Kent Academic Repository

Awoyomi, Clara Ajoke (2019) *Is Dance Cafe Effective to improve the quality of life of people with dementia?* Master of Research (MRes) thesis, University of Kent,.

Is Dance Café Effective to improve the quality of life of people with Dementia?
A Pilot Study

Clara Ajoke Awoyomi
September 2019

Thesis submitted in fulfilment for the degree of
MENHEA: MA-R

Tizard Centre

University of Kent

Is Dance Café Effective to improve the quality of life of people with Dementia?
A Pilot Study

Abstract:

Introduction

Dementia is increasing within the population and many people have little stimulation or activity. The aim of this study was to investigate the feasibility of a Dance Café within a residential home for people with dementia, seeing if the patient group were able to take part in dancing and the assessment of nutrition, quality of life and balance and mobility.

Methods

A waiting list intervention approach was used. Residents were allocated randomly to the intervention or a control group, who received the dance intervention at the end of the intervention period. A dance café was held weekly for 6 weeks and assessments taken of weight, amount eaten, balance, mobility and quality of life. Focus groups were held with staff and family members after the intervention period to assess their opinions of the dance café.

Results

It was possible to undertake the regular assessments of nutrition, balance and quality of life for these residents. They were able to join in the dance and enjoyed the experience. There was a trend for the dance participants to gain weight, eat a little more and have an improved quality of life, although the numbers were small. The staff and families all felt that the participants had benefitted from the dance café, with increased mobility, conversation and interest.

Conclusion

It is feasible to undertake this research within a residential home for people with dementia. Although the sample was too small for a clear comparison, some of the dance participants did seem to gain more weight, eat more and experience improved quality of life. A larger study would be required to confirm these results.

Declaration

I confirm that this dissertation is my own original work except where I have acknowledged the use of other people's ideas or words by referencing the material as outlined in the course handbook. I have not submitted this dissertation or any part of it for any other academic award. I have read and understood the definition of plagiarism in the course handbook.

Signature **Date 12/09/2019**

Acknowledgements

I would like to thank my supervisors Professor David Oliver and Professor Rachel Forrester-Jones who were patient and kind to go through my endless drafts and made huge and valuable constructive feedback that assisted me to bring out the best in this study. I would never have been able to make a successful application to the Integrated Research Application System (IRAS) without the guidance of Nicole Palmer (Research Services). Also, very significant person to acknowledge is Lucy Napleton, the professional community dance facilitator, Lucy was very patient and professional throughout the sessions.

I am indebted to all my professional colleagues, the care staff, the service users, the head of service for Darland House, Dementia and CASCADE Sam Robinson, Darland house activities group and the catering department. Without them this study would not have been possible. A big thank you to the Clinical Quality Control Team and Clinical Research Team (Chris, Claire, Sandra and Kerry) of Medway Community Healthcare.

Also deserves a note of thank you is Jim Skinner of the Drill Hall library for his patience in giving me some I.T tutorials during this project.

I thank my family, especially my husband and my brother in-law for their support, understanding and assistance all through the study.

Finally, this dissertation is dedicated to God Almighty who has always been my anchor, protector and provider.

Table of Contents

Total word count: 25,456 (including text, tables, figures, quotes in Introduction, Method, Results, Discussion and Conclusion, excluding Reference and appendix).

List of Figures

List of Tables

Chapter 1: Introduction

1.1. Introduction

People with dementia may spend long periods of time without undertaking any activities. Such inactivity may increase problems with mobility, stability and increase the risks of falls. Within the care home I have been working, we are increasingly aware of the need to help the residents remain active and involved every day. This study aims to consider the effectiveness of a dance café, where residents are able to take part in regular supported dance sessions.

1.2. Overview

The overview of this thesis takes the form of five chapters. Chapter 1, the Introduction gives a brief outline of how and why the research study and the effects of previous studies on quality of life of people with dementia and the effects and changes that the key findings of this study will make towards improving the quality of life of people suffering from dementia. The chapter ends with a brief description of the structure of all the 6 chapters.

Chapter 2 is a Systematic Literature Review and Chapter 3 discusses the methodological approach used for the study. This includes design, participants, recruitment, selection process (inclusion and exclusion), how the dance was delivered, and ethical considerations, the measures (qualitative and quantitative) used, the focus process, data collection and data analysis.

Chapter 4 reports on the results and these are discussed in greater depth in Chapter 5, including a discussion of the limitations and suggested research recommendations.

1.3. Aims of the study

The aim of this pilot study was to assess how effective a dance café can be to improve the quality of life of residents with severe dementia within a nursing home as part of therapy/intervention. The study intervention and secondary objectives were geared towards improving nutrition, reducing risk of falls, hospital admission as well as improvement in quality of life.

1.4. Objectives

The objective of the study was to investigate the possibility of carrying out measurements on people with dementia to see how effective a dance café could be to improve the quality of life of residents with dementia within a nursing home as part of therapy/intervention. The study interventions included participation in 45minutes of a 1950s-1960s CD music programme directed by a dance therapist involving facilitated engagement from staff and relatives, once a week for eight weeks. The pilot main objectives were on feasibility of doing this project with measurements carried out with these patients. The study was also to see if there would be improvement in nutrition, reduced risk of falls and hospital admission and improvement in quality of life.

Chapter 2: Literature review

2.1. Introduction

A review of the literature on the use of dance therapy and music for people with chronic illness and, in particular, dementia was undertaken.

2.2. Search Strategy

To identify studies for inclusion in this review the electronic databases were searched:

Web of Science
PubMed
Google scholar
Index on Nursing, Allied Health Literature
MEDLINE
Psych Info

2.3. Inclusion and Exclusion criteria

Any studies in peer-reviewed journals relating to dance in the care of people with dementia. The time period was 2000 – 2019. Only publications in English were considered

Exclusion criteria:

Studies not in peer reviewed journals, before 2000, not in English language, or not relating to dementia.

2.4. The search terms used were

Dance and dementia
Dance and health care
Nutrition and dementia
Exercise and dementia
Dementia
Dementia and other comorbidities

2.5. Review results

A total of 550 hits were initially made from the searches. 380 citation were made after removing some duplication, some written in foreign language, some were not in healthcare and some were not related to dementia or other mental health issues. Further 340 were excluded after reading the title or abstract. 40 articles were assessed as meeting the inclusion criteria - 26 articles on dance and dementia, 10 articles on exercise and dementia and another 4 articles on dementia and depression – see Figure 1 page 19.

Eighteen of the 40 studies were qualitative, nine were quantitative and thirteen were mixed methods. Studies used different approaches such as therapeutic dance, dance movement therapy, dance therapy, social dancing and psychomotor dance-based exercise, dance on depression and dancing as psychosocial intervention.

This literature review has looked at the evidence of the beneficial use of music and dance within health care and in particular for people with dementia. The review considers the conceptual understanding and theory relating to how dance can increase the quality of life of people suffering from dementia.

2.6. Use of dance in health care

Dance to Health was created by AESOP to demonstrate that an arts intervention can address a major health challenge (https://www.dancetohealth.org/). Dance is a universal form of cultural expression that is uniquely placed to achieve health and wellbeing outcomes. Optimally it combines physical activity, social interaction, creative and emotional expression (Department of Health 2017). Dance/movement therapy (DMT) is defined by the American Dance Therapy Association (ADTA) as the psychotherapeutic use of movement to promote emotional, social, cognitive, and physical integration of the individual, for the purpose of improving health and well-being**.** Dance is a performing art form consisting of purposefully selected sequences of human movement. This movement has aesthetic and symbolic value and is acknowledged as dance by performers and observers within a culture. Dance can be categorized and described by its choreography, by its repertoire of movements, or by its historical period or place of origin (Department of Health 2017).

Arts Enterprise with a Social Purpose (AESOP) has stated that there is a well evidenced urgency to engage older people in exercise in order to prevent falls. Falls are known to be traumatic for older people and a major challenge to the health system. Falls are the most frequent and serious type of accident in people aged 65 plus. They cost the NHS £2.3 billion per year (https://www.dancetohealth.org/). Audits have consistently revealed patchy falls prevention exercise provision. Every extra £1 spent on falls and bone health early intervention services would reduce NHS costs by £2.508. AESOP also confirmed that projections suggest that the number of people aged over 85 will almost double by 2030, with 600,000 more older people developing significant care needs over this period (https://www.dancetohealth.org/). For the problems highlighted above, Arts Enterprise with a Social Purpose (AESOP) created a pilot project on called “dance to health.”

In the evaluation of the pilot project on falls prevention, it was concluded that there was an improvement in physical activity/energy and a slight improvement to the peace of mind of participants over the six-month duration of their intervention (https://www.dancetohealth.org/). Dance to health is a nationwide pioneering community dance programme for older people. It combines evidence-based falls prevention principles with the creativity, expression and energy of dance. It however indicated that the effective standard falls prevention exercise programmes that are currently present in healthcare have practical problems of patchy provision, fidelity to the evidence base, recruitment, retention and maintenance. It was stated that the purpose of their project was to address these problems (https://www.dancetohealth.org/). AESOP wanted also to study other health benefits of dance on recruitment, sustainability, cost effectiveness. In order to achieve the objectives, AESOP partnered with the Sidney De Haan Research Centre for Arts and Health at Canterbury Christ Church University, formed a partnership with the London School of Economics and Political Science (LSE) Personal Social Services Research Unit, dance organisations in Arts Council England’s National Portfolio. AESOP commissioned a Middlesex University Business School report on social enterprise models for falls prevention services and a case study on Slimming World. The pilot programme included codification of Dance to Health, the Middlesex University Business School report and the creation of a business model for roll-out (https://www.dancetohealth.org/). Therefore, this pilot study will corroborate the calls of AESOP and other researchers to conduct more study on dance to help improve the quality of life of people suffering from dementia.

Keogh et al., (2009) in their review of literature on physical benefits of dancing for healthy older adults has described dance as a healing ritual for thousands of years and has its historical roots among indigenous people. Their participants comprised 5,681 randomly selected older people (≥ 65 years) who took part in the 2009 New South Wales (Australia) Fall Prevention Telephone Survey (61% response-rate). The instrument consisted of 11 prompted activities including two separate questions on participation in strength and balance training. Tai- Chi dance, team sports, golf, bowls and specific balance training were classified as balance-challenging activities. Thus, dance itself has been ascribed to have a curative power, whereby dance therapy has been developed in the last decades and follows a specific approach of treatment. Keogh et al., (2009) defines dance (movement) as "the psychotherapeutic use of movement as a process which furthers the emotional, social, cognitive, and physical integration of the individual. It is believed to have a positive impact on the well-being of people with social, physical, mental or psychological impairments". The study showed that there were some significant benefits of dance on the general well-being of older people. Hence, Keogh et al., (2009) recommended studies involving a dance-based exercise program.

Koch and his colleagues completed a meta-analysis where they evaluated the effectiveness of dance movement therapy and the therapeutic use of dance for the treatment of health-related psychological problems (Koch et al., 2014). They considered 23 primary trials on the variables of quality of life, body image, well-being, and clinical outcomes, with sub-analysis of depression, anxiety, and interpersonal competence. Their results suggested that Dance Movement Therapy and dance are effective for increasing quality of life and decreasing clinical symptoms such as depression and anxiety (Koch et al, 2014). Positive effects were also found in terms of subjective well-being, positive mood, affect, and body image. Effects for interpersonal competence were encouraging, but due to the heterogeneity of their data, their results remained inconclusive but with continued development dancing may be an effective means for health promotion and disease prevention, through social contact with other peers. Dancing can also enhance psychosocial well-being (Koch et al. 2014). They therefore recommended that dancing should be promoted in the community to senior citizens as a suitable and people suffering from any form of mental problems. This should be made enjoyable and beneficial form of leisure activity.

Eyigor et al., (2009) completed a randomized control trial focusing on Quality of Life (QoL) of older people. The study was carried out to investigate the effects of group-based Turkish folkloric dances on physical performance, balance, depression and quality of life (QoL) in 40 healthy adult elderly females over the age of 65 years. The participants were randomly allocated into Group 1 (folkloric dance-based exercise) and Group 2 (control). An eight-week dance-based exercise programme was undertaken. Outcome measures included a 20-minute walk test, a 6-minute walk test, stair climbing and chair rise time, Berg balance scale (BBS), the Medical Outcomes Study (MOS), 36-item short form health survey (SF-36), and geriatric depression scale (GDS) questionnaires. The study found that in group 1, statistically significant improvements were found in most of the physical performance tests, BBS and some SF-36 subscales after the exercise ($p < 0.05$) and that in the Group 2 there was no clinically significant change in the variables. They suggested that application of folkloric dance specific to countries as an exercise programme for elderly people may be helpful. However, all the participants were physically active and able to perform activities of daily living (ADL) independently, although none had any experience in strength or regular exercise training. However, the participants did not have any evidence of dementia and they were young people.

In Braun et al., (2015) a systematic review and meta-analysis was undertaken to examine the benefits to physical health of dance interventions among older adults. They considered eighteen studies to have met their inclusion criteria, conducted in North America, South America, Europe, and Asia. They concluded in the studies that there were some positive effects of dance on body flexibility, muscular strength and endurance, cognitive ability and cardiovascular endurance. They suggested that dance, regardless of its style, can significantly improve muscular strength and endurance, balance, and other aspects of functional fitness in older adults and they recommended that future researchers may want to analyse the effects of dance on mental health and explore ways to make this intervention attractive to both genders. However, there were issues in the review as outcome measures for dance were varied and there were suggestions that a standardised approach would facilitate meta-analysis.

Smith et al., (2012), a group of academics, dance artists and practitioners with Brighton and Hove Primary Care Trust with Brighton & Hove City Council involved in research about dance and dementia, carried out their pilot study to determine how people with dementia can respond to dance and whether dance can help them to develop and maintain relationships among themselves and with those who care for or support them. Their project involved six weekly dance movement sessions at Ireland Lodge Day Centre on a day on the residents who normally came there. They argued that there was evidence to suggest that dancing for people with dementia has been explored in hospital settings and day centres and positive effects have been noted. However, they commented upon the limitations of relying upon feedback interviews with participants and the need for future evaluations to include film and visual mechanisms especially in dance projects. However, there are similarities between Smith's study and this current pilot study in that they both measure qualitative, notwithstanding that this current study is a mixed method. On the other hand, Smith's study was carried out on people suffering from dementia but could still attend day centre for activities and were able to attend interview while the participants in this current study were confirmed not to have capacity to attend any interview due to cognitive impairment. Hence, personal consultees and nominated consultees voluntarily randomised to act on their behalf. Nevertheless, the two studies reported improved speech/ communication, social activities, bonding, mobility and quality of life in general, though, not very prominent in this pilot study due to the small number of samples.

In the same vein, Sixsmith and Gibson (2007) in their qualitative research that explored the role and importance of music in everyday life; the benefits derived from participation in music-related activities; and the problems of engaging with music, they collected their data during in-depth interviews with 26 people living with dementia and their carers, who lived either in their own homes or in residential care in different parts of England. They concluded that music is an important source of social cohesion and social contact supports participation in various activities within and outside the household. They further stressed that music provides a degree of empowerment and control over everyday situations. They also found that the ability to appreciate and engage with music remained intact even as cognitive functions have declined and suggested that people with dementia must not be excluded from any study that can improve their quality of life.

All these elements have independent evidence, cases have shown that dance may offer a holistic experience which provides pleasure to participants. There have been suggestions that there are ongoing health benefits, including:

- Reduces risk of a range of diseases, e.g. coronary heart disease, stroke, type 2 diabetes
- Helps maintain a healthy weight.
- Helps maintain ability to perform everyday tasks with ease
- Improves self-esteem.
- Reduces symptoms of depression and anxiety (Stuckey et al., 2010; Baker et al., 2010).

Baker et al., (2010) carried out a six-month, randomized, controlled, clinical trial on thirty-three adults (17 women) with mild cognitive impairment ranging in age from 55 to 85 years (mean age, 70 years). The purpose of their study was to examine the effects of aerobic exercise on cognition and other biomarkers associated with Alzheimer disease pathology for older adults with mild cognitive impairment and assess the role of gender as a predictor of response. Their study provides support, using rigorous controlled methodology, for a potent non-pharmacologic intervention that improves executive control processes for older women at high risk of cognitive decline. The outcome may support the hypothesis that cognition and other health issues can be helped by exercise like dance.

Stuckey et al., (2010) reviewed literature covering the period from 1995 through 2007 to explore the relationship between engagement with the creative arts and health outcomes, specifically the health effects of music engagement, visual arts therapy, movement-based creative expression, and expressive writing concluded that there is evidence that art-based interventions are effective in reducing adverse physiological and psychological outcomes.

Their review was to represent a sampling of many potential benefits of art in enhancing health and wellness. Stuckey and colleagues did claim that music appeared to be the most researched medium of art and healing, ant that there was a principal emphasis on the use music to improve quality of life. However, evaluations of the potential benefits of dance as therapy for patients with certain illnesses such as dementia, breast cancer, brain damage patients, eating disorders, depression and alcoholism were often performed with suboptimal study designs have been suggested that dance can have positive output. Hence, (Stuckey et al., 2010; Baker et al., 2010) have recommended more studies to confirm this.

