*, 26(1), R5–R9. Available at: https://doi.org/10.1016/j.cub.2015.11.031 [Accessed 12 May 2020].

Lam, F. M., Huang, M. Z., Liao, L. R., Chung, R. C., Kwok, T. C., & Pang, M. Y. (2018). Physical exercise improves strength, balance, mobility, and endurance in people with cognitive impairment and dementia: a systematic review. *Journal of physiotherapy*, *64*(1), 4–15. Available at: https://doi.org/10.1016/j.jphys.2017.12.001 [Accessed 12 May 2020].

Lapum, J. L., & Bar, R. J. (2016). Dance for Individuals with Dementia. *Journal of psychosocial nursing and mental health services*, *54*(3), 31–34.

Lawrence, V., Fossey, J., Ballard, C., Ferreira, N., & Murray, J. (2016). Helping staff to implement psychosocial interventions in care homes: augmenting existing practices and meeting needs for support. *International journal of geriatric psychiatry*, *31*(3), 284–293.

Lavrakas, P.J. (2008), *Encyclopedia of Survey Research Methods*, Sage Publications, Inc., Thousand Oaks, CA, [Accessed 1 July 2019], doi: 10.4135/9781412963947.

Leonard, M. (2005) 'Performing identities: music and dance in the Irish communities of Coventry and Liverpool', *Social & Cultural Geography*, 6(4), pp. 515-529. doi: 10.1080/14649360500200239.

Liamputtong, P. (2019). *Handbook of Research Methods in Health Social Sciences*. Singapore: Springer Singapore.

Limerick Institute of Technology (LIT) (2021). *Data Protection*. [online] Available at: https://lit.ie/en-IE/corporate-services/Information-Compliance/Data-Protection [Accessed 19 March 2021].

Limerick Institute of Technology (LIT) (2019) *LIT Ethics Policy for Researchers 2019-2022* [Online] Available at: https://lit.ie/admin/LIT/media/LIT/Quality/Quality%20Handbook%202019_2020/Volume%20(4)%20Ac%20Regs_Policies_Procedures/(27)-LIT-Ethics-Policy-forResearchers.pdf [Accessed 17 March 2021].

Limerick Institute of Technology (LIT) (2019) *LIT Research Integrity Policy* [online] Available at: https://lit.ie/admin/LIT/media/LIT/Quality/Quality%20Handbook%2020202021/(28)-LIT-Ethics-Policy-for-Researchers.pdf [Accessed 19 March 2021].

Lin, R., Yan, Y., Zhou, Y., Luo, Y., Cai, Z., Zhu, K. and Li, H., (2020). Effects of Creative Expressive Arts-based Storytelling (CrEAS) programme on older adults with mild cognitive impairment: protocol for a randomised, controlled three-arm trial. *BMJ Open*, 10(11), p.e036915.

Lorentzon, M. and Bryan, K. (2007). Respect for the person with dementia: fostering greater user involvement in service planning. *Quality in Ageing and Older Adults*, 8(1), pp.23-30.

Low, L., Carroll, S., Merom, D., Baker, J., Kochan, N., Moran, F. and Brodaty, H., (2016). We think you can dance! A pilot randomised controlled trial of dance for nursing home residents with moderate to severe dementia. *Complementary Therapies in Medicine*, 29, pp.42-44.

Majer, R., Simon, V., Csiba, L., Kardos, L., Frecska, E., and Hortobágyi, T. (2019). Behavioural and psychological symptoms in neurocognitive disorders: Specific patterns in dementia subtypes. *Open Medicine* 14, 1, 307-316, Available From: De Gruyter https://doi.org/10.1515/med-2019-0028 [Accessed 23 November 2020].

Martikainen, P., Bartley, M. and Lahelma, E., (2002). Psychosocial determinants of health in social epidemiology. *International Journal of Epidemiology*, 31(6), pp.1091-1093.

Mathers, N., Fox. N., Amanda., H. (2002). *Trent focus for research and development in primary health care: Using interviews in a research project*. Trent Focus.

Maxwell, J. (2015). *Qualitative research design: An Interactive Approach*. 2nd ed. London: Sage Publications.

May, T. (2011). *Social Research: Issues, Methods and Process*, 4th edition, Buckingham: Open University Press.

McDermott, O., Orrell, M., & Ridder, H. M. (2014). The importance of music for people with dementia: the perspectives of people with dementia, family carers, staff and music therapists. *Aging & mental health*, *18*(6), 706–716. Available at: https://doi.org/10.1080/13607863.2013.875124 [Accessed 18 February 2020]

McKechnie, L.E.F. (2008). Observational research. In Given, L.M. (Ed.), The Sage encyclopedia of qualitative research methods (pp.573-577). Thousand Oaks, CA: Sage.

McKenna, C. (2015): *"The Man who Danced on the Radio"*, Social Sciences ConneXions Autumn Series, Limerick Institute of Technology (October).

McKenzie, K., Bowes, R. and Murray, K., (2021). Effects of dance on mood and potential of dance as a mental health intervention. *Mental Health Practice*, 24(3), pp.12-17.

McKeown, J., Clarke, A., Ingleton, C., Ryan, T., & Repper, J. (2010). The use of life story work with people with dementia to enhance person-centred care. *International Journal of Older People Nursing*, *5*(2), 148–158.

McShane, R., Keene, J., Gedling, K., Fairburn, C., Jacoby, R. and Hope, T. (1997). Do neuroleptic drugs hasten cognitive decline in dementia? Prospective study with necropsy follow up. *BMJ*, 314(7076), pp.266-266.

Mehra, B. (2002). Bias in qualitative research: Voices from online classroom*,* The *Qualitative Report* 7, (1).

Melhuish, R., Beuzeboc, C. and Guzmán, A. (2017). Developing relationships between care staff and people with dementia through Music Therapy and Dance Movement Therapy: A preliminary phenomenological study. *Dementia*, 16(3), pp.282-296.

Milte, R., Shulver, W., Killington, M., Bradley, C., Ratcliffe, J., & Crotty, M. (2016). Quality in residential care from the perspective of people living with dementia: The importance of personhood. *Archives of gerontology and geriatrics*, *63*, 9–17. Available at: https://doi.org/10.1016/j.archger.2015.11.007 [Accessed 18 October 2020].

Milligan, L. (2016). Insider-outsider-inbetweener? Researcher positioning, participative methods and cross-cultural educational research, Compare: *A Journal of Comparative and International Education*, 46:2, 235250, doi: 10.1080/03057925.2014.928510.

Moniz-Cook, E. & Manthorpe, J., (2020). *Timely Psychosocial Interventions in Dementia Care: Evidence-based practice*. London: Jessica Kingsley Publishers.

Moreno-Morales, C., Calero, R., Moreno-Morales, P. and Pintado, C., (2020). Music Therapy in the Treatment of Dementia: A Systematic Review and Meta-Analysis. *Frontiers in Medicine*, 7.

Moss, H., & O'Neill, D. (2017). Narratives of health and illness: Arts-based research capturing the lived experience of dementia. *Dementia*, 18(6), 2008–2017. Available at: https://doi.org/10.1177/1471301217736163 [Accessed 15 March 2020].

Murrock, C. J., & Gary, F. A. (2010). Culturally specific dance to reduce obesity in African American women. *Health Promotion Practice*, 11(4), 465–473. Available at: http://dx.doi.org/10. 1177/1524839908323520 [Accessed 5 April 2020].

National Adult Literacy Agency. (2021). *Plain English Tips - Nala*. [online] Available at: https://www.nala.ie/plain-english/plain-english-tips/ [Accessed 11 February 2021].

Naples, N.A. (2003). *Feminism and method: Ethnography, discourse analysis, and activist research*. New York, NY: Routledge.

National Institute for Health and Care Excellence (UK). (2018). *Dementia: Assessment, management and support for people living with dementia and their carers*. National Institute for Health and Care Excellence (UK).