Serra et al., (2016) undertook a randomised controlled study on balance and muscle strength in elderly women to evaluate the postural balance and muscle strength among women participating in the "Wing of Baianas" Samba dancing in the carnival parades. One hundred and ten women, with an average age of 67.4±5.9 years, were divided into two groups: Baianas group elderly participants of the carnival parades in the “Wing of Baianas”, and a Control group of women who do not dance samba. Assessments included a physical activity questionnaire, isokinetic muscle strength testing for the knee extensors and flexors, and a postural balance assessment completed on a force platform (Serra et al., 2016). They concluded that there were no differences between groups, for postural balance outcomes, during the eyes open condition, but that with eyes closed, there was a significant effect between the groups in all variables (Serra et al., 2016). They considered that with the growth of the aging population, and the increasing risk for falls and related morbidity it was vital to seek efficient, comprehensive, and culturally relevant prevention programmes for elderly people to reduce risks for falls, such as samba dancing.

Keogh and colleagues undertook a study to examine whether 15 months of regular participation in Tai Chi (TC) exercise, dancing, instrument playing and singing, as part of a mind–body meditative approach (MBMA), improves brain executive function, psychological functioning and mental health in Chinese older adults (Keogh et al 2009). They suggested that some previous reports have indicated that older adults can significantly improve their aerobic power, lower body muscle endurance, strength and flexibility, balance, agility, and gait through dancing and that there has been evidence that dancing might improve older adults’ body bone materials and muscle power, as well as reduce episodic falls and cardiovascular health risks (Keogh el al., 2009). This study again suggested that further research is, however, needed to determine the efficacy of different forms of dance, the relative effectiveness of these forms of dance compared with other exercise modes, and how best to engage older adults in dance participation

2.7. Use of Dance for people with dementia

Kwan and colleagues undertook a study to determine whether depression and other mental health issues were important and independent predictors of falls in community-dwelling older people living in Taiwan (Kwan et al 2011). In their study they selected 280 community-dwelling people who not taking anti-depressant medication and who were aged 65–91 years (mean age 74.9) 80 participants completed the Geriatric Depression Scale and underwent a range of sensorimotor, balance and mobility tasks and were then followed up for 2 years with monthly telephone calls to determine falls incidence. The tests they used were of standing balance, with the single leg stance and near tandem stand tests; functional mobility assessed with the Timed Up and Go; six-metre walking speed; alternate step; sit-to-stand and minimal chair height standing tests (Kwan et al 2011). They concluded that exercise programmes did reduce the levels of the depression and improve cognitive abilities and the sleep quality in older people.

However, the study did not specifically state that people with dementia was involved although dementia was one of the aspects of mental health issues assessed. There were other problems as out of 280 participants, only 200 participants had their data analysed (Kwan et al., 2011). They also suggested that exercise appeared to counteract the age-related cognitive decline, reduce the cognitive resources expended to control a locomotor task and have beneficial effects in relation to depression and other mental health issues, but these changes were not statistically significant, due to the small sample, but the trends aligned with clinical observation. The findings of this study suggested a positive efficacy of dancing therapy on cognitive, physical, emotional and social performance of people with dementia, but they also realised that randomized controlled clinical trials should be conducted in this field.

A study from China involved community-dwelling volunteers from ten social centres for seniors in the Shatin District of Hong Kong was conducted by Hui et al., (2008). Following randomization, the active group began a 12-week, 23-session aerobics class while the control group was instructed to continue with their usual daily activities (Hui et al., 2008). They reported that 82.7% of their subjects in dancing group expressed that dancing was extremely helpful in improving their psychological well-being and the participants felt happy and enjoyed the dance training generally (Hui et al, 2008). Nevertheless, Hui et al., (2008) also reported that regardless of what the participants testified, psychological benefit may have been attributed to the social network and friendship developed while dancing in a group, rather than to the dancing itself. They were also of the opinion that the effects may have been due to the fitness level and highly motivated nature of the participants in the study (Hui et al., 2008). Nevertheless, they argued that a more significant result may be found if older, frailer, or depressed participants were studied. Overall, this indicates that everybody might benefit from dance and music, regardless of age and health status but this may be more noticeable in people with dementia. However, Hui et al., (2008) reported that there were some limitations in their study, stating that their study had a high female to male ratio and the findings may only not be applicable to men and women. Secondly, as Hui et al., (2008) only recruited young–old participants (60–75 years), the results only reflect the response of this age group, but not that of the older people (>75 years).

McDermott et al., (2013) in their rigorous evaluations of qualitative data from music therapy sessions, showed that responses from individuals may particularly be important to investigate what aspects of music therapy people with dementia themselves may find meaningful. Their study aimed to develop further insights into the musical experiences of people with dementia and explore the meaning of music in their lives. McDermott and colleagues had separate focus groups and interviews with care home residents with dementia and their families, day hospital clients with dementia, care home staff, and music therapists. The findings of the thematic analysis were investigated further in the light of psychosocial factors with the aim of developing a theoretical model on music in dementia.

This study demonstrated that the effects of music go beyond the reduction of behavioural and psychological symptoms and highlighted how music is closely linked to personal identity and life history of an individual, how people at all stages of dementia can access music and how music can help improve social psychology of care home environment (McDermott et al., 2013). Moreover, it is evident that the individual preference of music was preserved throughout the process of dementia. Thus, the importance of learning each person's musical history for those involved in dementia care cannot be overestimated. Sustaining musical and interpersonal connectedness, particularly when the progress of dementia becomes more prominent would help value who the person is and maintain the person's quality of life. There has been increased interest in the provision of music to help people with dementia. The Music and Memory project in the USA has shown that people with dementia, who have not been communicating and are withdrawn, may become animated when listening to music (https://www.youtube.com/watch?v=5FWn4JBYLU).

The Project is aiming to increase music availability throughout nursing homes in the USA, using an "I-pod" which is loaded with music that is known to have significance for the person in an individualised way (www. musicandmemory.org). This again shows the importance of music, which is a crucial part of the experience in dancing, for people with dementia.

Bruno and Jarrot (2008) conducted a qualitative study to explore the concepts of meaningful activity, as defined by older people with dementia living in care homes, staff and family carers. They included focus groups including 17 residents, 15 staff and eight family carers from three care homes. Residents found meaning in activities that addressed their psychological and social needs, which related to the quality of the experience of an activity rather than specific types of activities. In contrast, staff and family carers viewed activities that maintained. They also concluded that the quality of life of people with late-stage dementia is more likely to improve when they are integrated and engaged in sensory-motor type of activities such as simple physical games, food preparation and dance. They however were of the opinion that people with dementia, staff and carers had differing views about what made activities meaningful. Organisational limitations and social beliefs limited the provision of meaningful activities for the population. This implies that this facility is not almost always available. In any setting for dementia people, provision of music must be of priority as this has been proved to be effective in at stages of dementia.

Duignan and colleagues undertook a study which was an intervention to assess impact of Wu Tao dance therapy, for people with dementia, on agitation (Duignan et al., 2009). The four-week pilot study involved six clients with dementia attending dance sessions with members of staff in a residential dementia facility in Australia. In the study, agitation was measured using the Cohen Mansfield Agitation Inventory (CMAI) Agitation scores were reduced in four out of six residents (Duignan et al., 2009). The therapy was said to have also lifted the spirits of both residents and staff, and a therapeutic bond between the two groups developed and they concluded that there was reduction in agitation score in their pilot study. However, this was a very small study and firm conclusions cannot be made.

Cherkin et al., (2011) concluded in their systemic review to evaluate the hypothesis that dance therapy has therapeutic benefits by systematically analysing and summarizing the evidence. Thirteen databases were searched for systematic reviews and randomized controlled trials (RCTs) on the effectiveness of dance therapy. The Overall Quality Assessment Questionnaire (OQAQ) was used to assess review quality for the eight reviews and 18 RCTs about the effectiveness of dance therapy met their inclusion criteria (Cherkin et al. 2011). Seven of the eight reviews were assessed as being of poor methodological quality and the quality of the RCTs ranged from poor to good. The reviews and trials reported positive benefits of dance in improving quality of life, self-esteem, or coping with a disease. However, they further say that most studies have found therapeutic benefits of dance therapy, although these results are based on generally poor-quality evidence. They suggested that dance therapy should be considered as a potentially relevant add-on therapy for a variety of conditions that do not respond well to conventional medical treatments and well-performed RCTs and observational studies are highly recommended to determine the real value of dance therapy.

Myskja & Nord (2008) undertook a pilot study of young people living in an institution, being diagnosed with early onset of dementia or depression. The institution, Valerengen Bo–og service centre in Oslo, Norway, is a long–term institution with 84 residents, and has continually had regular music therapy activities with a music therapist in full–time employment since 1999. The institution was without music therapy services during the fall of 2003. At the end of the period without a music therapist, measurement of depression level by the use of Montgomery Aasberg Depression was conducted and this was found to be high (Myskja et al., 2008). It was reported that two months after music therapy services had been resumed with music therapy groups twice a week in each unit and individualized services other days, a new measurement of depression level of all residents was conducted, showing a significant fall in the music therapy condition, compared with the no music therapy condition in a cross-over design (Myskja et al., 2008). Staff at the institution reported that there were no significant changes in medication over this period (Myskja et al 2008). The study's findings indicate a positive impact of dance therapy on not just dementia but other mental health issues such as depression.

Se-Hong undertook a pilot study to look at the effects of dance exercise on cognitive function in elderly patients with metabolic syndrome (Se-Hong et al 2011). The participants included 38 elderly patients with metabolic syndrome (a cluster of conditions that occur together, increasing your risk of heart disease, stroke and type 2 diabetes and which is a recognised precursor for dementia) with normal cognitive function (26 exercise group and 12 control group). The exercise group performed dance exercise twice a week for 6 months. Cognitive function was assessed in all participants using the Korean version of the Consortium to Establish a Registry for Alzheimer's disease (Se-Hong et al., 2011).

There was a repeated measure to assess the effect of dance exercise on cognitive function and cardio metabolic risk factors. Compared with the control group, the exercise group significantly improved in verbal fluency (Se-Hong et al., 2011). Nevertheless, there was a limitation on the study, that is, the subjects were neither randomized nor blinded, and it is possible that those who agreed to participate in the study may have been more motivated. Participant expectancy and experimenter bias may have played a role in the observed improvements. Moreover, given the small sample size in this preliminary study, the generalizability of (Se-Hong et al., 2011) findings to the larger population of older persons should be approached with caution. Despite these limitations, the results of the study have supported the evidence showing a positive effect of dance exercise on cognitive function in elderly people with metabolic syndrome, which is a recognized risk factor for the progression to dementia. Se-Hong et al., (2011) suggested that further studies to evaluate the effect of various types of dance exercise as well as exercise intensity, frequency, and duration on cognitive function are needed to verify the improvements observed in the present study. Such studies would provide important information on methods to prevent degenerative neurological diseases among elderly people with other conditions which can eventually lead to dementia.

In a systematic review conducted by James et al (2013) aimed to raise awareness of the possibility of implementing dance work as an engaging activity in care homes. Of the evidence from studies related to dancing interventions for older people with dementia living in care homes, ten studies were identified that satisfied their inclusion criteria: seven qualitative and three quantitative. James and colleagues said they used different approaches such as therapeutic dance, dance movement therapy, dance therapy, social dancing and psychomotor dance-based exercise. They concluded that there was evidence that problematic behaviours decreased; social interaction and enjoyment in both residents and care staff improved, although, a few adverse effects were also acknowledged (James et al., 2013).
James et al (2013) concluded that evidence on the efficacy of dancing in care homes is limited in part owing to the methodological challenges facing such research as dance work may be a means to encourage relationships and sensory stimulation for both residents and staff (James et al 2013).

Hammer and Orrell (2008) undertook a qualitative study to determine a meaningful activity for people with dementia living in care homes. They compared the views of older people with dementia, staff and family carers by using focus groups including 17 residents, 15 staff and eight family carers from three care homes. They used a thematic approach to transcript the content analysis and the themes that emerged were of reminiscence, communication and mobility. They concluded that people with dementia, staff and carers had differing views about what made activities meaningful and organisational limitations and social beliefs limited the provision of meaningful activities for this population. For instance, people with dementia find it difficult to communicate effectively and the need for their independence can be overlooked. Nevertheless, Hammer and colleague also indicated areas for improving activity provision in care homes.

A further study carried was carried out by (Resnick et al., 2000) to test the impact of function-focused care for the cognitively impaired intervention on nursing home residents with dementia and attitudes of the nursing assistants who care for them. Their study was a cluster-randomized controlled trial using repeated measures and. They had a total of 103 cognitively impaired residents and 77 nursing assistants were recruited from four nursing homes. For residents, outcome measures included function, physical activity (survey and actigraphy), mood, behaviour, and adverse events (falls and hospitalization).

They included the main outcome measures for nursing assistants as knowledge, beliefs, and performance of function focused care. They reported that there were significant improvements in the amount and intensity of physical activity and physical function in the treatment group (Resnick et al., 2000). The study reported that older adults had an improved sense of well-being and happiness, better mood, decreased levels of stress, improved attention span, improved cognitive ability, better sleep, and a sense of accomplishment associated with regular exercise. In addition, there was a significant decrease in the number of residents who fell during the treatment period with those in the treatment sites having fewer falls (28% vs. 50% in the control group). They also suggested that nursing assistants were also observed to be providing a greater percentage of function-focused care during resident care interactions in the treatment group at 6 months following the completion of baseline measures (Resnick et al., 2000).

Thus, this study provides some evidence that nursing home residents with severe cognitive impairment can safely and successfully be engaged in physical and functional activities.

2.8. Summary

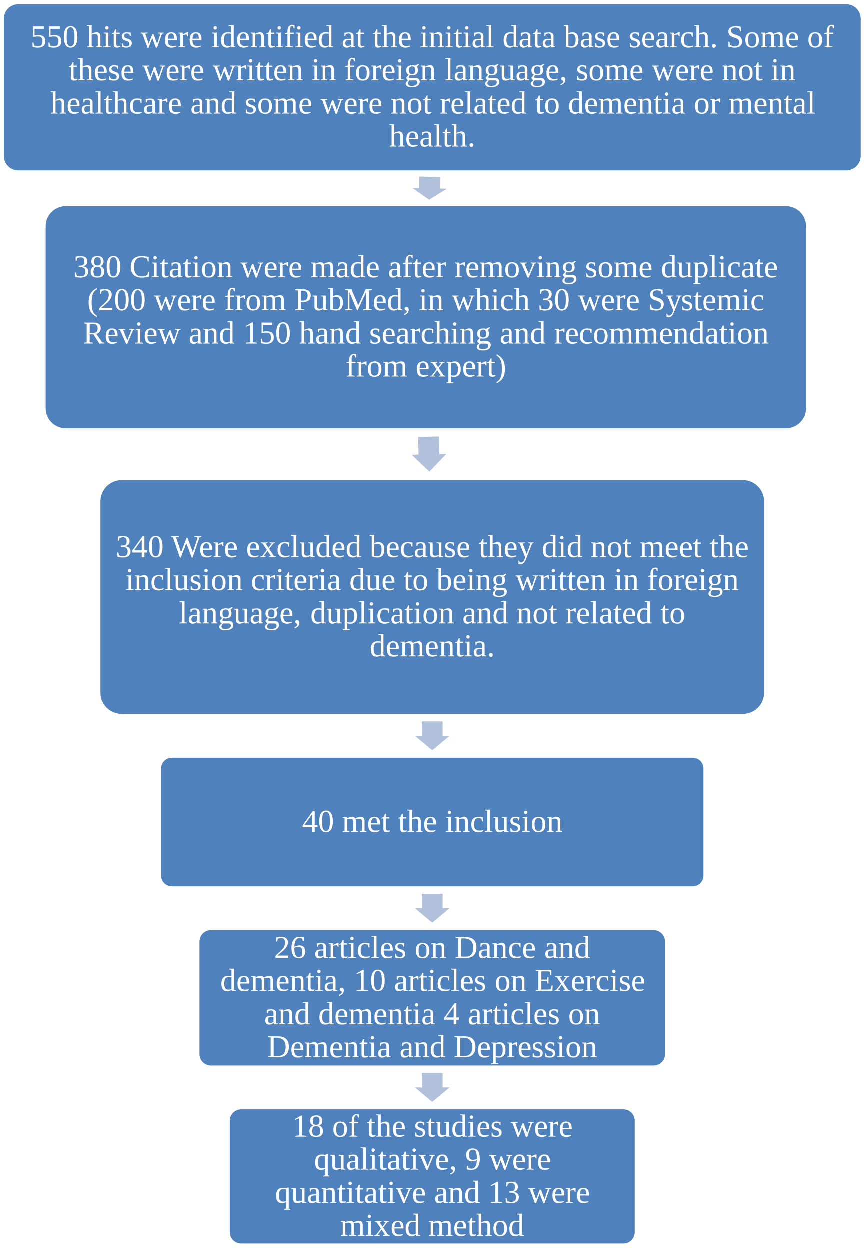
The literature review shows clear evidence that older people need a form of activities such as dance to avoid memory loss and to improve their quality of life. Being involved in musical activity such as dance is also therapeutic and beneficial to people with dementia. Dance has been shown to be acceptable for people with dementia and has shown to help in improving their quality of life in the areas of social interaction, cognition, mobility and overall quality of health.

In these previous studies, there were some evidence that problematic behaviours improved when people with dementia were able to take part in dancing and other physical activities. In particular, social interaction and enjoyment in residents that participated and relationships between residents and care staff were reported to have improved. Nevertheless, there were a few problems acknowledged, such as the limited evidence of the efficacy of dancing in care homes in part owing to the methodological challenges that were faced in the research process. Individuals with dementia need to feel attachment when they so often feel as though they are in a strange place and they need to be included and involved both in care and in physical activities. They need to be involved in past and current interests and sources of fulfilment and satisfaction. Different researchers in this area have indicated that the fulfilment of life of people with dementia can be achieved through physical stimulation which includes dance. It is also important to develop a more equitable, productive, healthier, and respectful way of involving people with dementia as collaborators in research dissemination could be realised. It is thus important to include people with dementia in planning any research and involving people with dementia, their families and their carers.

Studies have been undertaken with people with dementia but there is little evidence for severe dementia and no consideration of the effects of dementia on nutrition and no study has thought of assessing the effect that a dance therapy could help to improve nutritional intake of people living with severe dementia. Also, most studies have always been excluding people living with dementia with severe cognitive impairment in study as researchers always have the premonition of non-compliance.

Based on the studies in this literature review and the aims of this study, there is evidence that the quality of life of people with dementia may be improved with dance and that music and dance can be helpful to improve the social interaction in people with dementia and also improve the life for the carers and family of people affected by dementia.

The studies did show that it is possible to undertake research on dance with people who have dementia. There was limited evidence of how dance could help people with dementia and there is a need for a wider assessment – including diet and nutrition, stability and quality of life. The review has allowed the development of the pilot study which is described in the next chapter.



550 hits were identified at the initial data base search. Some of these were written in foreign language, some were not in healthcare and some were not related to dementia or mental health.

380 Citation were made after removing some duplicate (200 were from PubMed, in which 30 were Systemic Review and 150 hand searching and recommendation from expert)

340 Were excluded because they did not meet the inclusion criteria due to being written in foreign language, duplication and not related to dementia.

40 met the inclusion

26 articles on Dance and dementia, 10 articles on Exercise and dementia 4 articles on Dementia and Depression

18 of the studies were qualitative, 9 were quantitative and 13 were mixed method

Figure 1 Relevant search made: (Chart of literature review process).

Chapter 3: Methods

3.1. Introduction

A mixed methods approach was used in the study to allow not only the objective information on the residents to be recorded but to gain a greater insight into the effects of the intervention from a qualitative approach. This mixed methods approach allows a greater understanding of the study (Bradley et al. 2005).

Creswell et al., (2006) defined mixed methods research as a research design which considers philosophical assumptions as well as methods of inquiry. As a methodology, it involves philosophical assumptions that guide the direction of the collection and analysis of data and the mixture of qualitative and quantitative approaches in many phases in the research process (Creswell et al., 2006). It focuses on collecting, analysing, and mixing both quantitative and qualitative data in a single study or series of studies (Tashakkori & Teddlie 2008). Such use of quantitative and qualitative approaches in combination provides a better understanding of research problems than either approach alone (Creswell., 2006).

The study used focus groups for data collection. According to (Kidd & Marshall 2000), focus group data collection and analysis lends itself to the use of simple descriptive counts of categories, the authors reiterated that counts can provide very useful information, not only about level of consensus/dissent but also about response patterns among the focus group members. However, (Sandelowski, 2001) believes that counts should never be used to replace any qualitative data arising from focus groups because by themselves they can present a misleading picture. In particular, the fact that the majority or even all of the focus group members express a particular viewpoint does not necessarily imply that this viewpoint is important or compelling (Sandelowski, 2001).

However, (Sandelowski, 2001) supported the opinion that when data are contextualized, the use of counts can provide richer information than would be obtained by using qualitative data alone, Indeed, supplementing qualitative data with counts yields a form of mixed methods data analysis. Hence, the reason for using a mixed method approach in this study.

The mixing of data is a unique aspect of this approach (Creswell et al, 2006). By mixing the datasets, the researcher provides a better understanding of the problem than if either dataset had been used alone. Tashakkori & Teddlie (2008) state it is not enough to simply collect and analyse quantitative and qualitative data; they need to be "mixed" in some way so that together they form a more complete picture of the problem than they do when standing alone.

Creswell (2008) argued that mixed methods research provides strengths that offset the weaknesses of both quantitative and qualitative research. In the argument, Creswell (2008) says that quantitative research may be weak in understanding the context or setting in which people talk and the voices of participants are not directly heard in quantitative research. Further to these two opinions, Tashakkori & Teddlie (2006) also said quantitative researchers are in the background, and their own personal biases and interpretations are seldom discussed and that qualitative research makes up for these weaknesses. On the other hand, Creswell (2008) argued that qualitative research may be seen as deficient because of the personal interpretations made by the researcher, the ensuing bias created by this, and the difficulty in generalizing findings to a large group because of the limited number of participants studied and that quantitative research does not have these weaknesses.

Tashakkori & Teddlie (2006) also went further to argue that mixed methods research is practical in the sense that the researcher is free to use all methods possible to address a research problem. Creswell, (2006) p 9-15 also support the argument that it is also practical because, individuals tend to solve problems using both numbers and words, they combine inductive and deductive thinking, and they (e.g., therapists) employ skills in observing people as well as recording behaviour. It is natural, then, for the researcher to employ mixed methods research as the preferred mode of understanding the world.

3.2. Limitations of mixed method

Despite its value, some researchers have concluded that conducting mixed methods research is not easy. Graham (2009) has discussed that a mixed method takes time and resources to collect and analyse both the quantitative and qualitative data. Graham (2009) also argues it may complicate the procedures of research and requires clear presentation if the reader is going to be able to sort out the different procedures.

Nevertheless, these limitations are not insurmountable, and strategies can be used to address them. The value of mixed methods research seems to outweigh the potential difficulty of this approach.

Quantitative data includes closed-ended information such as that found on attitude, behaviour, or performance instruments. The collection of this kind of data might also involve using a closed-ended checklist, on which the researcher checks the behaviours seen (Creswell, 2006). Sometimes quantitative information is found in documents such as census records or attendance records (Tashakkori & Teddlie 2008). The analysis consists of statistically analysing scores collected on instruments, checklists, or public documents to answer research questions or to test hypotheses.

Qualitative data: At the end of the intervention, the data were collected from audiotapes of the participants from the focus groups, notes taken by the researcher and assistant. This is where there was discussion around perceptions, ideas, opinions, and thoughts (Creswell, 2006). Qualitative discussion should be fairly informal and participants feel they are taking part in a conversation or discussion rather than in a formal question and answer situation.

The data collected in qualitative measurement deals directly with quality, so that they are descriptive rather than numerical in nature. They are generally not measurable, and are only gained mostly through observation (Creswell, 2006)

Hence, in this study, the Qualitative data included in-depth focus group sessions with six members of staff and another one that was meant to be six members of participants' family but this was attended by only two members of family. The discussion allowed a more in-depth exploration of the views and experiences of the staff and family to detail their observation of the effects that the dance has had on the residents. Also, the field note from the research student and the comment from the dance instructor was part of the qualitative input.

3.3. Research question

Are residents with dementia in a residential care setting able to take part in a dance café and undertake the assessments during the study?

3.4. Aims

The study aimed to investigate the feasibility and acceptability of a dance café approach for people with dementia.

Objectives

1. To show that it is possible for residents with dementia to take part in a study on a dance café
2. To measure nutrition quality of life, risk of falls and hospitalisation and mobility on residents and ascertain if a dance café is helpful
3. To assess the effect of a dance café on residents, their families and staff

3.5. Design

Case–control quasi-experimental design was used for this pilot study, involving five residents receiving all the intervention including the dance and the control group of five residents receiving their standard care but no dance. In this study, case control design was preferred as it is relatively inexpensive to implement and requires comparatively fewer participants.

A mixed method of both quantitative and qualitative were used. The collected data information on instruments are based on measures completed by the carers and by the observation recorded.

3.6. Participants

The study was undertaken at the nursing home owned by a Community Healthcare Organisation in the South East of England. The Community Healthcare is a Social Enterprise Company, providing NHS Community service to the people of the local area. The site of the study is an old age psychiatric care home (Dementia). It is a purposely built home with 40 bedded single rooms with en-suite. The Care Quality Commission had an unannounced Inspection of the home in January 2016. CQC reported an overall good service as the home met all criteria for practice. There are forty residents living in the home. Staff provide nursing care and support to adults diagnosed with dementia. Accommodation is spread over two floors, divided into four units. Each unit provides ten beds for people who have high care dependency needs. High care dependency needs are when some people receive care or being nursed in bed, requiring specialist equipment to meet their needs or may have needing constant supervision or higher staffing input.

All the residents that live at the nursing home were known to have severe cognitive impairment and have speech and communication problem, their intentions can easily be misinterpreted, it was decided to hold focus groups for their family members and staff members who have been looking after them. Invitation letters for focus groups and research information sheets were sent to the family and staff of the nursing home who did meet the inclusion criteria. A dance therapist was also invited to take part in the research project.

3.6.1. Inclusion criteria

In order to reduce subjective interpretation of interest the student developed strict eligibility criteria:

- Age: The ages of the current residents at the home are between 54 and 100 years. The residents who are not frail and meet all the criteria for selection were enrolled to participate. There was no age limit.
- Sex**:** The residents at the nursing home are both male and female. There was encouragement of participation from both genders.
- Physical ability: Residents who are able to stand and walk, with a falls risk assessment of low or medium risk. This was confirmed following a falls risk assessment performed every twenty-eight days as routine care plan update at the home. This was checked by the use of a standardised falls risk assessment tool and documented. This tool measures who is at most risk of falls by considering all factors that predispose one falls.

It is scored in these three categories**:**

- 20 and above = High Risk
- 14-19 = Medium Risk
- 1-13 = Low Risk

Duration of stay in the home: Residents needed to have lived in the home for at least 6 months because new or changed environments can have a masking event on individuals' true behaviour (Carreon et al. 2000).

3.6.2. Exclusion criteria

Residents who had been at the home for less than 6 months
Residents with a high-risk assessment of falls or other mobility issues.

3.7. Mode of data collection

Traditionally, focus group research is a way of collecting qualitative data, which essentially involves engaging a small number of people in an informal group discussion focused around a particular topic or set of issues (Wilkinson, 2004).

The researcher decided to use focus group to collect the data due to the facts that some researchers have opined the benefits.

(Krueger & Casey, 2000) opined that focus groups are an economical, fast, and efficient method for obtaining data from multiple participants, thereby potentially increasing the overall number of participants in a given qualitative study. Another advantage to focus groups is the environment, which is socially oriented (Krueger &Casey, 2000). In addition, the sense of belonging to a group can increase the participants' sense of cohesiveness and help them to feel safe to share information (Duggleby, 2005). Furthermore, the interactions that occur among the participants can yield important data (Krueger, 2000). It can also create the possibility for more spontaneous responses (Wilkinson, 2004), and can provide a setting where the participants can discuss personal problems and provide possible solutions (Duggleby, 2005).

(Bloor, 2000) suggested that focus group has its own disadvantages, that listening to participants' views can generate expectations for the outcome of the research that cannot be fulfilled. Problem can elude if the topic of interest to the researcher is not a topic the participants wish to discuss or if a statistical data is required (Bloor, 2000). However, all the above disadvantages have been outweighed by the advantages of focus groups because, focus groups give depth and insight to data and will produce useful results.

3.8. Focus Groups

Group 1 – care staff

Inclusion criteria

- Care home staff, who provide day-to-day care to the participants (e.g. assisting the residents during meal time, helping with their personal care)
- Staff who consent to involvement in the group

Exclusion criteria

  - Staff who had not provided direct care to the participants involved in the study in the previous 2 weeks

Group 2 - families

Inclusion criteria:

Family members of the participants involved in the study who visited at least once a week to see the resident.

Family members who were able and willing to consent to involvement

Exclusion criteria:

Family members of residents who were not involved in the study.

Family members who did not visit the participants at least once a week

Family members who were unable or unwilling to consent to involvement

3.9. Methodology

The study used a waiting list approach with two groups of participants

Group 1 – who received the intervention of the Dance Café from the beginning for a period of 8 weeks - Dance Group

Group 2 – who received normal care within the home for 8 weeks and then received the Dance Café intervention - Control Group

Before the study started all the residents' family and staff of the nursing home were informed of the project by letter from the Head of Service stating that all residents would be considered for the study. The Head of Service, the Clinical Manager of the home, with the research student at the start of the study considered all the residents at the home and agreed the residents who fell into inclusion category. Twenty residents were identified as meeting the eligibility criteria and included both male and female and they lived across both floors of the home and all had a diagnosis of dementia recorded in their medical files.

Of the 40 residents living at the nursing home at this time, 20 residents met the eligibility criteria. The exclusions were: 7 residents were bed bound or not mobile, 8 residents were frail and at risk of falls, 5 residents were not able to follow instructions.

3.10. Randomisation

The randomization approach was considered to be the best way of measuring the efficacy of the interventions because of its ability to minimise bias and avoid false conclusions. This removes selection bias keeping study groups similar and making the results more reliable, as random assignment of individuals to the different treatment groups is the best way of achieving a balance between the two groups for the known and unknown factors that may influence outcome.

Randomisation was undertaken of those 20 residents that were eligible to be included within the study. Each resident's name was written in a small piece of paper, wrapped and placed in an opaque envelope. Ten of these were randomly picked by the home Administrator to define the potential study group. He then picked five of these envelopes to define the Dance Café group, the other 5 becoming the Control Group. The envelopes and the names were written out by the researcher and all were given an identifying number, to maintain anonymity later.

3.11. Consent

Once the participants had been randomized, consent and assent were obtained. If the participant had a family member who visited regularly, the family members were sent the Information Sheet and the Assent Form to be Personal Consultee – as the participant had been assessed as not having capacity to consent themselves. They were given 2 weeks to return this before a reminder was sent. For participants who had no close family visiting, a staff member who knew the person well was asked to give assent as a Nominated Consultee. The families were also sent an Information Sheet and Consent Form for their involvement in the Focus Groups and again were asked to return the Consent Form within 2 weeks.

It was possible to receive consent for 5 participants in both groups – the Dance Café Group and the Control Group.

3.12. Quantitative Measures

The following measures were used for the dance cafe, at 2 weeks prior, at 4th week and at the 8 weeks of the dance café: These methods were chosen due to the fact that the use has been justified by previous research:

3.12.1. Measurement of weight

The weight of each participant was recorded at baseline (T1) 2 weeks prior to the intervention and repeated at four weeks and eighth week completion of the intervention (T2, T3). Weight loss or gain are recorded. This allowed an assessment of nutrition for the participants. Fig: 2 and 3.

3.12.2. Food intake assessment

A standardised tool was used to measure the amount of food presented to residents and amount eaten. The food intake was recorded using the designed home's residents' Food Intake Assessment form, which is routinely used within the home. These were recorded in percentage format. These assessments allow an average Intake percentage to be calculated for the 2 weeks before the intervention T1, the fourth week T2 and the eighth week T3.
This has been shown to allow assessment of the appetite, ability to eat and the nutrition of participants (Bell et al, 2012). Fig:4 and 5.

3.12.3. Hospital admissions

Admissions to hospital for falls or other reasons. There was no hospital admission.

3.12.4. Records of falls

Falls are recorded routinely at the home and the records from incident of falls reports that occurred 2 weeks prior to the start of the intervention T1, also at the fourth week T2 and during the 8 weeks T3, of the study were recorded.

3.12.5. Timed Up and Go (TUG)

This test is widely employed in the examination of older people as a basic test for functional mobility (Podsiadlo et al. 1991). It measures the time that a person takes to rise from a chair, walk three meters, turn around, walk back to the chair, and sit down. It consists of four stages that go thus:

- Instruct the patient: 1. Stand up from the chair. 2. Walk to the line on the floor at your normal pace. 3. Turn. 4. Walk back to the chair at your normal pace. 5. Sit down again
- On the word “Go,” begin timing.
- Stop timing after patient sits back down.
- Record time.

Participants were encouraged to wear their regular footwear. Participants sit back in a standard armchair are asked to stand and walk 3 metres, to a premeasured line, turn, return to the chair and sit. The total time is recorded in seconds. The observer observed the participant’s postural stability, gait, stride length, and sway.

These areas are observed:

☐ Slow tentative pace
☐ Loss of balance
☐ Short strides
☐ Little or no arm swing
☐ steadying self on walls
☐ Shuffling
☐ En bloc turning
☐ Not using assistive device properly.

It is expected that an older adult who takes ≥12 seconds to complete the TUG is at high risk for falling (Podsiadlo et al. 1991).

Fig:6 and 7.

3.12.6.Tinetti Balance Assessment Tool

This simple, easily administered test measures a person's gait and balance, and has been widely used in studies on mobility in the elderly. In this test, balance and gait are tested (Tinette, 1986).

The participant is seated in hard, armless chair for the balance session, while the participant is advised to stand with therapist, walks across room (+/- aids), first at usual pace, then at rapid pace (Tinette 1986).

A score was awarded on a three-point ordinal scale with a range of 0-2. A score of 0 represents the most impairment, while a score of 2 represents independence (Tinette 1986). Individual scores were then combined to form three measures taken from two sections of balance and gait.

Overall gait assessment score plus the overall balance assessment Score (Tinette, 1986).

Risk Indicators:

≤18 High Risk

19-23 Moderate Risk

≥24 Low Risk

The higher the score the lower the risk.

Fig:8 and 9.

3.12.7. Measurement of Quality of Life

The DEMQOL-Proxy and DEMQOL (Mulhern et al. 2014 & Tinette 1986) was used to assess quality of life of the residents. This instrument assessed the following:

Co morbidity (other illness apart from dementia)

Level of independence

Social Relationship

Physical Senses

Psychological Well-being.

The DEMQOL-Proxy was completed by the staff and relatives who knew the participants well in collaboration with the student. It was used as it was not possible to assess quality of

life for the participants by assessing them individually as their cognitive state was too poor. This assessment, using the proxy assessment of the people who know them well, has been shown to be an effective way of assessment of quality of life (Mulhen et al, 2014).
Fig:10 and 11.