Nguyen, T. and Li, X. (2020) 'Understanding public-stigma and self-stigma in the context of dementia: A systematic review of the global literature', *Dementia*, 19(2), pp. 148–181. doi: 10.1177/1471301218800122.

Nowell, L., Norris, J., White, D. and Moules, N., (2017). Thematic Analysis. *International Journal of Qualitative Methods*, 16(1), p.160940691773384.

Nursing Homes Ireland. (2019), *Pre-budget 2020 submission*. Available at: https://nhi.ie/wp-content/uploads/2019/09/Nursing-Homes-Ireland-Budget-2020Submission-1-1.pdf [Accessed 20 November 2020].

O' Connor, B. (2013). *The Irish Dancing: Cultural Politics and Identities, 19002000*. Cork, Ireland: Cork University Press.

Oed.com. (2021). *Home : Oxford English Dictionary*. [online] Available at: https://www.oed.com/ [Accessed 18 March 2021].

O' Fearail, P. (1975). *The story of Conradh na Gaeilge: A history of the Gaelic League*. Dublin, Conradh na Gaeilge.

O hAllmhurain, G. (2005). Dancing on the Hobs of Hell: Rural Communities in Clare and the Dance Halls Act of 1935. *New Hibernia Review* 9(4), 9-18. doi:10/1353/nhr.2006.0010.

Øksnebjerg, L., Diaz-Ponce, A., Gove, D., Moniz-Cook, E., Mountain, G., Chattat, R. and Woods, B., 2018. Towards capturing meaningful outcomes for people with dementia in psychosocial intervention research: A pan-European consultation. *Health Expectations*, 21(6), pp.1056-1065.

O' Leary, Z. (2017). *The essential guide to doing your research project*. 3rd ed. London: SAGE Publications Ltd.

Opdenakker, R. (2006). Advantages and disadvantages of four interview techniques in Qualitative research. *Forum: Qualitative social research.*

Orellana, K., Manthorpe, J., & Tinker, A. (2020). Day centres for older people: A systematically conducted scoping review of literature about their benefits, purposes and how they are perceived. *Ageing and Society, 40*(1), 73-104. doi:10.1017/S0144686X18000843.

Outhwaite, W. (1998), 'Theory and observation in social sciences' In: *Routledge Encyclopedia of Philosophy*, Taylor and Francis, Available at: https://www.rep.routledge.com/articles/thematic/theory-and-observation-in-social-sciences/v-1 [Accessed 21 August 2021].

O' Rourke, H., Duggleby, W. and Fraser, K. (2015). Embedding the perceptions of people with dementia into quantitative research design. *Quality of Life Research*, 24(5), pp.1145-1155.

O' Shea, E., Keogh, F. and Cooney, A., (2019). *Continuum of Care for People with Dementia In Ireland*. Tullamore: National Dementia Office. Available at: https://cesrd.ie/wp-content/uploads/2019/11/The-Continuum-of-Care-for-Peoplewith-Dementia-in-Ireland.pdf [Accessed 21 November 2020].

O Shea, S.D, (2014). *An Exploration of the Lived Experience of those Caring for a Family Member with Early-Onset Alzheimer's Disease*, unpublished dissertation, Limerick Institute of Technology.

O Shea, S.D., (2019). *Reflective Journal,* unpublished. Limerick Institute of Technology.

O Shea, S.D. (2019) *Interview on The Ryan Tubridy Show* (Radio), RTE Radio 1, 2nd May 2019, 09:40. Available online at: https://www.rte.ie/radio/radioplayer/html5/#/radio1/21548852

O Shea, S.D. (2019) Arts, Humanities and Social Sciences Conference, *Some Dance to Remember: Exploring the Psychosocial Effects of the Introduction of an Adaptive Irish Céilí Dance group activity for People Living with Dementia and their Care Staff*, University of Limerick, 7th May 2019.

O Shea, S.D. (2019) Postgraduate Annual Progression Review Colloquium, *Some Dance to Remember*, Limerick Institute of Technology, 8th May 2019.

O Shea, S.D. (2019) Limerick Postgraduate Research Conference, *Some Dance to Remember: Exploring the psychosocial effects of the introduction of an adaptive Irish Céilí Dance group activity for People Living with Dementia and their Care Staff*, University of Limerick, 20th May 2019.

O Shea, S.D. (2020) Transforming care and Communities- Virtual 12th International Dementia Conference, *Some Dance to Remember- The First Steps,* 2nd November 2020.

O Shea, S.D. (2020) *Interview on The Saturday Supplement'* (Radio) Radio Kerry, 7th November 2020, 09:10 Available online at: https://www.radiokerry.ie/saturday-supplement-november-7th-2020/

Palaganas, E., Marian, S., Visitacion, M. and Caricativo, R. (2017). Reflexitivity in Qualitative research: A journey of learning. *Qualitative Report*, 22(2), pp.426438.

Palo-Bengtsson, L., & Ekman, S. L. (2002). Emotional response to social dancing and walks in persons with dementia. *American journal of Alzheimer's disease and other dementias*, *17*(3), 149–153. Available at: https://doi.org/10.1177/153331750201700308 [Accessed 29 October 2020].

Peacock, S., Danger, S., & Nicol, J. (2017). “The music is still there”: Hearing from individuals with dementia who sing together. *Alzheimer’s & Dementia*, 13(7), P1411–P1412. Available at: https://doi.org/10.1016/j.jalz.2017.06.2189 [Accessed 18 October 2020].

Pearce, N. D. (2007). *Inside Alzheimer’s: How to hear and honor connections with a person who has dementia.* Taylors, South Carolina: Forrason Press.

Pesonen, H., Remes, A. and Isola, A. (2013). Diagnosis of dementia as a turning point among Finnish families: A qualitative study. *Nursing & Health studies*, 15(4), pp.480-496.

Phelan, S. A. (2015) *Dance in Ireland: Steps, Stages and Stories*. Newcastle upon Tyne, England: Cambridge Scholars Publishing.

Pierse, T., Keogh, F., O’Shea, E., Cullinan, J. (2020) Geographic availability and accessibility of day care services for people with dementia in Ireland. *BMC Health Serv Res* 20**,** 476 . Available at: https://doi.org/10.1186/s12913-020-05341-z [Accessed 20 October 2020].

Poggenpoel, M. & Myburgh, C. (2003). The researcher as research instrument in educational research: A possible threat to trustworthiness? (A: research_ instrument)”. *Education*, 124(2), p418+

Porter, J. (2018). The Public Dance Halls Act, 1935: A re-examination. *Irish Historical Studies, 42*(162), 317-335. doi:10.1017/ihs.2018.35

Prince, M., Guerchet, M., Prina, M. (2016). Recent global trends in the prevalence and incidence of dementia, and survival with dementia. *Alzheimer’s research & therapy*, 8 (1), 23–23.

Rabiee, F. (2004) “Focus-group interview and data analysis,” *Proceedings of the Nutrition Society*. Cambridge University Press, 63(4), pp. 655–660. doi: 10.1079/PNS2004399.

Rapaport, Penny & Livingston, Gill & Murray, Joanna & Mulla, Aasiya. (2017). Systematic review of the effective components of psychosocial interventions delivered by care home staff to people with dementia. *BMJ Open*. 7. e014177. 10.1136/bmjopen-2016-014177.

Regier, N., Hodgson, N. and Gitlin, L., (2017). Characteristics of Activities for Persons With Dementia at the Mild, Moderate, and Severe Stages. *The Gerontologist*, 57(5) pp.987-997.

Ritchie, J., Lewia, J., McNaughton Nichols, C. and Ormston, R. (2014). *Qualitative research practice*. 2nd ed. London: Sage Publications.