3.13. Qualitative measures

Focus Group Discussion:

Two separate focus groups were held:
(1) Staff Members = 4 in number
(2) Family members = 2 families of 2 participants were present.

The main aim of the focus groups was to find out the effect that the dance has had on the participants by personally relating experience from family and staff members who have observed the participants from pre, during and after the intervention.

Similar questions were asked in both groups:

- Do you feel the participant in the Dance café has enjoyed the dance?
- Do you think of participant has benefitted from attending the dance?
- Have you in any way observed any improvement in these areas of participant's mobility or gait, speech, appetite or any problem with their attendance?
- Has the participant commented on the dance cafe?
- Any other comment?

A digital recorder was used to record the Focus Groups and the researcher also took notes – both were explained to the participants beforehand and consent obtained.

At the end of each session there was an informal meeting of the staff involved in the sessions and these were noted within the field notes of the researcher, but were not recorded in any other way.

3.14. Procedure for the Dance Café sessions

The professional community dance facilitator was asked to attend and deliver two out of eight of the dance sessions that occurred weekly for 2 hours from April – June 2017. The outline of the intervention was:

- 15 minutes for carers/relatives to motivate the participants in order to allow bonding, comfort and reassurance that will take them through the therapy.
  All participants were checked to ensure that their clothing and shoes were appropriate
- Risk assessment of the environment was risk assessed by the dance facilitator and care staff before each session to ensure that it was safe and free from items that could impede free movement.
- The intervention was to include 60 minutes of dance session which incorporated a professional dance safe practice model delivered by Lucy Napleton.
  - 20 minutes warm up of chair-seated exercises into cardiovascular either seated or standing
  - Drink and a break
  - 30 minutes of selected dance style
  - 10 minutes cool down.
  - The whole activities provided a social element to the dance café lasting 45 minutes.

Table 1 Music and activities undertaken

Warm Up 5-10mins	Soft chair-based exercises to begin: Rub hands, arms, thighs, legs/ Lift arms up and down slowly/Push forwards and pull back/Rotate shoulders Repeat above – observe participants and respond to their own movements i.e. Tapping hands on knees/clapping etc Lift heels up and down/Tap feet respond to participants own movement More vigorous chair-based exercises Chair March, move feet forward and back, tap knees – observe and respond to participants movements	Music: Soft and slow - percussive/lyrical piano guitar/ classical or alternative (no lyrics to begin with) Music: classical – i.e. Swan Lake Music popular – i.e. Abba

The same dance style was delivered over eight consecutive weeks to ensure reminiscence and memory. The styles chosen was to provide a person centred and holistic approach to the movement incorporating creative and improvised moves that individuals can follow easily, whether standing or seated to ensure its inclusivity.

3.15. Ethical Considerations

A Favourable Ethical Opinion was gained from the Health Research Authority (HRA East of England-Essex Research Ethics Committee, REC reference 17/EE/0005 IRAS 201332 in March 2017). At admission to the home, the qualified Nurse who are regularly updated by necessary training always carry out the mental capacity assessment with the care planning. This assessment is reviewed and documented on monthly basis and at as when due. A mental capacity assessment tool is used, to carry out the test to determine whether the resident has capacity or not to consent to procedure at the time of the assessment. The outcome of this will be documented and reviewed regularly.

As all the residents of the nursing home were under the care of the NHS Continuing care. Under the Governance Arrangements for NHS Research Ethical Committees, application to a NHS REC in England and Wales was made. A full online application was made to the Integrated Research Application System (IRAS). The Mental Capacity Act (MCA) 2005 in England and Wales and the Incapacity Act (ICA) 2000 in Scotland have established legal frameworks within Great Britain for people lacking the capacity to make decisions for themselves. All the residents are also under the Deprivation of Liberty Service (DOLs). This assessment is done to protect the right and freedom of resident according to their best interest purposes.

Ideally all participants of research projects should be capable of providing well informed and considered consent but the participants were unable to consent to their participation due to their lack of cognition. However, to exclude participants who could not decide for themselves would have deprived them of accessing the opportunity of active participation in this research including potentially innovative interventions. The decision to include potential participants was based on this Mental Capacity Assessment:

All of the potential participants were found to lack capacity to consent. Therefore, it was appropriate to utilise the help of Personal or Nominated Consultees to provide advises on what they think would have been the feelings and wishes of their family that lacks capacity if they were to have capacity and able to consent by themselves. It was considered very important to consider the mood and appearance of the residents when the project was mentioned to them. Even though, it was already established that they lack capacity, but there was some level of excitement seen in every one of them at the mentioning of dance. For this reason, it was easy for the family to assent to the participation of the residents. In some cases, there was no family to act as personal Consultee for three of the residents due to lack of interest in the care of the resident from family, someone said “I cannot do that because I do not know her anymore”, some were due to other family issues. It was then decided to advocate for the identification of others who were consulted about a prospective participant’s involvement. A letter, Information sheet and assent forms were sent to carers of the home who fell into the inclusion category. The identified persons were carers who are interested in that resident’s welfare. They were consulted about what the prospective participant’s wishes and feelings about participation in the project would be if the person had capacity. It was also established that none of the Personal or Nominated Consultees had a direct involvement with the project.

There are potential issues of power that could affect the involvement of residents, their families and staff in the project, as the researcher is the senior nurse in the home. It is possible that family members could have felt influenced to agree to their family member being involved, as they may have feared that a refusal could alter the care offered to the resident. However, the families were all informed by the Head of Service independently of the Researcher initially and were given Information Sheets on the project and a period of two weeks to consider the resident’s involvement. Moreover, the sheet stressed that assent was completely voluntary and if assent was not given this would not alter the care provided at the home in any way. The sheet also emphasised that involvement could stop at any time, without any change in the care provided. The families were seen on a regular basis to check that they were agreeable to the resident’s involvement, and several families attended sessions to see for themselves.

There are also potential issues of power for the staff who consented to join the Focus Groups. They may have felt unable to refuse involvement as the researcher was the senior nurse, and their manager. However, the Information Sheet again stressed that involvement was voluntary and withdrawal possible at any time, without any detriment to the staff member. They were also given a period of two weeks to consider their decision, and told, in the information Sheet, that refusal to join a group would not affect any other decision and that this decision would be respected and have no ongoing consequences. It is hoped that this ensured that staff members did not feel untowardly influenced or pressurised to be involved and give consent.

The researcher was aware of these possible power issues and at all times tried to explain that all participation was voluntary and not being involved would not influence the care provided for any resident or adversely affect the role or work of any staff member.

3.16. Qualitative data analysis

3.16.1. The Transcribing and Analysis

A thematic approach was chosen to analyze the qualitative data that were already collected by conversation approach. This was used to retrieve reoccurring themes and identify related/common comments. Thematic Analysis is a method for identifying and analyzing patterns of meaning in a dataset (Braun & Clarke 2006). All emerging themes were carefully color coded for easy analysis. This approach was preferred to other approaches for this small and a pilot study. Thematic also allows for flexibility in the researcher's choice of theoretical framework.

Gibbs (2007) describes coding as how you define what the data you are analysing are all about, coding is a way of indexing or categorizing the text in order to establish a framework of thematic ideas about it. Thus, all the text and so on that is about the same thing or exemplifies the same thing is coded to the same name. Then retrieving all the text coded about the dance enabled the researcher to list and compare what the participants said about them. Thematic approach refers to common themes in a transcribed document. This is a subjective report observed from a series of discussions. This can manifest in being said in different words but has the same meaning or it can be a repeated sentence or word. It can contain something that is particularly common the same group of subjects. Themes are thus patterns of explicit and implicit content.

There were two separate focus groups. The number of participants in the residents' family focus group was supposed to be six but only two members of family of two participants were able to make it. The home staff focus group consisted of four members and they were all present at the discussion. Focus group discussion were held just at the end sessions. Focus groups and discussions were audio recorded with consent from the participants. The student informed the participants that she was going to take note of their discussion. The student had to listen to the recordings on several occasions until she became clear and familiar with every word that was being said. The main purpose of listening to the recorded discussion was to bring out the common themes, identify key comments to support the outcome measure of the study. All words were transcribed in a word doc

Chapter 4: Results

Results were measured from seven domains (See graphs and tables below). Overall, the residents attended the sessions and were able to take part in the activities. One resident was not involved right from the initial assessment /randomisation due to ill health, but all the other residents that participated in the dance group and control group were able to be involved in the assessments and all assessments were completed at time. Hence, it was possible to carry out the tests on dementia residents.

4.1. Quantitative results

4.1.1 Weight

Weights were obtained for all the participants and recorded at all-time points – Appendix 1 and 2. For the participants within the control group the weights also varied. For instance, in figure 2 and 3, some participants indicated increase in weight at the end of the therapy while also, there was increase in the weight of the residents that did not participate in the dance. For instance, for the control group, participants 3 and 4 increased their weight at the end of the therapy. There were variations in the weight of the people that participated in the dance as well as the control group. This is an indication that a larger study is required as there were no clear conclusions due to small number of participants. However, the increase in the weight of people that danced and the control group might also be attributed to the fact that they all had extra meals apart from their normal routine diet on weekly basis throughout the eight weeks of the study. The variations in weight could be that the staff and family spent extra time to encourage them to eat their meal during the dance café or it was just a coincidence

Test 1: Weight of Participants

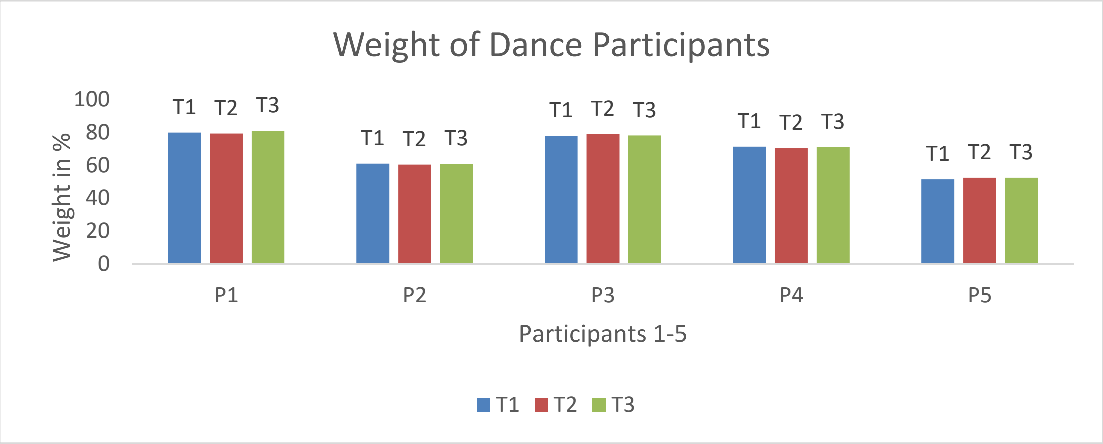


Figure 2 Weight of participants in dance group

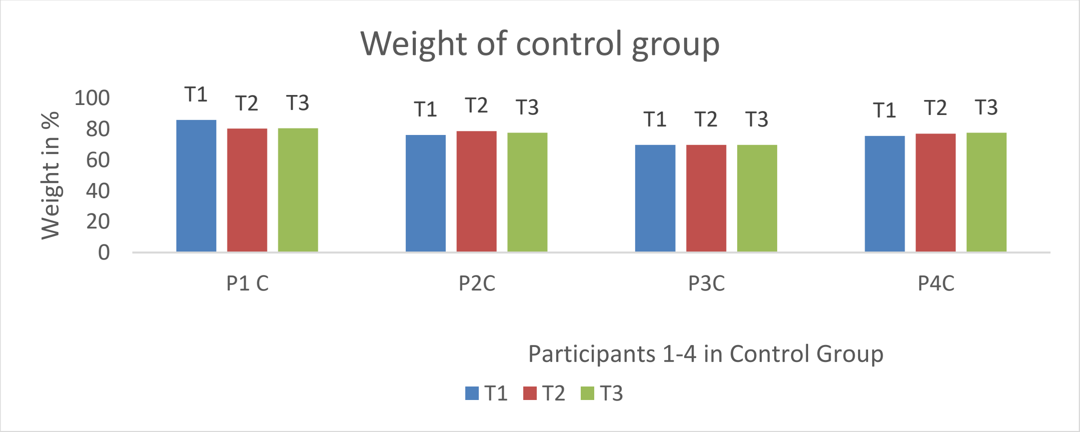


Figure 3 Weight of participants in control group

4.1.2. Food intake

Assessments of eating were obtained for all participants. Within the dance participant group, there was a small decrease for participant 1, the food intake went down by 2% at the end of the therapy, participant 2 finished the therapy with increase in food consumption participants 2 and 5 in dance. So also, were participants 3 and 4 that had steady increase in their consumption of food till the end of the therapy. The participants in the control group also experienced some variation in the percentage of food they consumed but not as evident as the participants that danced. Some had improved appetite. Within both groups there were no significant changes but the weight is a significant indication that they have eaten and drunk well in the eight weeks of the therapy. Although these are small numbers, it would seem that there may have been a trend towards dance participants eating a little more over the period of the study. Just as it was mentioned in the weight area, the improvement in food consumption could be due to the fact that participants received more support from staff and family during the dance café

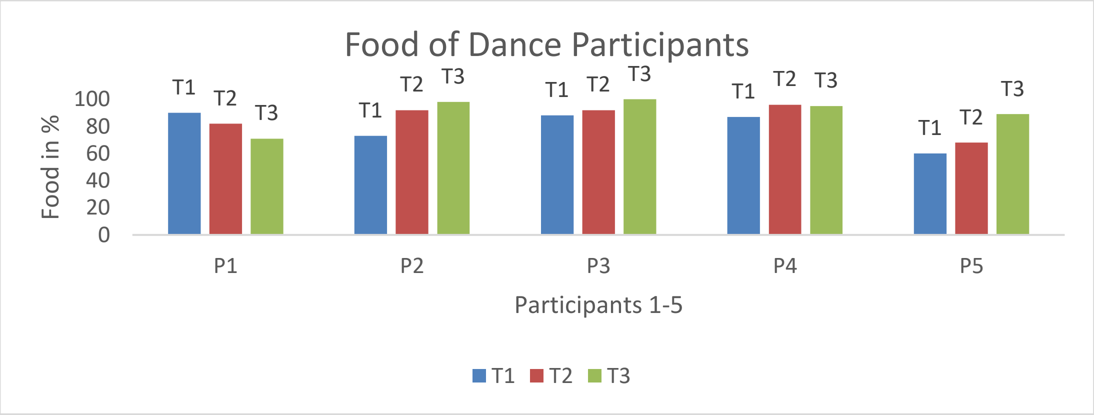


Figure 4 Food of participants in dance group

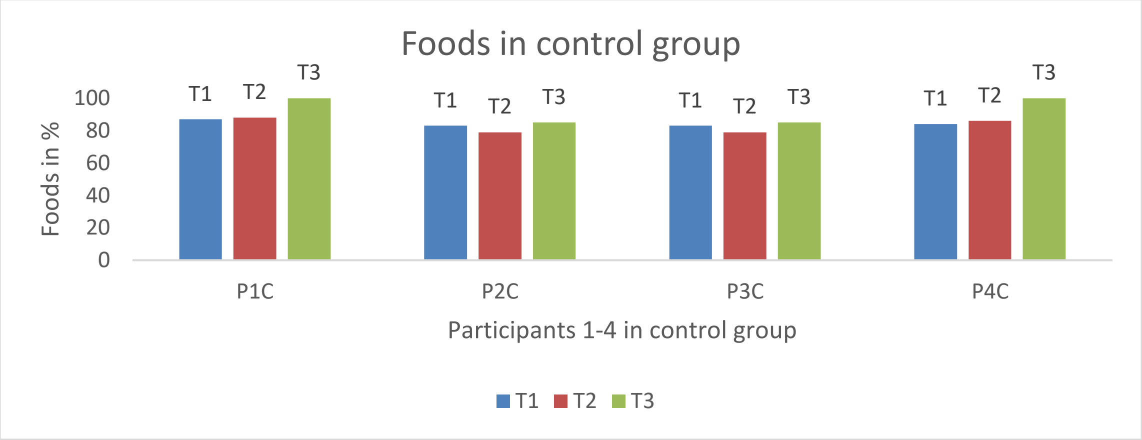


Figure 5 Food of participants in control group

4.1.3 Timed Up & Go

There were some differences between the time they started and at the end of the sessions especially in people that danced, and the control group did not show much difference except for participant 3 that had a rise on the second test best however had a drop on the 3rd test- figure 8. The rise could be due to the fact that the activity became more familiar to the participants and they are always on the go, not necessarily responding to instruction from the research student. Participants 1, 2, 4 and 5in dance appear to have responded well to the test. See figures 6 and 7

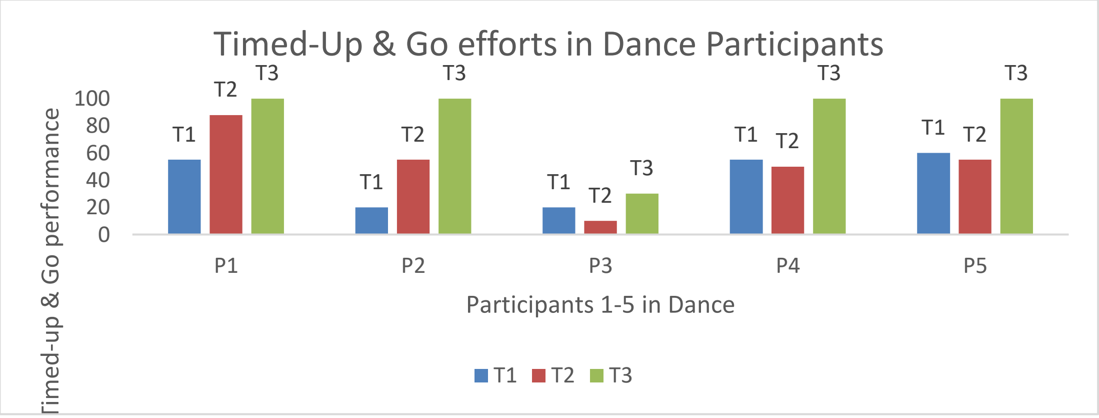


Figure 6 Timed-Up and Go (TUG) of Participants in Dance Group

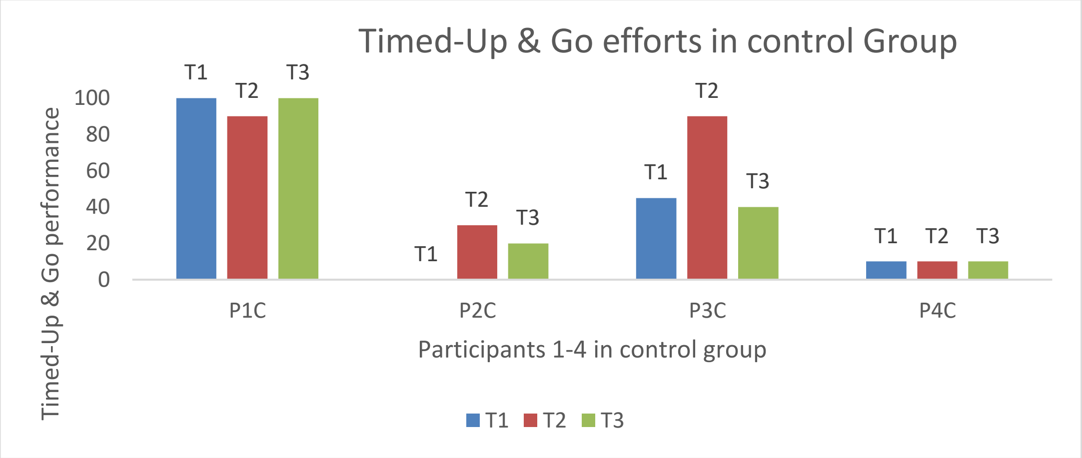


Figure 7 Timed-Up and Go (TUG) of Participants in Control Group

4.1.4. Falls

Participant 3 in the dance group that had 2 falls 2 weeks before the therapy, he had another fall at the middle of the therapy and ended up with no fall for the rest of the therapy. One could conclude that the dance café has been helpful and effective on him. On the other hand, it is possible that his safety was more ensured due to the increased attention that the participant was receiving from either the family or the carer while he was attending the sessions. See table 4. However, it is also possible that the participant got steadier and more stable in his mood, confidence and on his feet. There was no record of falls in the control group.

4.1.5. Tinetti Balance Test

Just as in other tests, there was no clear indication that people that participated in the dance did better than the people that did not dance. The participants that were poor before intervention remained poor till the end, and the participants with good balance from the start remained static. However, there were clear indications that it was possible to carry out the tests with people that have severe dementia. See figures 8 and 9

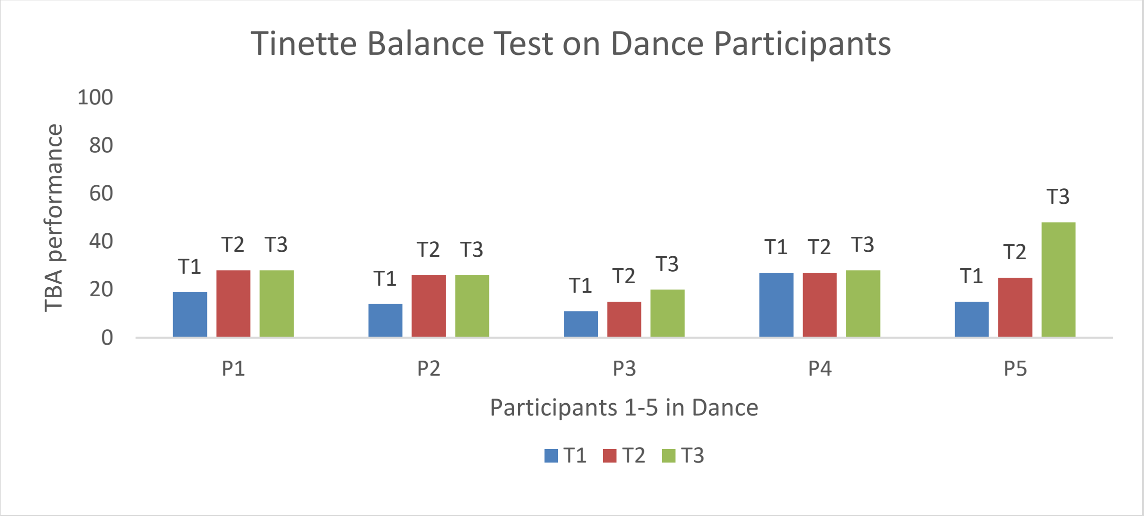


Figure 8 Tinette Balance Test on dance participants

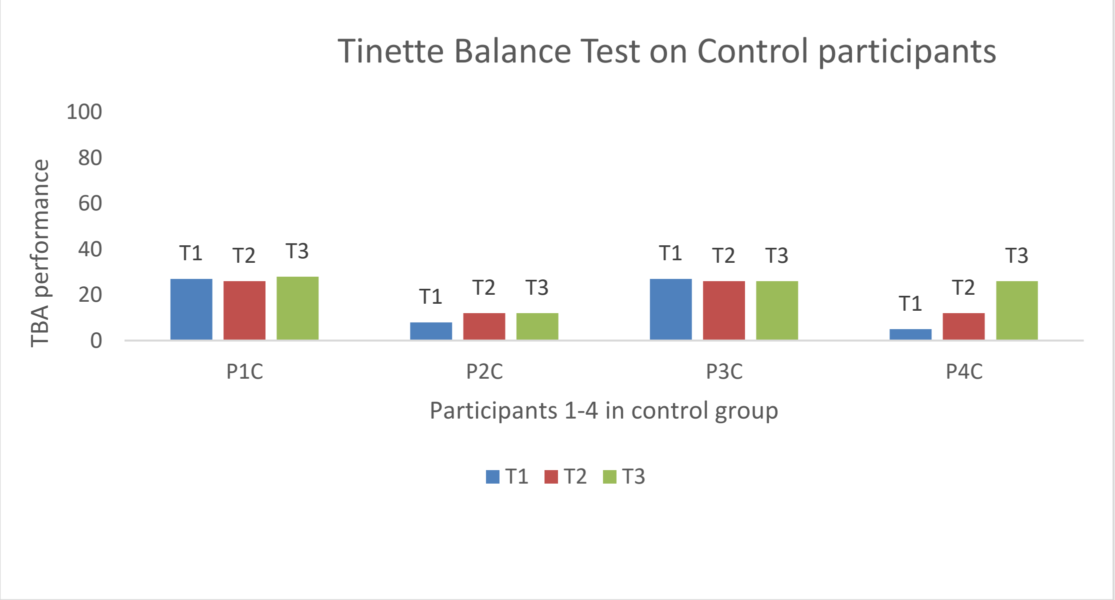


Figure 9 Tinette Balance Test on control participants

4.1.6. Dementia Quality of Life (DEMQOL) Proxy

This looked into the domain of the participant feelings/mood, memory/reminiscence and everyday life like bathing and dressing. The results are shown in Figures 10 and 11. Participants 1, 2, 3, 4 and 5 had very little improvement as in overall percentage. However, there was no clear evidence that the participants in the dance group performed better than the participants in the control group. The overall performance in both groups shifted more to a static phase. Nevertheless, based on the comment from people in control group, there is evidence that the people that danced did better than the people in the control group.

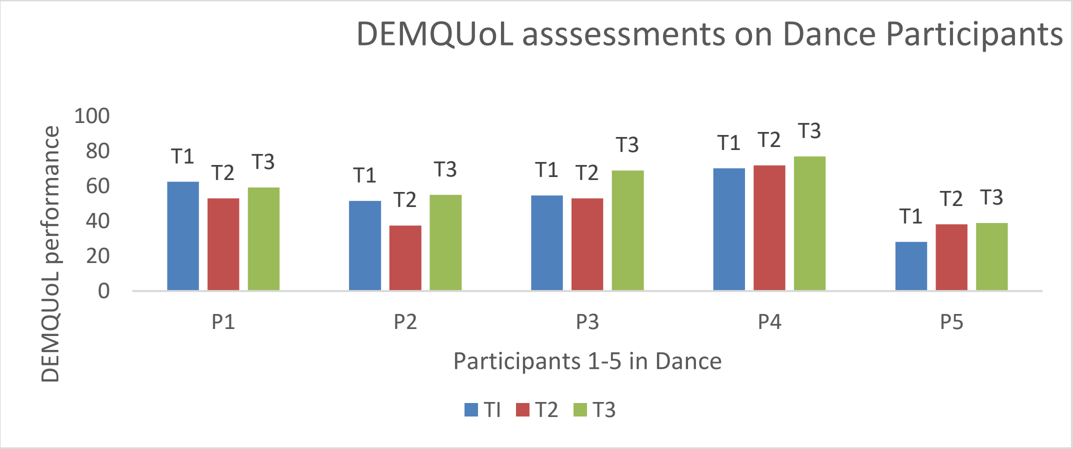


Figure 10 DEMQUoL assessments on Dance Participants

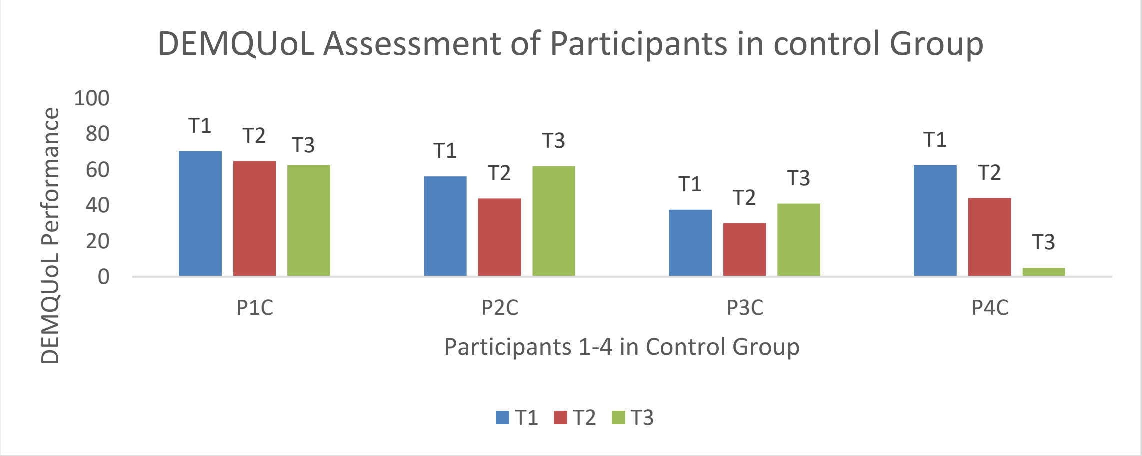


Figure 11 DEMQUoL Assessment of Participants in control Group

Test 3:
A dance participant was recorded to have had two incidents of falls in the two weeks before the dance and had another fall in the middle of the dance but became steadier on his feet by the end of the dance café and no further falls were recorded.

No fall was recorded in Control Group.

4.1.7. Unplanned Hospital Admission

There was no unplanned hospital admission on any of the nine residents. Although, one of the residents in controlled group did not participate due to ill health but this did not require hospital treatment.

4.2. Qualitative results

Focus groups were undertaken with four members of staff. It was difficult to hold a focus group with family members, as they were unable to attend together at the House but it was possible to discuss the participants with two family members. The filed notes, recorded by the research student after the sessions, and the comments of the Dance Facilitator have all added to the qualitative results.

4.2.1. Focus Group with Staff

Themes from staff focus group

The focus groups of staff suggested the following themes**:**

- Enjoyed = was mentioned 9 times
- Smile and laugh/happiness = was mentioned 9 times
- Appetite = was mentioned 3 times
- Dance to continue = was mentioned 2 times

- Reminiscence = was mentioned 8 times
- Danced = was mentioned 17 times
- Communication = was mentioned 8 Times

1) The first theme was linked to how the people with dementia have enjoyed and responded to the dance: There were words like: enjoyed, Smile and Laugh/happiness, every participant in the staff focus group has stated that resident appeared to have enjoyed the dance. Mood- happiness, this was repeatedly said and have been seen in the residents and staff that participated in the dance, this appeared at several times. All the six staff in the focus group confirmed it was a good experience for both staff and residents = 8 times. Singing: Staff reported that some of the residents were observed to be singing along during the dance.
2) The Second theme was linked to the effects of the dance experience has on their physical, social and emotional needs: Improved mobility, Reminiscence, Communication and Social engagement: Mobility in relation to being able to dance with feet and hands = 20 times, Staff affirmed that 2 members of the residents have shown some level of reminiscence- a participant was reported to have verbalized it to another resident that *"Do you know I have been dancing",* another resident entered in to the all where the dance normally take place and started dancing on an ordinary day a staff also reported that another participant was spotted dancing on the corridor on an ordinary day. These theme appeared = 8 times. Improved speech and total communication: This appeared = 6 times. Involvement and Relationship building through dance and music appeared, staff reported that resident build more relationship and bound very well among themselves and with staff. Appetite: Staff reported to have seen a great improvement in the food intake. All participants in the focus group advocated continuity of the dance. These appeared = 10 times.
3) The choice and loudness of the music: Staff advised was to implore music as per the age of the participants as staff claimed that the participants responded well to classical music. This appeared 7 times: It was reported that the louder the music the better. The recommendation to make music available for people at all stages of dementia appeared. = 8 times.

4) Another member of staff comment goes thus:

"To see Mr. B dance was a complete success of the study. He has never stopped in a place for more than 2 minutes. For him to stay that long in the dancing hall is a pleasant experience He was seen to be talking more about dance and walking better".

"Most of the residents have eaten more during the study. Mr. A, Mr. B and Mrs. C were found to be completing any food and fluid offered to them now. I am sure they must have had increase in their weight. The mobility of most of them have also improve in great deal".

5) Further comment from staff: Comments made by staff during / after the sessions were of positive one. *"I was not optimistic about the whole process when I heard that the residents were selected to be involved in a dance. My initial thought was, how we are going to get them to stand and stay in one place for about 45- 60 minutes when they all love to walk around. I was very disturbed to the point that I tried to discourage the research student that she should try another topic that will benefit them. She insisted, explained to me that the purpose of the study is because of that their condition and that the study was just a pilot study to see if it will be possible to carry out the measurements on them and eventually to see if dance can be effective to improve the quality of life of people with dementia".* The staff continued *"I was amazed and impressed at the rate the participants positively responded to the dance". "Most especially, I was surprised to see Mrs. A – dancing and smiling compared to how she was always aggressive, fighting and tearful all the time".*

4.2.2. Focus Group with Family

Family Focus group the following themes emerged:

- Enjoyed = mentioned 2 times
- Smile and Laugh/happiness = mentioned 6 times
- Appetite = mentioned 2 times
- Dance to continue = mentioned2 times
- Danced= = mentioned1 time

- Communication = 1 time

4.2.3. Themes from Family Focus Group

1) The first theme was linked to how the people with dementia have enjoyed and responded to the dance: The two families in the focus group concluded that the participation of their family in the dance was like a miracle. One of the families said, her dad has not moved his feet to dance in decades. This statement was emphasized. There were statements like: happy, enjoyed, smile and confirmed it was a good experience for them.
2) The second theme from family was also linked to the effects of the dance experience has on the physical, social and emotional needs of the participants: Family 1 reported that her dad can now move both feet better than before, she observed her dad to now have a bright face and smiles a lot each time they visit him. Family 2 stated that her dad is more engaged with them when they visit.
3) The Choice and loudness of the music: The 2 families both reported that the music has to be classical type. It also has to be loud enough for them to hear, age and disease progression might be having effects on their hearing. The both advised the continuity of the dance.

More comments from family:

Family 'A' *"I think it was a miracle to see my dad to move his leg to dance, this, I have not seen him do since I grew up as his daughter. He loves going to function but all was doing was just to sit and watch. He has actually enjoyed the dance. I will plead that this should continue to happen".*

Family 'B' "*I hope this is going to continue, my husband always smiles more now a days, he has less episodes of aggression towards me or his daughter now a days and no staff has reported any episode of aggression of late".*

4.2.4. Field Notes and Observations

Field notes were made throughout the project and comments from staff recorded. The care staff felt the participants needed verbal prompting and direction to motivate and encourage movements, their observation and concern was due to the fact that the stage of their dementia. Staff believed there was not going to be any response from the participants as they would not have understood the instruction. Initial intervention was more passive participation of the residents. However, things took a new stand from the third week of intervention. Two members of the participants appeared to have understood the whole logic of coming together in to the dance room. Two of them started taking the lead, moving their legs and waves their hands in the same pattern that the dance facilitator and instructor of the dance had done it in the previous week. They felt very excited when they realized that their instructions were well followed by other participants and staff in the room. Some care staff expressed the participants had a positive mood and even saw some of them dancing outside of the dance café session, even those that would not normally want to dance.