Robertson, J. and McCall, V. (2018). Facilitating creativity in dementia care: the co-construction of arts-based engagement. *Ageing and Society*, 40(6), pp.11551174.

Rolland, Y., Andrieu, S., Crochard, A., Goni, S., Hein, C. and Vellas, B. (2012). Psychotropic Drug Consumption at Admission and Discharge of Nursing Home Residents. *Journal of the American Medical Directors Association*, 13(4), pp.407.e7-407.e12.

Rylatt, P., (2012). The benefits of creative therapy for people with dementia. *Nursing Standard*, 26(33), pp.42-47.

RTÉ Archives. (2020). *Take The Floor Achill*. [online] Available at: https://www.rte.ie/archives/exhibitions/681-history-of-rte/685-rte-1950s/288210take-the-floor/ [Accessed 23 December 2020].

Sabat, S. (2005). Capacity for decision-making in Alzheimer's disease: selfhood, positioning and semiotic people. *Australian and New Zealand Journal of Psychiatry*, 39(11-12), pp.1030-1035.

Sakamoto, M., Ando, H. and Tsutou, A. (2013). Comparing the effects of different individualized music interventions for elderly individuals with severe dementia*. International Psychogeriatrics,* 25(5), pp.775-784.

Savva, G. M., Zaccai, J., Matthews, F. E., Davidson, J. E., McKeith, I., Brayne, C. (2009). Prevalence, correlates and course of behavioural and psychological symptoms of dementia in the population. *The British journal of psychiatry: the journal of mental science*, *194*(3), 212–219. Available at: https://doi.org/10.1192/bjp.bp.108.049619 [Accessed 6 March 2020].

Scales, K., Zimmerman, S. and Miller, S. (2018). Evidence-Based Non-pharmacological Practices to Address Behavioural and Psychological Symptoms of Dementia. *The Gerontologist,* 58(1), pp 88-102.

Schneider, L. S., Dagerman, K. S., & Insel, P. (2005). Risk of death with atypical antipsychotic drug treatment for dementia: meta-analysis of randomized placebo-controlled trials. *JAMA*, *294*(15), 1934–1943. Available at: https://doi.org/10.1001/jama.294.15.1934 [Accessed 6 March 2020].

Schweitzer, P. and Bruce, E., (2008). *Remembering Yesterday, Caring Today: Reminiscence in Dementia Care*. Jessica Kingsley.

Shanagher, S. (2014), *Recreational Dance in Ireland 1940-1960: Politics and Pleasures*, unpublished thesis (Ph.D), Dublin City University, School of Communications.

Shanahan, J., Morris, M., Bhriain, O., Volpe, D., Richardson, M. and Clifford, A. (2015). Is Irish set dancing feasible for people with Parkinson's disease in Ireland?. *Complementary Therapies in Clinical Practice*, 21(1), pp.47-51. Available at: https://doi.org/10.1016/j.ctcp.2014.12.002 [Accessed 23 October 2020].

Shanahan, J., Bhriain, O., Morris, M., Volpe, D. and Clifford, A. (2016). Irish set dancing classes for people with Parkinson's disease: The needs of participants and dance teachers. *Complementary Therapies in Medicine*, 27, pp.12-17.

Shaw F. E. (2002). Falls in cognitive impairment and dementia. *Clinics in geriatric medicine*, *18*(2), 159–173. Available at: https://doi.org/10.1016/s07490690(02)00003-4 [Accessed 23 October 2020].

Sherrat, K., Thornton, A. and Hatton, C. (2004). Music interventions for people with dementia: a review of the literature. *Journal Mental Health and Aging* 8, 1, 3-12.

Silvester, D. and Frampton, S. (2013). *A Handbook For Activity Coordinators And Carers*. London: Jessica Kingsley.

Sims, M., Erwin, H., Abel, M., Clasey, J., Beighle, A. and Fedewa, A., (2019). Descriptive Analysis of the System for Observing Dance Activities in the Classroom Environment (SODANCE). *Journal of Dance Education*, 20(4), pp.189-196

Skinner, M., Herron, R., Bar, R., Kontos, P., & Menec, V. (2018). Improving social inclusion for people with dementia and carers through sharing dance: a qualitative sequential continuum of care pilot study protocol. *BMJ Open*, 8(11), e026912–e026912. Available at: https://doi.org/10.1136/bmjopen-2018-026912 [Accessed 29 October 2020].

Smebye, K. L., & Kirkevold, M. (2013). The influence of relationships on personhood in dementia care: a qualitative, hermeneutic study. *BMC nursing*, *12*(1), 29. Available at: https://doi.org/10.1186/1472-6955-12-29 [Accessed 12 May 2020].

Smith, M., Hall, G., Gerdner, L. and Buckwalter, K. (2006). Application of the Progressively Lowered Stress Threshold Model Across the Continuum of Care. *Nursing Clinics of North America*, 41(1), pp.57-81.

Smith, N., Waller, D., Colvin, A., Naylor, M. & Hayes, J. (2012). *Dance and Dementia Project: Findings from the Pilot Study*. Brighton: University of Brighton.

Social Care Institute for Excellence (2021). *The person behind the dementia - SCIE*. [online] Available at: https://www.scie.org.uk/dementia/afterdiagnosis/communication/person.asp [Accessed 12 February 2021].

Spradley, J., (1980). *Participant Observation*. Long Grove, Illinois: Waveland Press Inc.

Stuckey, H. L. (2013). Three types of interviews: Qualitative research methods in social health. *Journal of Social Health and Diabetes*. 1. 56. 10.4103/23210656.115294.

Subramaniam, P., & Woods, B. (2016). Digital life storybooks for people with dementia living in care homes: an evaluation. *Clinical interventions in aging*, *11*, 1263–1276. Available at: https://doi.org/10.2147/CIA.S111097 [Accessed 18 February 2021].

Subramaniam, P., Woods, B., & Whitaker, C. (2014). Life review and life story books for people with mild to moderate dementia: a randomised controlled trial. *Aging & mental health*, *18*(3), 363–375. Available at: https://doi.org/10.1080/13607863.2013.837144 [Accessed 12 February 2021].

Sudnow, D. (1967). *Passing on*. Englewood Cliffs, NJ: Prentice Hall.

Sutton, John & Williamson, Kellie (2014). Embodied remembering. In L. Shapiro (ed.), *The Routledge Handbook of Embodied Cognition*. Routledge. Available at: https://philarchive.org/archive/SUTER [Accessed 12 February 2021].

Sweeting, H. and Gilhooly, M. (1997). Dementia and the phenomenon of social death. *Sociology of Health and Illness*, 19(1), pp.93-117.

Testad, I., Mikkelsen, A., Ballard, C., & Aarsland, D. (2010). Health and wellbeing in care staff and their relations to organizational and psychosocial factors, care staff and resident factors in nursing homes. *International journal of geriatric psychiatry*, *25*(8), 789–797.

The Open College (2021). QQI Accredited Healthcare, Childcare & Business Online Courses. *Healthcare Support Assistant (General) – Major Award Level 5*. [online] Available at: https://www.theopencollege.com/courses/qqi-healthcarecourses/healthcare-support-5m4339-fetac-level-5-major-award/ [Accessed 1 February 2021].

The National Institute for Health and Care Excellence (2018). Dementia: assessment, management and support for people living with dementia and their carers. *NICE guidelines [NG 97]*, published date: 20th June 2018. [online] Available at: <https://www.nice.org.uk/guidance/ng97/chapter/About-thisguideline > [Accessed 12 November 2020].

Thompson, N., & Doka, K. (2017). Disenfranchised grief. In N. Thompson & G. R. Cox (EDs.), *Handbook of the sociology of death, grief and bereavement* (1st ed.). London, England: Routledge.

Thorne, S. (2000). Data analysis in qualitative analysis. *Evidence Based Nursing*, 3, pp.68-70.