At one point, a member of the participants was seen to have wandered into a meeting being 4eld in the hall where the dance was usually taking place and she stated dancing even without music. This was highlighted by everyone in the meeting, thinking why the resident was dancing. This of course brings about the reminiscence. For instance, a participant was very frightened at the beginning, later she was dancing and moving, particularly to Abba ad smiling and it was very unusual for her to smile nor dance.

With this development, we all agreed to continue the remaining sessions with a limited verbal communication and ensure all movement was person-centered and unaided. Even though it can be difficult to have non-verbal communication it can provide a particular quality in the interaction which involves tuning into another person's body, with the person who has dementia initiating the movement and their partner going along with the flow.

The dance session always started with a seated physical warm up concentrating on breath, physically touching and rubbing parts of the body with limited verbal dialogue led by the dance facilitator. The dance facilitator and care staff were encouraged to use a person-centred and participant led approach for the selected dance styles and different props were introduced to add a sensory and playful environment. The musical accompaniment was specifically selected to suit the structure of the sessions.

Even though movements were minimal from some of the participants, they all responded well to the seated warm up exercises and engaged. Also, the similar format each week became familiar to the participants creating a safe environment. The choice of music had a positive effect on mood and energy and there were moments when the participants were highly engaged in the dance activity and becoming playful with the props.

The dance facilitator offered to come back and deliver two more sessions for week seven and eight and care staff were really supportive of this decision. Feedback at the end of the dance café intervention was overall positive and care staff felt the participants had benefited. Some staff felt that some speech (words) had improved and some participants becoming more vocal following the dance café.

The facilitating method of the musical intervention was explored, and was determined by the needs of group and were shaped by the theoretical power and experiences of the music therapists. However, the use of well-known songs combined with exploratory improvisation with the home activities group selections were also utilized. There was a three-week break from the dance therapists and the staff took the lead on rotational based when the dance therapist was not around.

4.2.5. Comments from the dance facilitator

The dance facilitator commented “I could see them relaxing”

“*I would encourage care staff to continue with dance, movement to music sessions with the participants following a similar outline below allowing a flexible approach for spontaneity, playfulness and being in the moment. It is important that a person-centred and participant led approach is applied to encourage free movement and expression”.*

“*It would be useful to explore the potential of funding professional facilitators, such as the dance facilitator, to build on the dance café intervention already delivered and to continue the positive ongoing relationship with care home staff and participants/residents”.*

The start of a dance session always began with movement/exercises while sitting in an armless chair to warm-up. The sitting position allowed the participants to see the team leader and other staff members in the hope that they follow instructions. The team became more confident on weekly basis. It is amazing to see that some of the participants that were in the first two weeks felt reluctant to participate were sometimes seen to be taking the lead as the study progressed.

Varying speeds of music were used, there were alternating method of using fast and slower songs. The participants tend to be more responsive to the loud old music from the 1950s to 1970s. The faster energetic music was popular among the participants. After the warm-up exercise, the chairs are moved back to the wall to give room for maximum space to dance.

Observation and feedback from the dance facilitator included limiting the verbal communications for the warm up, so one voice could be heard, to avoid confusion. The dance facilitator also expressed it was important to ensure the movement was person-centred and participatory led and unaided by care staff.

Sometime, participants preferred to pair up with one another or sometimes with staff. Props such as glittery scarfs, balls and pomp poms were used to stimulate the mood. After the dance, the other four residents in focus group (one resident was dropped as he was not well from the start of intervention) were invited to the room. All the nine residents were served with their food which was already put in a plate after being equally distributed. The food and drink were followed by 15 to 20 minutes' rest and a final round-up gentle music dance. At the end of the gentle dance, the participants were assisted back to their respective units. The staff always stayed behind for an informal discussion with the researcher. In this meeting, the staff always discussed on what had worked and what had not worked well and suggestion for applause or improvements.

Chapter 5: Discussion

This study shows that it is feasible to involve people with dementia in a Dance Café approach. Although there were numerous assessments, the participants were able to undertake these, with encouragement. Moreover, the participants attended and participated in the café sessions. Some participants were reluctant to be fully involved in the dancing but with the encouragement of the dance coordinator, the staff at the House and the researcher most were able to join in. The choice of music did seem to influence the involvement, and enjoyment, of participants and from the discussion in the focus groups and observation of the dance sessions it seemed that ABBA was most appreciated and this was testified by a Cassie Tongue's report of Friday 16th February 2018 in the Guardian that says "There is something Australian about the musical composition of an Abba song, Muriel says that her life is finally as good as an Abba song, it is as good as dancing Queen".

The study was made possible to undertake with the consent/assent of family and staff members. In the past, people with dementia were often not included in research about issues directly affecting them, such as service evaluation, as it was thought they would not be able to contribute due to cognitive impairments and the views of their relatives or carers were used instead (Higgins, 2013). People with dementia should be supported to take part in research if they wish to do so. None of the participants was felt to be able to consent for themselves, when assessed under the Mental Capacity Act, but with discussion with family members, and staff, for those who had no close family, assent was obtained. All the participants assented to attend the Dance Café sessions when approached each week. This approach shows that research on people with advanced dementia is possible.

Higgins (2013) has suggested that the only way to understand the experiences of people with dementia is through including them in research. Using words such as "memory problems" instead of "dementia" protects participants from the unnecessary distress of accidental diagnosis but also allows for them to use the word "dementia" themselves. This enables them to participate in the study, which may also be a pleasant experience for them. It will also allow

us to gain a greater understanding and might benefit others with the same diagnosis in the future.
The challenge is for researchers to find the best ways to do this; it undoubtedly requires a flexible and sensitive approach that may take longer and be emotionally demanding but, nevertheless, is worth the effort. Researchers must ensure the best interest of participants as of highest importance.

There was little evidence of an effect of the Dance café on the criteria that were assessed. This was because of the small numbers involved in this pilot study. However, changes were reported by staff and family, in particular improved interaction and social relationships and an increased vocabulary and increased speech of some participants and improved mobility. One participant was noted to smile in the dance sessions, whereas this was rare the rest of the week, and often she tended to become distressed when meeting others, in day to day interactions. This was noted by both family and staff.

The study has in some extent showed some evidence that a dance-based exercise aid reminiscence. There seemed to be some improvements in the residents' appetite from the second week to the seventh week of the therapy. Most of the residents were found to be eating most of their meals presented to them and these improvements were more prominent in the people that participated in the dance, as there was an increase in the percentage of food consumption from the participants who danced. These changes were also seen in the control group, but to a smaller extent. The participation in the Dance café may have led to an increased appetite or the increased social interaction, which was noted for several participants, may have been a larger influence on appetite and eating.

Previous studies had shown similar improvements. Koch et al (2014) found that that Dance Movement Therapy and dance are effective for increasing quality of life and decreasing clinical symptoms such as depression and anxiety. Eyigor et al (2009) suggested in their study that application of folkloric dance specific to countries as an exercise programme for elderly people may be helpful, but these participants were physically active and able to perform activities of daily living (ADL) independently before the study, although none had any experience in strength or regular exercise training and did not have any evidence of dementia.

The Eyigor et al (2009) result is an indication that dances can be very useful to everybody, whether suffering from dementia or not.

The results of the study cannot be generalized due to its small number of subjects and short period of intervention but can however be a call for more study in the field.
(https://www.youtube.com/watch?v=5FWn4JB2YLU). This is an example of how magical a dance and music can be in the life of people that suffer from severe dementia with loss of cognition.

In this study only one of the participants has improved gait and mobility. An increase in consumption of food was recorded in 2 of the participants but for other participants food consumption rates remain unchanged. At the end of the dance therapy the quality of life of people with dementia, as shown by the DEMQoL proxy assessment, did seem to show some improvement. This result is similar to the study undertaken by Duignan et al (2009) and Bruno et al (2008) which examined the quality of life of people living with dementia and stated that the majority of their participants indicated that their quality of life had improved following the dance intervention.

There were small changes in the Tinette balance test which was similar to the results found by Earhart (2009) who found a significant improvement on the measures of confusion, tension, anger and mood after a dance exercise. Staff and family of participants also reported on the positive effects the dance has had on the life of the participants, such as a participant that had not made any effort to move his feet spontaneously before the Dance Cafe was seen to be dancing. Also did one family commended the exercise by saying “seeing my dad move his feet has not happened in the last 5 years, so seeing him dance was a miracle that can never be forgotten”.

The family members and staff also felt that there had been an improvement in their own lives, signifying that they were happy seeing the results on the participants and that the focus group sessions gave the opportunity for their voice to be heard. Everyone signified that they liked the dance instructor. The family and the carers emphasised that the dance in general seem to have beneficial effects for the well-being and quality of life of the residents that participated.

Given the possibility that the dance effect might be short term, it has been suggested by families and carers of the residents in the home that the dance should continue as part of the social activities in the home. The nature of the advanced stage of the dementia of the participants might make it difficult to actually categorise whether the mood elation was due to their participation in the dance or it was as a result of something else, such as the generally increased activity and socialisation. Nevertheless, this can mostly be linked to the exercise as this is a new and current event in their lives.

Everyone liked the dance instructor, the family and the carers nevertheless emphasised that the dance in general did seem to have beneficial effects for the well-being and quality of life of the residents that participated.

5.1. Research recommendations

This was a pilot study to assess if people with advanced dementia would be able to enjoy and benefit form a Dance Café approach and to see if they would be able to complete the various assessment tools and investigations, with the aim to increase their quality of life. This appear to be so and further research is needed to fully assess the use of a Dance café approach:

- A larger study would allow a clearer view and allow a statistical analysis. It would be helpful to look at nutrition / balance / quality of life / overall activities, and the total quality life of individual with dementia.
- More studies to include dementia patients in the studies that have to do with them.
- Dance is included within the major activities in the nursing home and this is being included within the home routinely. Staff are seriously encouraging residents who are able to participate in dance to join the dance every fortnightly at the home.

5.2. Research limitations

It was difficult to get the family to regularly attend the sessions despite the fact that they consented to participation. To get a convenient time for family to attend focus groups proved to be more challenging than initially anticipated due to the participants' family and work commitments. It appeared that the same members of family attended all the sessions. For this reason, the focus group interviews were limited as there was no other family to interact with. There was also an initial problem around the participating staff as they all wanted to be on duty every Wednesday so that they would not have to be at the nursing home on their rest day. As a result, the home made used of staff on zero-hour contract until this was resolved. The families and staff had known the researcher as a nurse working in the establishment and this would have affected how the participants responded during the focus groups and interviews. However, all the initial obstacles were resolved within the few days of starting the study. For instance, with staff coming on the days were off duty, the service Manager agreed to allow the participating staff to claim the hours they come for the dance café session. The few families that were actively participating from the beginning were consulted and they agreed with the research student of convenient time for them to meet for the focus group discussion. Research student had also informed the participants' carers and the family in focus group the need for them to be factual and objective in their thought about the study and the report they make during the focus group. She reassured them that whatever they said in the focus group will never interrupt the care their family are receiving from the home.

However, one advantage of conducting interviews was observing direct interactions between family and carers and listen to them talk about the residents. This allowed the research student to quickly pick some common themes. This supported with field notes taken during and after the sessions, ensured that relevant information was captured. Such notes included the initial reaction of staff and families immediately after the sessions, which could have been lost if their thoughts were only expressed at Focus Group most likely at a later time. The field notes also allowed the recording of participants' reaction and involvement.

5.3. Conclusion

The study was piloted to see if it was possible to carry out some measurements on people with dementia to find out if a dance café can be effective to improve their quality of life. The tests were carried out from the perspectives of the participating residents, family, carers, music coordinator and the research student. This has been the first study to use nutrition as part of tests to explore if dance can be effective to improve quality of life of people with dementia. The study showed that it was possible to undertake such a study and to measure the various aspects on a regular basis with this group of patients with severe dementia. From these results it can be said that there was some evidence that music can bring about reminiscence, improved psychological wellbeing and a relief from tension to family and carer of people with dementia. The study showed how the relevant a choice of music can be to people, as the music should be appropriate with age of individuals. Dance is now included within the major activities in the nursing home and this is being included within the home routinely. Staff are seriously encouraging residents who are able to participate in dance to join the dance every fortnight at the home. Every patient suffering from dementia must be seen as an individual, all aspects of their lives must be considered while assessing any therapy that is aimed at improving their quality of life.

References:

Arts Enterprise with a Social Purpose (AESOP)- "Dance to Health". https://www.danceto-health.org/. Assessed 17/07/2019.

Alzheimer's Society. (2014). *Dementia 2014; the hidden voice of loneliness*. London, England:

Bell C, L., Tamura B., K, Masaki K., and Amella E. J: *Prevalence and measures of nutritional compromise among nursing home patients: weight loss, low body mass index, malnutrition, and feeding dependency.* A systematic review of the literature. J Am Med; 14(2):94-100. Epub 2012 Dec 13.

Bloor M, Frankland J, Thomas M, Robson K. (2000) "*Focus groups in social research".* London: Sage Publications, 2001.

Braun, K.L and Hwang, P.W. Altern Ther Health Med. 2015 Sep-Oct; 21(5):64-70.

Braun, V. and Clarke, V. (2016): *Mis conceptualising themes, thematic analysis and other problems. Sample-size tool for thematic analysis*. International journal of Social Research Methodology, 19(6), pp.739-743.

Brighton and Hove Primary Care Trust with Brighton & Hove City Council (2009) Brighton and Hove Older People Mental Health Planning Framework 2009. Brighton

Creswell, J. W. (2006). Research design: Qualitative, quantitative, and mixed methods approaches (4th ed.): 9-15 Thousand Oaks, CA: Sage

Department of Health (2017): *Start Active, Stay Active*: Assessed from https://www.gov.uk/govern-ment/organisations/department-of-health 0n 25/09/2017.

Department of Health (2005): *Mental Capacity Act 2005*: Assessed from https://www.gov.uk on 02/04/2017.

Duggleby, W. (2005). *What about focus group interaction data?* Qualitative Health Research, 15, 832–840.

Gibbs, G. R., (2007) thematic coding and categorizing. *Analysing Qualitative Data.* London: SAGE Publications, Ltd.

Harmer, BJ; Orrell, M; (2008). *What is meaningful activity for people with dementia living in care homes? A comparison of the views of older people with dementia, staff and family carers.* **Aging & mental health,** 12 (5) pp. 548-558.10.10.1080/13607860802343019

Heritage, J. (2004). Conversation analysis and institutional talk: Analysing data. In D. Silverman (Ed.), Qualitative research: Theory, method, and practice (pp. 222–245). Thousand Oaks, CA: Sage.

Hui, E., Chui, B.T and Woo, J (2008): *Effects of Dance on physical and psychological well-being in older persons.* Archives of gerontology and geriatrics: Volume 49, issue 1, pages 45-55.

Kidd, P., & Parshall, M. (2000). *Getting the focus and the group*: Enhancing analytical rigor in focus group research. Qualitative Health Research, 10, 293–308.

Klimova et al (2017) *Dancing as an Intervention Tool for People with Dementia*: A Mini-Review Dancing and Dementia. Volume 14, Number 12, 2017, pp. 1264-1269 (6) Bentham Science Pub.

Koch, S. C., Kunz, T., Lykou, S., and Cruz, R. (2014). *"Effects of dance and dance movement therapy on health-related psychological outcomes*". A meta-analysis. *Arts Psychotherapy*. 41, 46–64. doi: 10.1016/j.aip.2013.10.004.

Krueger, R. A., & Casey, M. A. (2000). Focus groups: A practical guide for applied researchers (3rd ed.). Thousand Oaks, CA: Sage.

Kwan MM, Close JC, Wong AK, Lord SR (2011): *Falls incidence, risk factors, and consequences in Chinese older people:* a systematic review, J Am Geriatr Soc, vol. 59 (pg. 536-43)

Lacono D., Geraci-Erck M., Rabin M., Adler C., Serrano G., Beach T. and Kurlan R. (2015): *Parkinson disease and incidental Lewy body disease*. Neurology Nov 2015, 85 (19) 1670-1679; DOI:10.1212/WNL.0000000000002102.

Landeiro F, Walsh K, Ghinai I, (2018) *Measuring quality of life of people with pre-dementia & dementia and their caregivers:* a systematic review protocol *BMJ Open* 2018; 8: e019082. doi: 10.1136

Mulhern, B., Rowen, D., Brazier, J., Smith, S., Rormeo, R and Tait, R. (2014): Development of DEMQOL-U and DEMQOL-PROXY-U
Palo-Bengtsson L, Ekman SL. Sch Inq Nurs Pract. 2017 spring; 11(2):101-18; 119-23

Peters O, Lorenz D, Fesche A, Schmidtke K, Hull M, Perneczky R, Rüther E, Möller HJ, Jessen F, Maier W (2012): *Drug and Exercise Treatment of Alzheimer Disease and Mild Cognitive Impairment:* A Systematic Review and Meta-Analysis of Effects on Cognition in Randomized Controlled Trials J Nutr Health Aging. 2012; 16(6):544-8.

Podsiadlo D and Richardson S. (1991) *'the timed "Up & Go": a test of basic functional mobility for frail elderly persons'.* J Am Geriatr Soc. 1991 Feb; 39(2):142-8.

Potter, J. (2004). *Discourse analysis as a way of analysing naturally occurring talk*. In D. Silverman (Ed.), Qualitative research: Theory, method, and practice (pp. 200–221). Thousand Oaks, CA: Sage.

Sandelowski, M. (2001). *Real qualitative researchers don't count*: The use of numbers in qualitative research. Research in Nursing & Health, 24, 230–240.

Sixsmith, A., & Gibson, G. (2007) *Music and the wellbeing of people with dementia.* Ageing and Society; 27(1): 127–145.

Tashakkori, A., & Teddlie, C. (2006). Mixed methodology: *Combining qualitative and quantitative approaches*. Thousand Oaks, CA; Sage.

Tinette, M.E. (1986) *Performance- Oriented Assessment of Mobility Problems in Elderly Patients.* Journal of American Geriatrics Society, 34-:119-126. Assessed online 02/12/2015

Tornatore J., Grant L. (2002) *Burden among family caregivers of persons with Alzheimer's disease in nursing homes. Gerontologist.* 42:497–506 (PubMed).

Wilkinson, S. (2004). Focus group research. In D. Silverman (ed.), Qualitative research: Theory, method, and practice (pp. 177–199). Thousand Oaks, CA: Sage

Woods B, Thorgrimsen L, Spector A, Royan L, Orrell M (2006). *"Improved quality of life and cognitive stimulation therapy in dementia Aging Ment Health*". May; 10(3):219-26 (Aging Ment Health. 2006).

Websites used to provide general information:

Age Concern: www.ageconcern.co.uk

Alzheimer's Society: https://www.alzheimers.org.uk

Audit Commission: www.auditcommision.gov.uk

British Journal of Social Workers: www.bjswoxfordjournals.org

Care Quality Commission (CQC): www.cqc.org.uk

Department of Health: https://www.gov.uk

Health Service Journal: www.hsj.co.uk

Help the Aged: www.helptheaged.org.uk

Nursing Older People: www.nursing-standard.co.uk

Journal of Physical Rehabilitation

https://www.scopus.com/inward/record.url

PubMed: (National Institute of Health and Medicine)

http://www.ncbi.nlm.nih.gov/pubmed/.

https://www.caloriesecrets.net/does-exercise-increase-the-appetite-assessed 12/03/2019.

https://www.theguardian.com/stage/2018/feb/16/mamma-mia-review-thank-abba-for-the-music-and-leave-your-cynicism-at-home.

(https://www.dancetohealth.org/) assessed 17/07/2019.

(https://www.youtube.com/watch?v=5FWn4JBYLU).

APPENDICES:

Appendix1: Tables of all participants at time point 1,2,3

	Weight Kg	Food eaten	Falls Number	TUG Seconds	Tinette Score	DemQuol
1	79.1	90	0	55	19	62
2	61.0	73	0	20	14	51
3	77.9	88	2	20	14	52
4	71.3	87	0	55	27	70
5	51.4	60	0	60	15	28

Table 1 Dance group – Time 1 (T1)

	Weight kg	Food eaten	Falls Number	TUG Seconds	Tinette Score	DemQuol
1	79.1	82	0	88	28	53
2	60.3	92	0	55	26	38
3	78.8	92	1	55	26	38
4	70.3	96	0	50	27	72
5	52.4	68	1	55	25	38

Table 2 Dance Group – Time 2 (T2)

	Weight Kg	Food eaten	Falls Number	TUG Seconds	Tinette Score	DemQuol
1	80.8	71	0	100	28	59
2	60.8	98	0	100	26	55
3	78.0	100	0	100	26	55
4	71.0	95	0	100	28	77
5	52.4	89	0	100	25	39

Table 3 Dance Group – Time 3 (T3)

	Weight Kg	Food eaten	Falls Number	TOG Seconds	Tinette Score	DemQuol
1	85.9	87	0	100	27	70
2	76.3	83	0	0	8	56
3	69.8	83	0	45	27	38
4	75.5	84	0	10	5	63

Table 4 Control Group – Time 1 (T1)

	Weight Kg	Food eaten	Falls Number	TUG Seconds	Tinette Score	DemQuol
1	80.3	88	0	90	26	65
2	78.8	79	0	30	8	44
3	69.8	79	0	90	26	30
4	77.1	86	0	10	12	44

Table 5 Control Group – Time 2 (T1)

	Weight Kg	Food eaten	Falls Number	TUG Seconds	Tinette Score	DemQuol
1	80.5	100	0	100	28	63
2	77.6	85	0	20	12	62
3	69.8	85	0	40	26	41
4	77.6	100	0	10	15	64

Table 6 Control Group – Time 3 (T3)

Appendix 2: Results for all participants

Table 2 Patient 1 in dance

Weight

1st	2nd	3rd	Change T1-T3
79.9	79.1	80.8	0.9

Food

1st	2nd	3rd	Change T1-T3
90	82	71	-19

Falls

1st	2nd	3rd	Change T1-T3
0	0	0	0

TUG

1st	2nd	3rd	Change T1-T3
55	88	100	45

Tinetti Balance Assessment (TBA)

1st	2ND	3RD	Change T1-T3
19	28	28	9

DEMQUoL

1st	2nd	3rd	Change T1-T3
63	53	59	-4

Table 3 Patient 2 in dance

Weight

1st	2nd	3rd	Change T1-T3
61.0	60.3	60.8	-0.02

Food

1st	2nd	3rd	Change T1-T3
73	92	98	25

Falls

1st	2nd	3rd	Change T1-T3
0	0	0	0

TUG

1st	2nd	3rd	Change T1-T3
20	55	100	80

Tinetti Balance Assessment (TBA)

1ST	2nd	3rd	Change T1-T3
14	26	26	12

DEMQoL

1st	2nd	3rd	Change T1-T3
52	38	55	3

Table 4 Patient 3 in dance

Weight

1st	2nd	3rd	Change T1-T3
77.9	78.8	78	0.01

Food

1st	2nd	3rd	Change T1-T3
88	92	100	12

Falls

1st	2nd	3rd	Change T1-T3
2	1	0	-2

TUG

1st	2nd	3rd	Change T1-T3
20	55	100	80

Tinetti Balance Assessment (TBA)

1ST	2ND	3RD	Change T1-T3
14	26	26	12

DEMQUoL

1ST	2ND	3RD	Change T1-T3
52	38	55	3

Table 5 Patient 4 in dance

Weight

1st	2nd	3rd	Change T1-T3
71.3	70.3	71	-0.3

Food

1st	2nd	3rd	Change T1-T3
87	96	95	6

Falls

1st	2nd	3rd	Change T1-T3
0	0	0	0

TUG

1st	2nd	3rd	Change T1-T3
55	50	100	45

Tinetti Balance Assessment (TBA)

1st	2nd	3rd	Change T1-T3
27	27	28	1

DEMQUoL

1ST	2ND	3RD	Change T1-T3
70	72	77	7

Table 6 Patient 5 in dance

Weight

1st	2nd	3rd	Change T1-T3
51.4	52.4	52.4	1.0

Food

1st	2nd	3rd	Change T1-T3
60	68	89	29

Falls

1st	2nd	3rd	Change T1-T3
0	1	0	0

TUG

1st	2nd	3rd	Change T1-T3
60	55	100	40

Tinetti Balance Assessment (TBA)

1st	2nd	3rd	Change T1-T3
15	25	25	10

DEMQUoL

1st	2nd	3rd	Change T1-T3
28	38	39	11

Table 7 Patient 1 in control

Weight

1st	2nd	3rd	Change T1-T3
85.9	80.3	80.5	-5.4

Food

1st	2nd	3rd	Change T1-T3
87	88	100	13

Falls

1st	2nd	3rd	Change T1-T3
0	0	0	0

TUG

1st	2nd	3rd	Change T1-T3
100	90	100	0

Tinetti Balance Assessment (TBA)

1st	2nd	3rd	Change T1-T3
27	26	28	1

DEMQUoL

1st	2nd	3rd	Change T1-T3
70	65	63	-7

Table 8 Patient 2 in control

Weight

1st	2nd	3rd	Change T1-T3
76.3	78.8	77.6	1.3

Food

1st	2nd	3rd	Change T1-T3
83	79	85	2

Falls

1st	2nd	3rd	Change T1-T3
0	0	0	0

TUG

1st	2nd	3rd	Change T1-T3
10	30	20	20

Tinetti Balance Assessment (TBA)

1st	2nd	3rd	Change T1-T3
8	8	12	4

DEMQUoL

1st	2nd	3rd	Change T1-T3
56	44	62	6

Table 9 Patient 3 in control

Weight

1st	2nd	3rd	Change T1-T3
69.8	69.8	69.8	0

Food

1st	2nd	3rd	Change T1-T3
83	79	85	2

Falls

1st	2nd	3rd	Change T1-T3
0	0	0	0

TUG

1st	2nd	3rd	Change T1-T3
45	90	40	-5

Tinetti Balance Assessment (TBA)

1st	2nd	3rd	Change T1-T3
27	26	26	-1

DEMQUoL

1st	2nd	3rd	Change T1-T3
38	30	41	3

Table 10 Patient 4 in control

Weight

1st	2nd	3rd	Change T1-T3
75.5	77.1	77.6	1.5

Food

1st	2nd	3rd	Change T1-T3
84	86	100	16

Falls

1st	2nd	3rd	Change T1-T3
0	0	0	0

TUG

1st	2nd	3rd	Change T1-T3
10	10	10	0

Tinetti Balance Assessment (TBA)

1st	2nd	3rd	Change T1-T3
5	12	15	10

DEMQUoL

1st	2nd	3rd	Change T1-T3
63	44	64	1

Figure 12 Letter of Approval from Site of study (MCH)

13th March 2017

Clara Awoyomi
Principle Investigator
Senior Nurse
Darland House

29 Darland Avenue
Gillingham
Kent
ME7 3AL

Research & Design Department
Medway Community Healthcare
MCH House

Gillingham Business
Gillingham,
Kent
ME8 0PZ
Direct line: 01634 334638

Dear Mrs Awoyomi,

Permission for research

I am writing to inform you that permission has been granted to the NHS organisation or organisations listed below, for the following research project, on the basis described in the application form, protocol and supporting documentation. Please also accept this letter as confirmation of our capacity and capability to undertake the study.

Study details:

Study Title	Is Dance Café Effective to Improve the Life of People with Dementia?
Chief Investigator	Professor Rachel Forrester-Jones
Sponsor Representative	Nicole Palmer
Sponsor's reference number	n/a
IRAS number	**IRAS Project ID: 201332**
REC number (REC name)	17/EE/005

NHS organisations and locations:

Organisation giving permission	**Date of Permission**	**Site or sites to which permission applies**
Medway Community Healthcare CIC	16/12/2016	Darland House

Amendments to date	**Amendment number (local ref)**
n/a	

Permission is granted on the understanding that the study is conducted in accordance with the Research Governance Framework, ICH GCP (ONLY if applicable), The Data Protection Act (1998) and NHS Trust policies and procedures. Permission is only granted for the activities for which a favourable opinion has been given by the REC or university ethics committee and which have been authorised by the HRA (ONLY if applicable).

The following local conditions will apply:

1.	**Sponsorship of study**	The research sponsor will be the organisation named above; the management and design of the study is not the responsibility of the trust or trusts giving permission.
2.	**Confidentiality**	You are required to ensure that all information regarding participants remains *secure* and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the Data Protection Act (1998) and the NHS Confidentiality Code of Practice (www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf). Furthermore, you should be aware that under the Data Protection Act (1998), unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.
3.	**Researcher authorisation**	**Important.** Only those researchers holding a Letter of Access or Honorary Research Contract, as appropriate, from the NHS organisation or organisations may have direct contact with the participants of the study or the patients' notes, unless they already hold a substantive or honorary clinical contract with the organisation or organisations.
4.	**Urgent safety actions**	The research sponsor, or the Chief Investigator, or the local Principal Investigator at a research site, may take appropriate urgent safety measures in order to protect research participants against any immediate hazard to their health or safety. This office should be notified that such measures have been taken. The notification should also include the reasons why the measures were taken and the plan for further action. This office should be notified within the same time frame of notifying the REC and any other regulatory bodies.
5.	**Serious adverse events (SAE)**	Should an SAE occur during the course of the project, this office must be notified immediately. This is in addition to your legal duty to report such events to the Sponsor.

6.	**Amendments**	All amendments (including changes to the local research team) need to be submitted in accordance with guidance in IRAS. This office should be informed at the same time as the REC or university ethics committee is notified in order to avoid unnecessary delays.
7.	**Indemnity**	You must check with the Sponsor that the indemnity arrangements, as confirmed in the Sponsor's Declaration and described in the application forms, are in place before any participants are recruited.
8.	**Study progression**	You will inform us of any significant developments that occur as the study progresses. You will complete and return any report forms that we send you and provide up-to-date information on the number of participants recruited when asked.
9.	**Audit of Study**	You may also be subject to a random audit of research which will involve a site visit, a requirement to view study documents and a request to interview researchers.
10.	**Study completion**	You will notify the Chief Investigator and this office when the study has completed recruiting participants and when the study is finally finished at your site. You will complete and return the final report that we send you and inform us of any publications relating to the study.
11.	**Presentation of findings**	Medway Community Healthcare CIC expects that the findings of this study will be presented to members of the organisation at an appropriate meeting. You should contact the clinical quality director upon completion of the study to arrange a suitable venue and time.
12.	**Consent training**	Medway Community Healthcare CIC expects that members of the study team will have undertaken consent training, before starting work on the study.

13.	**Good Clinical Practice (GCP) Training**	Before starting work on the study members of the research team, employed by Medway Community Healthcare must have received GCP training or must be booked to onto a GCP training course.

Finally, I wish you every success with the study.

Yours sincerely,

Chris Gedge
Research and Design Clinical Lead
Medway Community Healthcare

Figure 13 Favourable Opinion from Ethics Committee

East of England - Essex Research Ethics Committee
The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

08 March 2017

Mrs Clara. Ajoke Awoyomi
Medway Community Healthcare (Darland House)
29, Darland Avenue
Gillingham Kent.
ME7 3AL

Sub Title	Dance Cafe: Is dance cafe effective to improve the quality of life of people with dementia?
REC Reference	17/EE/0005
IRAS Project ID	201332

Thank you for your letter of 27 February 2017, responding to the Committee's request for further information on the above research and submitting revised documentation.

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

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Confirmation of ethical opinion

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

Mental Capacity Act 2005

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

Conditions of the favourable opinion

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

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

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publicly accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

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

Ethical review of research sites

NHS sites

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

Non-NHS sites

The Committee has not yet completed any site-specific assessment (SSA) for the non-NHS research site(s) taking part in this study. The favourable opinion does not therefore apply to any non-NHS site at present. We will write to you again as soon as an SSA application(s) has been reviewed. In the meantime, no study procedures should be initiated at non-NHS sites.

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

Documents:	***Version***	***Date***
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Uni Insurance]	2.0	23 January 2017
Interview schedules or topic guides for participants [Interview Schedule for Resident]	1.0	30 December 2016
Interview schedules or topic guides for participants [Interview Schedule for Focus Group (Family)]	2.0	23 January 2017

Interview schedules or topic guides for participants [Interview Schedule for Focus Group(Staff)]	2.0	23 January 2017
IRAS Application Form [IRAS_Form_15122016]		15 December 2016
Letter from sponsor [Letter from Sponsor]	2.0	23 January 2017
Letters of invitation to participant [Letter of Introduction from Darland House Manager]	2.0	23 January 2017
Other [DEMQoL Proxy questionnaires for Family in Focus Group]	1.0	30 December 2016
Other [Nominated Consultee Inf Sheet]	2.0	23 January 2017
Other [Nominated Consultee Assent Form]	2.0	23 January 2017
Other [Personal Consultee Information sheet]	2.0	23 January 2017
Other [Personal Consultee Assent Form]	2.0	23 January 2017
Other [Information Sheet for Family in Focus Group]	2.0	23 January 2017
Other [Information Sheet for carer in Focus Group]	2.0	23 January 2017
Other [Consent Form for Carer in Focus Group]	2.0	23 January 2017
Other [DEMQoL questionnaires for Family in Focus Group]	2.0	23 January 2017

Other [DEMQoL Proxy questionnaire for Staff in Focus Group]	2.0	23 January 2017
Other [Evidence of Site Insurance. Medway Community Healthcare]	2.0	23 January 2017
Other [Timed Up and Go (In Dance Session)]	2.0	23 January 2017
Other [Tinette Assessment Tool (In Dance Session)]	2.0	23 January 2017
Other [Tinette Description]	2.0	23 January 2017
Other [Introduction to Focus Group]	2.0	23 January 2017
Other [Falls Risk Assessment Tool]	2.0	23 January 2017
Other [Family consent form (Focus)]	2.0	23 January 2017
Other [Dance Activities]	2.0	23 January 2017
Participant consent form [Resident Consent Form]	2.0	23 January 2017
Participant information sheet (PIS) [Participant Information Sheet]	2.0	23 January 2017
Participant information sheet (PIS) [Resident Information Sheet]	2.0	23 January 2017
Research protocol or project proposal [Research Protocol]	2.0	23 January 2017
Response to Request for Further Information [Further information regarding access to PID]		02 January 2017

Summary CV for Chief Investigator (CI) [Rachel Forrester- Jones C.V]	1.0	15 December 2016
Summary CV for student [Clara Awoyomi (PI) C.V]	2.0	23 January 2017
Summary CV for supervisor (student research) [Professor Oliver's C.V]	1.0	30 December 2016
Summary CV for supervisor (student research) [Summary of David's C.V]	2.0	23 January 2017

Statement of compliance

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

After ethical review

Reporting requirements

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

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

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

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

17/EE/0005 Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely

pp **Dr Niki Bannister**

Chair

Email: NRESCommittee.EastofEngland-Essex@nhs.net

Enclosures: "After ethical review – guidance for researchers"

Copy to:

Is Dance Café Effective to improve the quality of life of people with Dementia?
A Pilot Study

Ms Nicole Palmer,
Professor Rachel Forrester-Jones
Ms Claire Pegg, Medway Community HealthCare CIC

Figure 14 Resident information sheet

University of Kent | Tizard Centre

T: +44 (0)1227 827373
F: +44 (0)1227 763674
E: tizard-info@kent.ac.uk
www.kent.ac.uk/tizard

Tizard Centre, University of Kent
Canterbury, Kent, CT2 7LZ
Research student: Clara Awoyomi
E-mail: ca413@kent.ac.uk
Tel. number: 01227 827955
Supervisor: Prof Rachel Forrester-Jones
E-mail: R.V.E.Forrester-Jones@kent.ac.uk
Tel. number: 01227 82 3194

Dance Café: Is a dance café effective to improve the life of people with dementia?