Tierney, S., Wong, G., Roberts, N., Boylan, A., Park, S., Abrams, R., Reeve, J., Williams, V. and Mahtani, K., (2020). Supporting social prescribing in primary care by linking people to local assets: a realist review. *BMC Medicine*, 18(1).

Understandtogether. (2020). *Information on Health Services And Supports*. [online] Available at: https://www.understandtogether.ie/get-support/living-wellwith-dementia/health-professionals-information/ [Accessed 27 October 2020].

VandenBos, G. R. (eds.) (2006). *APA Dictionary of Psychology*, 1st ed. Washington, DC: American Psychological Association.

Van Winkle, L.,J., Schwartz, B.D., Horst, A. & Michels, N. (2018). "An evidence Based model program to foster empathy, mitigate bias, and promote wellbeing through critical reflection on service - Learning by public health/health administration and practitioner student teams", *The Journal of health administration education,* vol. 35, no. 4, pp. 475-490.

Vernooij-Dassen, Myrra & Vasse, Emmelyne & Zuidema, Sytse & CohenMansfield, Jiska & Moyle, Wendy. (2010). Psychosocial interventions in dementia care in long term care. *International psychogeriatrics* / IPA. 22. 1121-8. 10.1017/S1041610210001365.

Vizzotto A.D.B., de Oliveira A.M., Elkis H., Cordeiro Q., Buchain P.C. (2013) Psychosocial Characteristics. In: Gellman M.D., Turner J.R. (eds) *Encyclopedia of Behavioral Medicine*. Springer, New York, NY. Available at: https://doi.org/10.1007/978-1-4419-1005-9_918. [Accessed 12 February 2021].

Volkmar F.R. (2020) Psychosocial. In: Volkmar F. (eds) *Encyclopedia of Autism Spectrum Disorders*. Springer, New York, NY. Available at: https://doi.org/10.1007/978-1-4614-6435-8_1574-3. [Accessed 17 February 2021].

Volpe, D., Signorini, M., Marchetto, A., Lynch, T., & Morris, M. E. (2013). A comparison of Irish set dancing and exercises for people with Parkinson's disease: a phase II feasibility study. *BMC geriatrics*, *13*, 54. [online] Available at: https://doi.org/10.1186/1471-2318-13-54. [Accessed January 2021].

Walsh, K., Sinnott, C., Fleming, A., McSharry, J., Byrne, S., Browne, J. and Timmons, S (2018) 'Exploring Antipsychotic Prescribing Behaviours for Nursing Home Residents with Dementia: A Qualitative Study', *Journal of the American Medical Directors Association*, 19(11), 948-958, available at: https://www.sciencedirect.com/science/article/pii/S1525861018303864 [Accessed 12 February 2021].

Woods, B., O'Philbin, L., Farrell, E. M., Spector, A. E., & Orrell, M. (2018). Reminiscence therapy for dementia. *The Cochrane database of systematic reviews*, *3*(3), CD001120. [online] Available at: https://doi.org/10.1002/14651858.CD001120.pub3 [Accessed 12 February 2021].

Woolhouse, M. and Lai, R., (2014). *Traces across the body: the influence of music-dance synchrony on the observation of dance*. Frontiers in Human Neuroscience, 8.

World Health Organization (WHO). (2012). *Dementia: A public health priority.* United Kingdom: World Health Organization .

World Health Organization (WHO) (2015). *First WHO Ministerial Conference on Global Action against Dementia*. Geneva: World Health Organisation.

World Health Organisation (WHO) (2019). iSupport for dementia: training and support manual for carers of people with dementia. *World Health Organization*. [online] Available at: https://apps.who.int/iris/handle/10665/324794. [Accessed 7 January 2021].

World Health Organisation (WHO) (2020). *Dementia*. [online] Available at: https://www.who.int/news-room/fact-sheets/detail/dementia [Accessed 18 October 2020].

World Health Organisation (WHO) (2021). *First WHO Ministerial Conference on Global Action Against Dementia*. [online] Available at: https://www.who.int/mediacentre/events/meetings/2015/global-action-againstdementia/en/ [Accessed 19 March 2021].

Wu, E., Barnes, D. E., Ackerman, S. L., Lee, J., Chesney, M., & Mehling, W. E. (2015). Preventing Loss of Independence through Exercise (PLIÉ): qualitative analysis of a clinical trial in older adults with dementia. *Aging & mental health*, *19*(4), 353–362. https://doi.org/10.1080/13607863.2014.935290

Young, R., Camic, P. M., & Tischler, V. (2016). The impact of community-based arts and health interventions on cognition in people with dementia: a systematic literature review. *Aging & mental health*, *20* (4), 337–351. Available at: https://doi.org/10.1080/13607863.2015.1011080 [Accessed 19 March 2021].

Zeilig, H., Killick, J. and Fox, C. (2014). The participative arts for people living with dementia: A critical review. *International Journal of Ageing and Later Life*, 9(1), pp.7-34.

Appendix B- Ethical Approval

Ethical Approval Application form

Limerick Institute of Technology

APPLICATION FOR ETHICAL APPROVAL TO COLLECT DATA FROM HUMAN RESEARCH PARTICIPANTS

For completion by Research Postgraduates/Academic Staff/Data Collection

in LIT

In accordance with LIT's Ethics Policy for Research, all researchers at LIT are obliged to complete this Application for Preliminary Ethical Approval Form ***prior*** to the commencement of any research. No retrospective ethical approval will be given. Failure to comply with the LIT Ethics Policy for Research will result in disciplinary action.

The applicable legislation is the Horizon 2020 legislative acts (i) (see legal references at the end of the section).

Please answer all questions – enter N/A if not applicable.

For further explanation on the questions, please see the "Ethical Approval Process" outlined in Section 5, page 13 of the LIT Research Ethics Policy document located on the LIT Staff Portal. **Research Activity Prohibited at LIT (Art. 6 EC**

Commission 1982/2006/EC)

i. Research activity aiming at human cloning for reproductive purposes ii. Research activity intended to modify the genetic heritage of human beings which could make such changes heritable.

iii. Research activities intended to create human embryos solely for the purpose of research or for the purpose of stem cell procurement, including by means of somatic cell nuclear transfer.

Section 1: Please answer all questions – enter N/A if not applicable.

1.	**Applicant's Name:** Sean Donal O Shea	
1.1	**Preliminary Ethical Approval Reference Number:**	
1.2	**School/Faculty:** Faculty of Business and Humanities	**Department:** Applied Social Sciences
1.3	**Research Centre or Group:** Loss and Grief	
1.4	**Principal Supervisor:** Jennifer Moran Stritch	

1.5	**Award Sought:**	*M.A.*	*M.Bus* .	*M.Eng* .	*M.Sc* .	*Ph.D* .
		☒	☐	☐	☐	☐
1.6	**Title of Proposed Research** Some Dance to Remember: Exploring the psychosocial effects of the introduction of an adaptive Irish Céilí Dance group activity with people living with dementia and their carers.					
1.7	**Research Question** What are the psychosocial effects of the introduction of an adaptive Irish Ceili Dance group activity with people living with dementia? • What are the experiences of the local facilitators who would be introducing this adapted Céilí activity in their host organisation? • What are the experiences of participants who are living with dementia and taking part in the dance activity? • What are the attitudes/perceptions of informal family carers and professional care staff who support the participants to engage in this kind of activity? • While this project does not expressly intend on studying adapted Céilí dancing as an intervention that					

	provides therapeutic effects for the individual with dementia, it does pose the question: what is the potential value of “dance for the joy of dance alone” for people living with dementia, especially dance that is adapted to the abilities of the participants and is arguably a good cultural “fit” for them as well? • How can this kind of activity be incorporated in the practice of care professionals, especially social care workers and therapeutic activity professionals working in the dementia care sector who may not have a dance background?
1.8	**Proposed Programme of Research (in the form of an abstract 500 words)** This arts-based social science research project aims to explore, in the context of the psychosocial effects of dance and movement, the experiences of facilitators and participants in a newly-developed adaptive Céilí dance programme for people living with dementia. It is envisioned that an adaptive Céilí dancing activity will be introduced in services that support people with dementia in the greater Limerick/Clare/Tipperary area. These services may include a nursing home, community day programme or respite centre for people in the early or middle stages of dementia. The Céilí dance activity will be adapted to allow for a range of abilities that reflect

	participants' levels of mobility, focus, cognitive skills and interest. The lead facilitator/researcher is a social care professional who has a background in Irish dance. This research poses an interesting ethical dilemma to be negotiated in relation to obtaining consent as the individuals with a dementia diagnosis will have a range of capacities to give consent. However the researcher believes not to involve them will further stigmatise this vulnerable group. Therefore this ethical dilemma will be resolved using progressive legislative provision under the Assisted Decision-Making (Capacity) Act 2015, which provides a statutory framework for individuals to make legally-binding agreements to be assisted and supported in making decisions about their welfare and their property and affairs. This assistance and support is particularly required where the person lacks, or may lack, the capacity to make the decision unaided. The overall decision regarding involving people with dementia will be guided by the values of enablement, inclusiveness, minimum harm and integration into a holistic framework of positive collaboration with families, management and staff members of the host organisation. Additionally, throughout the research process the researcher will make every effort to ensure ethical research protocols are adhered to in line with the provisions of Alzheimer Europe,

	Alzheimer Society of Ireland, Health Research regulations as well as LIT Research Ethics and LIT research Integrity and Good Conduct policies.	
1.9	**Applicant's Signature:**	**Date:**
1.10	**Principal Supervisor's Signature:**	**Date:**

Section 2: Detail the Ethical Issues Identified

Please answer all questions – enter N/A if not applicable.

2.1 Recruitment and Selection of Participants

How will potential research participants be identified and recruited?

This research will take a phenomenological epistemological stance in which the lived experiences of people living with dementia are paramount, therefore participants with a diagnosis of mild/moderate dementia will be sought. will be asked to identify a minimum of 8 and a maximum of 16 people to take part in this research. This will be divided equally between participants with a diagnosis of mild/moderate dementia and professional care workers.

What Inclusion criteria will be applied to participant selection? People identified by the as receiving services for people with a diagnosis of mild/moderate dementia.

Participants deemed by the relevant professionals in to have capacity at the commencement of the activity and have the ability to give consent.

Participants must be attending day care centre. Only participants wishing to take part in the research will be included.

Inclusion of staff is essential to the research project as their knowledge of the person with dementia, their daily care needs and challenges will all be valuable information.

What exclusion criteria will be applied to participant selection?

Individuals who don’t attend will not be included.

Additionally individuals identified by as having a diagnosis of advanced dementia will not be included.

Individuals who do not wish to participate will not be included.

Individuals who do not want to give consent will not be involved.

Care staff not directly involved in the care of the person with dementia will not be included.

How many participants will be recruited?

There will be a minimum of 8 (4 people with a diagnosis of mild/moderate dementia and 4 care workers) and a maximum of 16 (8 people with a diagnosis of mild/moderate dementia and 8 care workers).

What benefits will accrue from this research?

There has been very limited previous research done in this area therefore the researcher believes that this study will give a better knowledge of exploring the psychological effects of the introduction of an adaptive Céilí group activity with people with dementia in a day care centre setting. Additionally, the researcher hopes that this process will help to develop a piece of work that can be used to benefit people with a diagnosis of mild/moderate dementia that attend a day care setting as well as developing a curriculum which can be disseminated widely to allow other organisations to incorporate this into the activities in their respected centres.

An important benefit of this research is that people with dementia will play an active role throughout the whole process which can in itself benefit the individual by instilling a sense of helping others in a similar situation (Oksmebjerg, 2018).

Does your research activity require the permission/co-operation of a gatekeeper? Please explain:

Yes. The researcher has met with the management and staff of prior to commencing the research. Furthermore, permission will be sought from the management to include services users of the centre with a diagnosis of mild/moderate dementia in this research project. Additionally, permission will be sought from the family members/carers of the individuals taking part in the research. Most importantly, permission will be sought from the individuals taking part in the research.

If participants belong to any of the following vulnerable groups please give details.

☐ Children under 18 years of age.

☐ People who have language difficulty

☒ People who have a recognised or diagnosed intellectual or mental impairment

☒ Elderly people

☐ People confined to institutions *(prisoners, residents in 24 hour nursing facilities)*

☐ Persons in unequal relationships with the researcher *(teacher/student; therapist/client; employer/employee)*

☐ Others *(please specify)*

Details:

Discuss the power dynamics between the researcher/s and the research participants and say how the researcher/s has/have accounted for this in their data collection (100 words).

There is a power inequality between the researcher and the participants as the researcher does not have a diagnosis of a cognitive impairment. The researcher is very aware of this inequality as he has personal experience of caring for a person with dementia as well as a BA in Applied Social Studies in Social Care.

Additionally within the consent structure, ongoing consent will be sought from each participant throughout the research.

The researcher proposes to meet with the primary carers and the host organisation's management prior to and during the research process to discuss this power dynamic further.

All participants will be fully informed of the research programme that will be carried out prior to its commencement as well of their right to withdraw up to 1 month after the activity has concluded.

All questions for participants will be carefully constructed prior to interviews.

All interviews will be carried out in a safe environment identified by allowing each participant to feel comfortable and safe during this process.

Where participants belong to any of the vulnerable groups listed above, please confirm you have undergone Garda Vetting (or equivalent process)? The researcher has received Garda Vetting clearance from LIT.
Will incentives/inducements and/or payment of any kind, including expenses, be made to participants for taking part in this research project? If YES, please attach the details to this application. No.

2.2 Additional Documentation	
Where applicable the following supplementary information **must** be attached to your application.	
	Attached
Participant Information Sheet (including possible ways in which the data may be used)	☐

Participant Informed Consent Form (including a statement detailing the right of the participant to withdraw)	☒	
Interview schedule/Questionnaire	☒	
Letters, ads, e-mails, etc. used to recruit participants	☒	
	Attached	**Not Applicable**
Parent/Responsible Other Information Sheet	☒	☐
	☐	☐
Parent/Responsible Other Informed Consent Form (including a statement detailing the right of the participant to withdraw)	☒	☐

	☐	☐
Stimulus materials e.g. visual or auditory materials	☐	☒
Ethical Approval form other Committees	☐	☐
Garda Vetting	☒	☐

2.3 Safety and Security of Participants/Researcher

Please discuss your assessment of any potential risks to participants: Every effort will be made to reduce any risk to the participants of this research project. This research will involve each person participating in an adaptive Céilí dance activity therefore the health and safety guidelines of will be adhered to throughout the whole process. Previous research has illustrated that music and dance have the capacity to evoke emotions and memories for people living with a diagnosis of dementia therefore the researcher will facilitate de-briefing sessions after every group activity.

What measures will be put in place to ensure the safety of participants?

Please explain:

Throughout the dance activities each person with a diagnosis of mild/moderate dementia will be partnered up with a carer as a physical support. Additionally each participant will be encouraged to take several breaks throughout each activity. Furthermore consent will be sought from each participant throughout the research and participants can choose to withdraw from the research up to 1 month after the activity has concluded.

All interviews will take place in an environment that is safe and familiar to the participants.

What processes will be put in place for de-briefing participants?

The researcher will facilitate individual or group de-briefing sessions after each interview and dance session. Here the researcher will read through the information sheet and ask each participant if they have any questions or concerns.

Additionally the researcher will disseminate the contact details of relevant services should the participant require them.

Furthermore, all participants will be informed that they can withdraw from the research up to 1 month after the activity has concluded.

What support measures are available for participants and how will these be communicated?

Participants will be informed before and after each session of the supports available for people living with dementia such as the Alzheimer Society of Ireland and Understand together (www.understandtogether.ie). Additionally, the researcher will have contact details for the Samaritans (www.samaritans.org) and these will be made available to each participant throughout the research. The researcher will provide a leaflet with all the relevant contact details for these services to each participant.

Furthermore, all participants will be informed that they can withdraw from the research up to 1 month after the activity has concluded.

Please discuss your assessment of any potential risks to the researcher, and what measures will be put in place to ensure the safety of the researcher:

The researcher has personal experience of caring for a person with dementia therefore he will keep a reflective journal throughout the duration of the research which will enable him to explore any possible impact that the process is having on him. Additionally, the researcher will meet with his supervisors regularly throughout the process as well as having access to counselling services through LIT.

2.4 Privacy

What measures will be taken to ensure confidentiality of collected data?

The researcher is extremely aware of the importance of confidentiality throughout all stages of the process.

Any data collected will be pseudonymised therefore names of any participants and will be kept confidential.

Pseudonyms will be assigned when transcribing audiotapes and these tapes will be destroyed on completion of the research examination by the relevant examiners.

Where and how will the data be stored / retrieved? See policy on data storage.

All data will be securely stored on a computer which will be password protected. Additionally, all hard copies of transcriptions will be kept in a locked, fireproof cabinet in LIT until the completion of the project.

Furthermore, all audio files will be transferred from the original source and will be stored, password encrypted on a computer file.

Who will have custody of, and access to, the data?

The researcher and the principal supervisor will have access and custody of the data which will be stored on a password encrypted device.

For how long will the data from the research project be stored? ***(Please justify)***

All data collected will be stored for 7 years in accordance with LIT regulations.

Describe the procedures by which consent will be obtained

Participants will be provided with a written information sheet and consent form. This information sheet will be in large bold writing which will make it easier to read for the participant. Additionally this information will be worded in plain language as per NALA (National Adult Literacy Guidelines) guidelines. This will be helpful for the participant who may have challenges with short term memory with and who may forget what they were told by the time they are asked to sign the consent form. The participant information sheet can also serve as a reminder throughout the course of the research as to what the study is about and what is involved. The written information sheet will provide the relevant information in relation to the research. Additionally the information sheet will inform the participant that they can withdraw from the research at any time up to 1 month after the final activity has concluded. Furthermore consent will be sought (from family members, carers and participants) at regular intervals throughout the research. This has the advantage of reminding people with dementia that they are participating in a study and that they are free to withdraw up to 1 month after the final activity has concluded.

2.5 Signed Declarations

Supervisor

(To be completed in cases where the applicant is a research postgraduate student.)

I hereby declare that I have read, understood, and agree to abide by the most recent LIT Ethics Policy for Researchers. I also hereby authorise the named Principal Investigator to conduct this research project in accordance with the requirements of LIT Ethics Policy for Researchers. I have informed the Principal Investigator of their responsibility to adhere to the recommendations and guidelines in set out in the LIT Ethics Policy for Researchers.

Supervisor Signature : ________________________________ **Date:** ____________

Print Name :

Investigator

The information contained in this application form is accurate to the best of my knowledge and belief. I have:

- Read the most recent LIT Ethics Policy for Researchers.
- Agreed to abide by the LIT Ethics Policy for Researchers in conducting this research.
- Accepted without reservation that it is my responsibility to ensure the implementation of the policies outlined in the LIT Ethics Policy for Researchers.
- Undertaken to inform the LIT Ethics Committee of any changes in the protocol.

- Understood that it is my sole responsibility and obligation to comply with all domestic Irish and European legislation and to obtain such statutory consents as may be necessary.
- Agreed not to commence any research until any such consents have been obtained.
- Understood that neither the University, the Committee, nor individual members of the Committee accept any legal obligation (to me or to any third party) in relation to the processing of this application or to any advice offered in respect of it nor for the subsequent supervision of the research.

Candidate Signature : ____________________________ Date :

____

Print Name:

FOR OFFICIAL USE:

Section 3 – Coverage of Ethical Issues
(to be completed by the Standing Committee on Research Ethics)

(It is necessary to complete this section ***only*** if there are '**Yes**' replies in **Section 2**)

Coverage of Ethical Issues	YES	NO
If the research involves use of human embryos or human Embryonic Stem Cells (hESCs), do you consider that this research methodology is necessary in order to achieve the proposal's scientific objective?	☐	☐

Are the ethical issues raised in **Section 2** above adequately addressed in the proposal?	☐	☐
Do the applicants demonstrate familiarity with the guidelines and established ethical standards?	☐	☐
Have the applicants indicated in which country(s) any research raising ethical issues will be carried out?	☐	☐
Have they indicated which national, EU and/or international regulations will apply?		

Section 4 – Conclusion by the Standing Committee on Research Ethics

Conclusion	**YES**	**NO**
PROPOSAL NOT APPROVED	☐	☐
ADDITIONAL INFORMATION REQUIRED	☐	☐
PROPOSAL APPROVED WITHOUT MODIFICATIONS	☐	☐
PROPOSAL APPROVED WITH THE FOLLOWING MODIFICATIONS	☐	☐
Comments:		

Chair LIT Standing Committee on Research Ethics:

__________________ Date : ________________

Approval from Research Ethics Committee- Phase 1

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Sean Donal O' Shea
13 Cill Chaoide
Clarina
Limerick

26 March 2019

Re: Application for Research Ethical Approval

Dear Sean Donal,

I wish to inform you that your application for research ethical approval was reviewed at a recent meeting of LIT's Research Ethics Committee.

The Research Ethics Committee made the following recommendation in relation to your application: **Application approved without modification/amendment**

The initial stage questions are approved only.

Please note the following:

This grounded theory approach will allow new questions to be generated. Such questions will need to be submitted at a later stage for the committee to review.

Yours sincerely,

Dr Lisa Rourke cott
Chair of the Research Ethics Committee

c.c. Jennifer Stritch, Principal Supervisor
Carmel McKenna, Co- Supervisor

Phase 2 - Ethical Approval Application

1.	**Applicant's Name:** Sean Donal O Shea					
1.1	**Preliminary Ethical Approval Reference Number:**					
1.2	**School/Faculty:** Faculty of Business and Humanities		**Department:** Applied Social Sciences			
1.3	**Research Centre or Group:** Loss and Grief					
1.4	**Principal Supervisor:** Jennifer Moran Stritch **Co Supervisor:** Carmel McKenna					
1.5	**Award Sought:**	*M.A.*	*M.Bus.*	*M.Eng.*	*M.Sc.*	*Ph.D.*
		☒	☐	☐	☐	☐

1.6	**Title of Proposed Research** Some Dance to Remember: Exploring the psychosocial effects of the introduction of an adaptive Irish Céilí Dance group activity with people living with dementia and their carers.

Loss and Grief Research Group
LIT
LIMERICK INSTITUTE OF TECHNOLOGY
Munster Academy

Questions for participants living with dementia

Can you tell me if you danced when you were younger?

If so was there a specific dance or tune that you liked?

Who would you dance with when you were younger?

What other activities did you take part in when you were younger? Can you please tell me more about them?

Can you tell me about some of your memories while you were dancing or taking part in other activities? E.g. meeting with friends etc.

Can you tell me about the Irish Céilí dance activity that you take part in here?

Do you take part in other activities here?

If you like to dance, what is it that you enjoy the most about it?

Is there anything that you would like to mention that I have not included?

Questions for care staff

In your opinion, why do you feel each individual participates/ does not participate in this adaptive Irish Céilí dance activity?

What changes in behaviour/mood have you noticed after an individual participates in the adaptive Irish Céilí dance activity in the centre?

Do you think that this adaptive Irish Céilí dance activity is/is not benefitting the participants? Why so?

What are the risks or challenges to the individuals participating in this research that have arisen since the activity commenced? Please expand.

What are the benefits for the participants living with dementia and the care staff in continuing with this dance activity?

Do you have any further comments to add?

Approval from Research Ethics Committee- Phase 2

LfT
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Sean Donal O' Shea
13 Cill Chaoide
Clarina
Limerick

04 December 2019

Re: Application for Research Ethical Approval

Dear Sean Donal,

I wish to inform you that your re-submitted application for research ethical approval was reviewed at a recent meeting of LIT's Research Ethics Committee.

The Research Ethics Committee made the following recommendation in relation to your application:

Application approved without modification

The Research Ethics Committee were impressed with your application and look forward to reading your research.

Yours sincerely,

p.p Joanne Prout
Dr. Lisa O'Rourke Scott
Chair of the Research Ethics Committee

c.c. Jennifer Stritch, Principal Supervisor
Carmel McKenna, Co- Supervisor

Final Phase Ethical Application

1.	**Applicant's Name:** Sean Donal O Shea					
1.1	**Preliminary Ethical Approval Reference Number:**					
1.2	**School/Faculty:** Faculty of Business and Humanities	**Department:** Applied Social Sciences				
1.3	**Research Centre or Group:** Loss and Grief					
1.4	**Principal Supervisor:** Jennifer Moran Stritch **Co Supervisor:** Carmel McKenna					
1.5	**Award**	*M.A.*	*M.Bus.*	*M.Eng.*	*M.Sc.*	*Ph.D.*

	Sought:					
		☒	☐	☐	☐	☐
1.6	**Title of Proposed Research** Some Dance to Remember: Exploring the psychosocial effects of the introduction of an adaptive Irish Céilí Dance group activity with people living with dementia and their carers					

Questions for Participants Living with Dementia

Can you tell me if you danced when you were younger?

If so was there a specific dance or tune that you liked?

Who would you dance with when you were younger?

What other activities did you take part in when you were younger? Can you please tell me more about them?

Can you tell me about some of your memories while you were dancing or taking part in other activities? E.g. meeting with friends etc.

Can you tell me about the Irish Céilí dance activity that you take part in here?

Can you give me your overall opinion on this adaptive Irish Céilí Dance activity?

What do you like/dislike most about it? Please expand

What changes (if any) would you suggest that could be made to this adaptive Irish Céilí Dance activity?

Would you like to continue with this dance activity? Why?

Is there anything that you would like to mention that I have not included?

Loss and Grief Research Group

LIT
LIMERICK INSTITUTE OF TECHNOLOGY

Munster Academy

Questions for Care Staff

In your opinion, why do you feel each individual participated/ did not participate in this adaptive Irish Céilí dance activity?

What changes in behaviour/mood have you noticed after an individual participates in the adaptive Irish Céilí dance activity in the centre?

Do you think that this adaptive Irish Céilí dance activity is/is not benefitting the participants? Why so?

What are the risks or challenges to the individuals participating in this research that have arisen since the activity commenced? Please expand.

What are the benefits for the participants living with dementia and the care staff in continuing with this dance activity?

Can you give me your overall opinion on this adaptive Irish Céilí Dance activity?

What did you like/dislike about the dance activity?

What changes (if any) would you suggest that could be made to this adaptive Irish Céilí Dance activity?

Do you think that the centre will continue with this dance activity?

Are there any possible barriers you can think of that would prevent this activity from continuing here?

Do you have any further comments to add?

Approval from Research Ethics Committee- Final Phase

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Sean Donal O' Shea
13 Cill Chaoide
Clarina
Limerick

27 January 2020

Re: Application for Research Ethical Approval

Dear Sean Donal,

I wish to inform you that your re-submitted application for research ethical approval was reviewed at a recent meeting of LIT's Research Ethics Committee.

The Research Ethics Committee made the following recommendation in relation to your application:

Application approved without modification

Yours sincerely,

Dr. Rita 8cully
Vice Chair of the Research Ethics Committee

c.c. Jennifer Stritch, Principal Supervisor
Carmel McKenna, Co- Supervisor

Recruitment sheet

My name is Sean Donal O Shea and I am completing a Masters by Research in Limerick Institute of Technology. I am writing to ask you if you would be willing to participate in my research. I am conducting research where I will be **Exploring the psychosocial effects of the introduction of an adaptive Irish Céilí Dance group activity with people living with dementia.**

Interview

I will ask participants (both people living with dementia and care staff) a range of questions about their experience of coming to the centre as well as their experience of dance. These questions will be semi-structured and will enable the conversation to flow. The interview will take approximately 10 minutes and I will be recording (voice only) these interviews. It is up to the individual to decide which questions that they want to answer and I will respect any decision completely. Participation in this research is entirely up to the individual and they may withdraw at any time, up to 1 month after the final activity has finished.

Activity

This research will also include the introduction of an adaptive Irish Céilí Dance group activity with people living with dementia and Care Staff. It is proposed that this activity will last approximately 6 weeks, with one session per week.

Confidentiality

As these interviews are very personal, I will protect the individual's identity throughout the research. If the individual agrees to participate in this research, there will be no incentives or benefits compelling them to do so. However if they do wish to participate in this research, it will help me to explore the psychosocial effects of the introduction of an adaptive Irish Céilí Dance group activity with people living with dementia.

If you have any questions about the research, please do not hesitate to contact me and I will answer your queries as soon as possible.

Yours sincerely

Sean Donal O Shea

Email: SeanDonal.OShea@lit.ie Tel: 087 7720921

Loss and Grief Research Group

LIT LIMERICK INSTITUTE OF TECHNOLOGY

Munster Academy

Information sheet for Participants Living with Dementia and Family/carer

Information sheet for participants living with dementia and family/carer

Thank you for your interest in my research. This form will give you a brief description of the research and your rights if you wish to participate.

The aim of the research is to **explore the psychosocial effects of the introduction of an adaptive Irish Céilí Dance group activity with people living with dementia**.

- This research will include a dance activity once a week in .
- I will conduct several brief interviews with you to explore your experiences of dancing and its benefits/drawbacks for the participants with dementia.
- The interview will take approximately 10 minutes and you can choose to answer or not answer any of the questions.
- The interview may be audio recorded so that I can transcribe and analyse them. You can still take part in the research if you do not want to be recorded.
- You do not have to participate in the research and you can withdraw at any stage of the process up to 1 month after the activity has ended.
- Your confidentiality and privacy is very important throughout the research and your identity will be protected throughout.

If you wish to take part, please let me know and I will be in contact again with the details regarding the interview and activity. I have also attached the details of my supervisors and you may contact them with any queries regarding the research.

Thanking you sincerely, and I hope that you can take part in the research.

Sean Donal O Shea,

SeanDonal.OShea@lit.ie

Tel: 087 7720921

My supervisor team for this research project are:

Principal Supervisor

Jennifer Moran Stritch

Email: Jennifer.stritch@lit.ie

Tel: 061 293000

Carmel McKenna

Email: Munsterdanceactivity@gmail.com

Tel: +87 6410180

Information sheet for Care Staff

Thank you for your interest in my research. This form will give you a brief description of the research and your rights if you wish to participate.

The aim of the research is to **explore the psychosocial effects of the introduction of an adaptive Irish Céilí Dance group activity with people living with dementia**.

- This research will include a dance activity once a week in

- I will conduct several brief interviews with you to explore your experiences of dancing and its benefits/drawbacks for the participants with dementia.
- The interviews will take approximately 10 minutes and you can choose to answer or not answer any of the questions.
- The interview may be audio recorded so that I can transcribe and analyse them. You can still take part in the research if you do not want to be recorded.
- You do not have to participate in the research and you can withdraw at any stage of the process up to 1 month after the activity has ended.
- Your confidentiality and privacy is very important throughout the research and your identity will be protected throughout.

If you wish to take part, please let me know and I will be in contact again with the details regarding the interview and activity. I have also attached the details of my supervisors and you may contact them with any queries regarding the research.

Thanking you sincerely, and I hope that you can take part in the research.

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Participant Living with Dementia and Family/carer Consent Form

- I agree to take part in this research project which will include a dance activity.
- I am aware that this interview may be audio recorded and that I can choose to answer or not to answer any of the questions.
- I am aware that I can still take part in this research if I don't want the interviews to be recorded.
- I agree to take part in several brief interviews around my experience of the adaptive dance experiences in . • I am

aware that my identity will be protected throughout the research process.

- I am aware that I can withdraw from this process up to 1 month after the final activity is completed and any time during the research.
- This consent form has been clearly explained to me.

Signed:

____

Family/Primary Carer

signature:_____________________________ Witness signature:

____

Care Staff Consent Form

I have read the information sheet and I agree to participate in this research study which will explore the psychosocial effects of the introduction of an adaptive Irish Céilí Dance group activity with people living with dementia.

- I understand that this research will include a dance activity.
- I understand that participation involves taking part in several interviews and that

I can choose to answer or not to answer any questions.

- I agree to my interview being audio-recorded. I am aware that I can still participate in the research if I do not want to be recorded.
- I understand that all the information that I provide for this research will be treated confidentially.
- I am aware that I can withdraw from this process up to 1 month after the final activity is completed and any time during the research.
- This consent form has been clearly explained to me.

Signed: ____

Witness signature: _____________

Loss and Grief Research Group

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Munster Academy

Interview 1- Questions for Participants Living with Dementia

Can you tell me if you danced when you were younger?

If so was there a specific dance or tune that you liked?

Who would you dance with when you were younger?

What other activities did you take part in when you were younger? Can you please tell me more about them?

Can you tell me about some of your memories while you were dancing or taking part in other activities? E.g. meeting with friends etc.

Describe some of the activities that you do here in .

How long have you been coming to the centre?

Do you take part in the activities here?

If you like to dance, what is it that you enjoy the most about it?

Tell me what it was like after you received your diagnosis?

Has your diagnosis influenced your ability/willingness to dance?

Is there anything that you would like to mention that I have not included?

Interview 1- Questions for Care Staff

In your opinion, why does each individual participate/ not participate in activities organised in the centre?

Can you describe if you have noticed a change in behaviour/mood after an individual participates in an activity in the centre?

Why you think that an adaptive Irish Céilí dance activity would/would not benefit the participants?

Do you believe that there will be any risks or challenges to the individuals participating in this research? Please expand.

Do you have any further comments to add?

Interview 2- Questions for Care Staff

In your opinion, why do you feel each individual participates/ does not participate in this adaptive Irish Céilí dance activity?

What changes in behaviour/mood have you noticed after an individual participates in the adaptive Irish Céilí dance activity in the centre?

Do you think that this adaptive Irish Céilí dance activity is/is not benefitting the participants? Why so?

What are the risks or challenges to the individuals participating in this research that have arisen since the activity commenced? Please expand.

What are the benefits for the participants living with dementia and the care staff in continuing with this dance activity?

Do you have any further comments to add?

Final Interview Questions for Participants Living with Dementia

Can you tell me if you danced when you were younger?

If so was there a specific dance or tune that you liked?

Who would you dance with when you were younger?

What other activities did you take part in when you were younger? Can you please tell me more about them?

Can you tell me about some of your memories while you were dancing or taking part in other activities? E.g. meeting with friends etc.

Can you tell me about the Irish Céilí dance activity that you take part in here?

Can you give me your overall opinion on this adaptive Irish Céilí Dance activity?

What do you like/dislike most about it? Please expand

What changes (if any) would you suggest that could be made to this adaptive Irish Céilí Dance activity?

Would you like to continue with this dance activity? Why?

Is there anything that you would like to mention that I have not included?

Loss and Grief Research Group

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Final Interview Questions for Care Staff

In your opinion, why do you feel each individual participated/ did not participate in this adaptive Irish Céilí dance activity?

What changes in behaviour/mood have you noticed after an individual participates in the adaptive Irish Céilí dance activity in the centre?

Do you think that this adaptive Irish Céilí dance activity is/is not benefitting the participants? Why so?

What are the risks or challenges to the individuals participating in this research that have arisen since the activity commenced? Please expand.

What are the benefits for the participants living with dementia and the care staff in continuing with this dance activity?

Can you give me your overall opinion on this adaptive Irish Céilí Dance activity?

What did you like/dislike about the dance activity?

What changes (if any) would you suggest that could be made to this adaptive Irish Céilí Dance activity?

Do you think that the centre will continue with this dance activity?

Are there any possible barriers you can think of that would prevent this activity from continuing here?

Do you have any further comments to add?

Letters of support

THE ALZHEIMER SOCIETY of IRELAND

The Alzheimer Society of Ireland,
Temple Road,
Blackrock, Co.
Dublin.

07/03/2019

To whom this may concern,

On behalf of The Alzheimer Society of Ireland, I can confirm that we are happy to provide support in relation to the research study proposed by Sean Donal O'Shea, 'Some Dance to remember: Exploring the psychological effects of the introduction of an adaptive Irish Ceili Dance group activity with people living with dementia'. We understand that this study will explore the psychosocial effects of the introduction of an adaptive Irish Ceili Dance group activity with people living with dementia. We welcome progress in furthering our understanding of this cohort, and the significant benefits this activity and insight will bring in relation to supporting those living with dementia and improving quality of life.

We feel that we can support the overall study by providing advice and guidance, and also in relation to supporting recruitment of people with dementia to the study. ASI is currently developing a national PPI panel of people with dementia and carers, who are willing to actively participate in various aspects of the research process. This PPI resource will be available for this proposed study. The ASI looks forward to contributing our expertise and assistance to support this valuable research.

Yours sincerely,

Dr Bernadette Rock

Bernadette Rock

Research and Policy Manager.

Munster

MUNSTER ACADEMY OF DANCE

1st March 2019

Re:

Support for LIT Master of Arts by

Research Project To whom it concerns

I wish to confirm that Munster Academy of Dance is fully supportive of the following Master of Arts by Research project:

Researcher	Project Title
Sean Donal O'Shea	Some Dance to Remember: Exploring the psychosocial effects of the introduction of an adapted Céili Dance group activity with people living with dementia and their carers

Munster Academy of Dance is registered with An Comhdháil na Múinteoirí le Rincí Gaelacha (Congress of Irish Dance Teachers), an association of professional Irish Dance teachers, adjudicators and examiners. Organised in a network of branches throughout the world, the primary purpose of An Chomhdháil is to foster, encourage and promote the art and practice of Irish dancing across all boundaries including, but not limited to, age, ability, and gender.

As a member of An Chomhdhäil, Munster Academy of Dance is fully committed to the principles enshrined in Sport Ireland's Lifelong Involvement in Sport and Physical Activity (LISPA). In this regard, Munster Academy of Dance has developed an adapted Céilî Dance programme for those who may face mobility, agility and/or fragility challenges. With the support of Limerick Sports Partnership, this adapted programme has already been trialled with four disparate groups of participants aged over 55. "Some Dance to Remember" seeks to extend this programme, and provide evidence-based support for the benefits of introducing a similar, yet distinct, programme for people living with dementia and their carers.

As external collaborator on this project, Munster Academy of Dance will provide professional, fully qualified, and Garda-vetted Ceili dance teacher(s), on a probono basis, to advise and guide the postgraduate researcher in the teaching of the programme for the duration of the research project.

I trust the above is in order however should you have any queries please do not hesitate to contact me.

Yours sincerely

Carmel McKenna

Carmel McKenna
MA MBS TCRG Chartered MCI