You are being invited to take part in a study to find out if a dance café can improve your quality of life. This study is part of a MSc course at the University of Kent.

Why have I been invited to take part?

You have been invited as you are a resident of Darland House, who has been at the House for at least 6 months and you may be able to join in this dance café project.

Where the study will take place?

The study will take in one of the communal rooms on the first floor of Darland House

What will happen?

You will be allocated to one of two groups of people. The first group will take part in the dance café first; the second group will take part in the dance café at a later date.

All participants will have their weight, food intake, the number of any falls or hospital admissions, balance and walking ability recorded throughout the study. If you are able to, we would also like to ask you some questions about your quality of life.

A Dance Café will be set up over 8 weeks. Each dance café will last for 2 hours each week. Each session will involve dances led by a dance therapist.

You can participate in the dance as much or as little as you wish. Snacks will be available for you.

How much time will it all take?

The study will take 8 weeks with a 2-hour session held each week.

Do I have to take part?

No, you do not have to take part in the study and it is entirely up to you to decide whether or not you want to take part.

You do not have to give a reason if you do not want to be involved.

Whatever you decide will have no effect on the care you receive now or in the future. If you agree to take part but then change your mind you can withdraw from the study at any time without giving a reason. If you do withdraw, you can decide whether we can use any information you have already given us.

What are the benefits of taking part?

This research may help to improve your mobility, your nutrition and your wellbeing. The results of the study may also help others by providing information about how dance can help to improve the life of people with dementia, their carers and families.

What are the risks of taking part?

There is a risk that you may fall, but the following checks will help to minimise this risk:

- Your slippers/shoes will be checked to make sure that they are the right size
- The dance will be done by an experienced dance therapist.
- There will be attendants to accompany you whilst dancing if needed.

What will happen to the results of the study?

Clara will collect the data from the observations and interview conducted during the project. Material gathered during this research will be treated as confidential and securely stored. The data generated during the study will be stored/accessed for three years after the study has ended. After this period, the paper records will be shredded and recycled and the records stored on computer hard drive, telephone or tape recorder will be erased.

Complaints procedure

We have a clear complaints procedure. If you did not like things Clara said or did, you can complain by firstly telling Clara herself about it, if you can. You may also contact the Supervisor at the University of Kent.

Professor Rachel Forrester-Jones
Tizard Centre, Woodlands, Giles Lane, University of Kent, Canterbury CT2 7LR
01227 823194.
R.V.E.Forrester-Jones@kent.ac.uk
Or
Tizard Centre Ethics Committee
Contact: j.ruffels@kent.ac.uk (or 01227 827373).

Thank you.

Researcher's details:
Clara Awoyomi
Tizard Centre
University of Kent
Canterbury, Kent.
CT2 7LR, Tel: 01634852323 or 07985144777 Email: clara.awoyomi@nhs.net; ca413@kent.ac.uk.

Figure 15 Personal consultee's information sheet

University of Kent
Tizard Centre

T: +44 (0)1227 827373
F: +44 (0)1227 763674
E: tizard-info@kent.ac.uk
www.kent.ac.uk/tizard

Tizard Centre, University of Kent
Canterbury, Kent, CT2 7LZ
Research student: Clara Awoyomi
E-mail: ca413@kent.ac.uk
Number: +44(0)1227 827955
Supervisors: Prof Rachel Forrester-Jones;
E-mail: R.V.E.Forrester-Jones@kent.ac.uk

Title: Dance café: Is a dance café effective to improve the life of people with dementia?

Your family member who is resident at Darland House is felt to be suitable to take part in a research study conducted by Clara Awoyomi as part of a MSc course which is supervised by Prof Rachel Forrester-Jones & Prof David Oliver from the Tizard Centre, University of Kent.

What is the purpose of the study?

This study is planned to assess how effective a Dance café can be to improve the quality of life of residents with dementia. The residents will take part in a weekly session for 8 weeks and encouraged to be involved in dance and activity. We would like to see if this helps the person's appetite, balance and reduces their risk of falls and hospital admissions.

Why has this resident been invited to take part in the study?

The resident is invited to participate in this study as he/she resides in Darland House and it is felt that they would be able to take part in a dance session and could benefit from this activity.

Why have I been invited to be involved?

We have asked you to be involved as your family member is not able to consent (agree) with the research them self and we need you help in agreeing that they may be involved, on the resident's behalf. This involves you acting as a "personal consultee"

What would the adult that you act as an advocate for, have to do if you agreed for him/her to take part?

As an advocate of the adult that you are a family/friend of, if you advise that he/she would like to participate in the current study, the following will happen:

1. The research student will firstly randomly place each participating resident into two groups (the group who will be involved immediately in the Dance café and a group who will wait for 8 weeks before starting).

Clara will use a variety of measures to test out nutrition, balance and falls at the start of the study for both groups and again, after the intervention. **IRAS: 201332 REC Ref: 17/EE/0005 Version: 2.0 Date: 23.1.17**

Staff at Darland House who knows the resident well will be asked about the quality of life and their impression about the resident’s feelings about the dance café.

2. Clara will also interview participants, if they are able to do so, about their experiences of the dance café – their enjoyment of the sessions and what they liked best or worse. These interviews will be recorded to help her remember what he/she (or the carer/staff member) tells her and will only be available to those people involved in the research.

Do I have to agree for the adult I act as an advocate for to take part?

The resident’s involvement in this project will be entirely voluntary. However because of their dementia it may be very difficult to ask them if they would like to be involved.

We would therefore like to involve you in this decision, on behalf of the resident. We would like to ask you if you feel that your family member would agree to be involved in the project, if they were able to make this decision themselves.

The Mental Capacity Act (2005) allows family members to be a “personal consultee” and to give consent for involvement in a research project if the person cannot make the decision themselves – a short summary is included at the end of this form. You are being asked whether you think the person would agree and it is not your personal views on the project.

The persons’ participation in this study is entirely voluntary and they may withdraw from the project at any time. If a resident does not join in the project this will not affect any other aspect of care at Darland House.

How will the information be dealt with?

All the result and the interviews gathered during this research will be treated as confidential and securely stored. Only Clara and her supervisor will have access to the completed material (interviews etc.) and personal information of the adults with dementia

The data generated during the study will be stored/accessed for three years months after the study has ended. After this period, the paper records will be shredded and recycled and the records stored on computer hard drive, telephone or tape recorder will be erased by software designed to remove all stored data.

If Clara finds out something that may lead to concerns that the resident or someone else is in danger, she will consult you about this if she needs to tell someone else.

What will happen to the results of the research study?

The information you provide us with will be used to produce a one to two-page accessible summary of the findings sent to all participants. A 'feedback' workshop will be offered to Darland House, to which all family members and staff will be invited and the results of the research project will be published in a scientific journal.

IRAS: 201332 REC Ref: 17/EE/0005 Version: 2.0 Date: 23.1.17

Who is organising and funding this research?

Darland House is part-funding, together with Medway Community Healthcare CIC.

Complaints Procedure

We have a clear complaints procedure. If you did not like things Clara said or did, you can complain by firstly telling Clara herself about it, if you can.

You may also contact the Supervisor at the University of Kent

Professor Rachel Forrester-Jones
Tizard Centre, Woodlands, Giles Lane, University of Kent, Canterbury CT2 7LR
01227 823194.
R.V.E.Forrester-Jones@kent.ac.uk

Or

Tizard Centre Ethics Committee
Contact: j.ruffels@kent.ac.uk (or 01227 827373).

Thank you for taking the time to read this.

APPENDIX

THE ROLE OF A PERSONAL CONSULTEE

“The consultee is not being asked for advice on their personal views on participation in the specific project, or research in general. The consultee is not being asked to consent on behalf of the person who lacks capacity. The consultee must set aside any views they may have about the research and consider only the views and interests of the person who lacks capacity. A consultee should be asked to consider the broad aims of the research, the risks and benefits and the practicalities of what taking part will mean for the person who lacks capacity. The consultee should consider the past and present views of the person who lacks capacity on the overall nature of the research. It is also essential to consider their present views and wishes for example, the study might involve activities in the afternoon when the person who lacks capacity is most tired so would find it a strain, or conversely it might involve an activity that the person who lacks capacity particularly enjoys. At any stage the consultee can advise the researcher that the person who lacks capacity would not want to remain in the project and their advice must be respected by the researcher."

Figure 16 Personal consultee (family) member assent (Record of consultation) form

University of Kent | Tizard Centre

T: +44 (0)1227 827373
F: +44 (0)1227 763674
E: tizard-info@kent.ac.uk
www.kent.ac.uk/tizard

Tizard Centre, University of Kent
Canterbury, Kent, CT2 7LZ
Research student: Clara Awoyomi
E-mail: ca413@kent.ac.uk
Number: +44(0)1227 827955
Supervisors: Prof Rachel Forrester-Jones;
E-mail: R.V.E.Forrester-Jones@kent.ac.uk

Researcher: Clara Awoyomi
Supervisor: Professors Rachel Forrester-Jones & Professor David Oliver

E-mail: ca413@kent.ac.uk; r.v.e.forrester-jones@kent.ac.uk
Telephone number: 01227 82 7955 or 01227 82 3194

Please tick and write your initials

- I confirm that I have read and understood the information letter attached for the above study. ☐
- I understand that the participation of the adult that I advocate for, is voluntary and that he or she is free to withdraw at any time without giving any reason. ☐
- I agree to have the focus meetings and my voice tape recorded during the interview. ☐

- My questions have been answered to my satisfaction by the researcher. ☐

- I advise that the adult that I am the advocate for, would want to participate in the above research study if he/she would be able to express his/her view. ☐

____
Name of resident

________________________	______________	_________________
Name of advocate/ Family member	Date	Signature
Name of the person obtaining the consent	Date	Signature

Please sign all the copies, return the signed copies to Clara Awoyomi
You will retain one copy, one copy will be in your file and the 3rd copy will be kept in the site file: Alternatively, you can return the signed copies to:

Clara Awoyomi, Tizard Centre, University of Kent
Canterbury, Kent, CT2 7LZ

Figure 17 Nominated consultee’s information sheet

University of Kent | Tizard Centre

T: +44 (0)1227 827373
F: +44 (0)1227 763674
E: tizard-info@kent.ac.uk
www.kent.ac.uk/tizard

Tizard Centre, University of Kent
Canterbury, Kent, CT2 7LZ
Research student: Clara Awoyomi
E-mail: ca413@kent.ac.uk
Number: +44(0)1227 827955
Supervisors: Prof Rachel Forrester-Jones;
E-mail: R.V.E.Forrester-Jones@kent.ac.uk

Title: A Pilot Study of Dance Café for People with Dementia

Dear Consultee,

Your resident is felt to be suitable to take part in a research study conducted by Clara Awoyomi as part of a MSc course which is supervised by Prof Rachel Forrester-Jones & Prof David Oliver from the Tizard
Centre, University of Kent.

What is the purpose of the study?

This study is planned to assess how effective a Dance café can be to improve the quality of life of residents with dementia. The residents will take part in a weekly session for 8 weeks and encouraged to be involved in dance and activity. We would like to see if this helps the person’s appetite, balance and reduces their risk of falls and hospital admissions.

Why has this resident been invited to take part in the study?

The resident is invited to participate in this study as he/she resides in Darland House and it is felt that they would be able to take part in a dance session and could benefit from this activity.

Why have I been invited to be involved?

We have asked you to be involved as your resident who you look after is not able to consent (agree) with the research them self and we need your help in agreeing that they may be involved, on the resident's behalf. This involves you acting as a "nominated consultee"– which is explained below in the Appendix.

What would the adult that you act as an advocate for, have to do if you agreed for him/her to take part?

As an advocate of the adult that you are a carer of, if you advise that he/she would like to participate in the current study, the following will happen:

1. Clara will firstly randomly place each participating resident into two groups (the group who will be involved immediately in the Dance café and a group who will wait for 8 weeks but have their standard care). Clara will use a variety of measures to test out nutrition, balance and falls at the start of the study for both groups and again, after the intervention. Staff at Darland House who knows the resident well will be asked about the quality of life and their impression about the resident's feelings about the dance café.
2. Clara may also interview the participants, if they are able to do so, about their experiences of the dance café – their enjoyment of the sessions and what they liked best or worse. These interviews will be recorded to help her remember what he/she (or the carer/staff member) tells her and will only be available to those people involved in the research.

Do I have to agree for the adult I act as an advocate for to take part?

The resident's involvement in this project will be entirely voluntary. However, because of their dementia it may be very difficult to ask them if they would like to be involved.

We would therefore like to involve you in this decision, on behalf of the resident. We would like to ask you if you feel that your resident member would agree to be involved in the project, if they were able to make this decision themselves.

The Mental Capacity Act (2005) allows carers to be a “nominated consultee” and to give consent for involvement in a research project if the person cannot make the decision themselves – a short summary is included at the end of this form. You are being asked whether you think the person would agree and it is not your personal views on the project.

The persons’ participation in this study is entirely voluntary and they may withdraw from the project at any time. If a resident does not join in the project this will not affect any other aspect of care at Darland House.

How will the information be dealt with?

All the result and the interviews gathered during this research will be treated as confidential and securely stored. Only Clara and her supervisor will have access to the completed material (interviews etc.) and personal information of the adults with dementia.

The data generated during the study will be stored/accessed for three years months after the study has ended. After this period, the paper records will be shredded and recycled and the records stored on computer hard drive, telephone or tape recorder will be erased by software designed to remove all stored data.

If Clara finds out something that may lead to concerns that the resident or someone else is in danger, she will consult you about this if she needs to tell someone else.

What will happen to the results of the research study?

The information you provide us with will be used to produce a one to two-page accessible summary of the findings sent to all participants. A 'feedback' workshop will be offered to Darland House, to which all family members and staff will be invited and the results of the research project will be published in a scientific journal.

Who is organising and funding this research?

Darland House is part-funding, together with Medway Community Healthcare CIC.

Complaints Procedure:

We have a clear complaints procedure. If you did not like things Clara said or did, you can complain by firstly telling Clara herself about it, if you can.
You may also contact the Supervisor at the University of Kent

Professor Rachel Forrester-Jones
Tizard Centre, Woodlands, Giles Lane, University of Kent, Canterbury CT2 7LR
01227 823194.
R.V.E.Forrester-Jones@kent.ac.uk

Or
Tizard Centre Ethics Committee
Contact: j.ruffels@kent.ac.uk (or 01227 827373).

Thank you for taking the time to read this.

THE ROLE OF A PERSONAL CONSULTEE

"The consultee is not being asked for advice on their personal views on participation in the specific project, or research in general. The consultee is not being asked to consent on behalf of the person who lacks capacity. The consultee must set aside any views they may have about the research and consider only the views and interests of the person who lacks capacity. A consultee should be asked to consider the broad aims of the research, the risks and benefits and the practicalities of what taking part will mean for the person who lacks capacity. The consultee should consider the past and present views of the person who lacks capacity on the overall nature of the research. It is also essential to consider their present views and wishes for example, the study might involve activities in the afternoon when the person who lacks capacity is most tired so would find it a strain, or conversely it might involve an activity that the person who lacks capacity particularly enjoys. At any stage the consultee can advise the researcher that the person who lacks capacity would not want to remain in the project and their advice must be respected by the researcher." (Department of Health, 2005, p. 7)

Figure 18 Nominated consultee assent
& record of consultation form

University of Kent | Tizard Centre

T: +44 (0)1227 827373
F: +44 (0)1227 763674
E: tizard-info@kent.ac.uk
www.kent.ac.uk/tizard

Tizard Centre, University of Kent
Canterbury, Kent, CT2 7LZ
Research student: Clara Awoyomi
E-mail: ca413@kent.ac.uk
Number: +44(0)1227 827955
Supervisors: Prof Rachel Forrester-Jones;
E-mail: R.V.E.Forrester-Jones@kent.ac.uk

Title: **A Pilot Study of a Dance Cafe for People with Dementia**

Researcher: Clara Awoyomi
Supervisor: Professors Rachel Forrester-Jones

Please write your initials in the box to confirm

E-mail: ca413@kent.ac.uk; r.v.e.forrester-jones@kent.ac.uk
Telephone number: 01227 82 7955 or 01227 82 3194

- I confirm that I have read and understood the information sheet attached for the above study. ☐

- I understand that the participation of the adult that I advocate for, is voluntary and that he or she is free to withdraw at any time without giving any reason. ☐

- My questions have been answered to my satisfaction by the researcher. ☐

- I agree to have the focus meetings and my voice tape recorded during the interview. ☐

- I advise that the adult that I am the advocate for, would want to participate in the above research study if he/she would be able to express his/her view. ☐

____
Name of resident

______________________	____________	_______________
Name of advocate/ Staff member	Date	Signature
____________________	____________	___________
Name of person Obtaining the consent	Date	Signature

Please sign all the copies, return the signed copies to Clara Awoyomi
You will retain one copy, one copy will be in your file and the 3rd copy will be kept in the site file: Alternatively, you can return the signed copies to: