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THE EXPERIENCE OF PHYSICAL ACTIVITY AND WELL-BEING AMONGST OLDER PEOPLE FROM ETHNICALLY DIVERSE BACKGROUNDS LIVING WITH DEMENTIA

ALAN MICHAEL WRIGHT

A thesis submitted to the University of Huddersfield in part fulfilment of the requirements for the degree of Doctor of Philosophy

The University of Huddersfield

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Copyright Statement

For my children, Lewis and Martha, who constantly inspire me to learn.

Acknowledgements

Abstract

This qualitative study investigates the impact of physical activity on the well-being of a group of older people with dementia from diverse ethnic backgrounds. The study is influenced by the theoretical perspectives of symbolic interactionism, social constructionism and embodiment. Participant observation and semi-structured interviews are used in eight well-being cafés and day centres in a northern city in the UK, where people with dementia living in the community perform different types of exercise and dance. Nineteen people with dementia and eight carers took part in the participant observation stage. Thirteen individuals with dementia from the participant observation phase are asked about their relationship with physical activity. Thematic analysis is used to generate themes and Van Manen's hermeneutic phenomenological approach is used to guide interpretation.

Participants from all ethnic groups express positive beliefs and attitudes towards physical activity and some individuals overcome substantial barriers in order to be physically active. Participants experience a range of benefits including enjoyment, social contact and enhanced mood. Physical activity provides the context in which participants could employ their embodied ability to express themselves, communicate, locate themselves effectively in the social world and connect socially with others in a non-verbal manner. The well-being profile devised by Bradford Dementia Group (Bruce 2000) is applied to identify positive effects of physical activity. Engagement in physical activity is found to fulfil participant's psychosocial needs and therefore positively affect well-being.

Barriers and facilitators which influenced participants' engagement in physical activity are identified. Engaging in physical activity can be easily disrupted. Staff and volunteers are not always effective in facilitating physical activity and their efforts sometimes result in participants expressing ill-being. Some participants find it difficult to perform physical activity because their ethnic identities are incompatible with the cultural characteristics of available activities. A number recommendations relating to policy and practice are made to assist in the provision of physical activity that is likely to support the well-being of people with dementia.

Dissemination of knowledge

Conference Presentations (oral presentations)
Huddersfield University Research Festival. Human and Health Science Open day. March 27th 2009 "How older people perceive the influence of physical activity on their sense of wellbeing".

Huddersfield University Student Conference 22nd May 2009 "The role of physical activity in the promotion of older people's mental health and wellbeing".

British Society of Gerontology, Annual Conference 3rd September 2009. University of Western England "How older people living with dementia perceive the influence of physical activity on their sense of wellbeing".

West Yorkshire Evidence-based Practice Conference 12th November 2009. Bradford Royal Infirmary "The role of physical activity in the promotion of older people's mental health and wellbeing".

British Society of Gerontology, Annual Conference 12th July 2012. Keele University. "Connecting with the world through physical activity: an exploration of the perceptions and experiences of people with dementia".

Conference Presentations (posters)
British Sociological Association, Medical Sociology Group Annual Conference. University of Durham September 1st 2010. "Connecting with the world through physical activity; the experiences of older people with dementia from diverse ethnic backgrounds".

Bradford Ageing Learning Disability and Dementia Group (BALDAD). National Conference on Dementia in People with Learning Disabilities, 22nd November 2010. "Physical Activity and Wellbeing amongst older people with dementia from diverse ethnic backgrounds".

Bradford Institute for Health Research Inaugural Research Conference, Research into Practice. Wednesday 16th March 2011, "The experience of physical activity and well-being amongst older people with dementia from ethnically diverse backgrounds".

British Sociology Association Ageing Body and Society Study Group, Body Work in Health and Social care: Critical Issues, New Agendas. September 6th 2011 British Library, London. "Living through the body: what people with dementia tell us about their relationship with physical activity".

List of Abbreviations

BME= Black and minority ethnic (communities).
BPSD = Behavioural and psychological symptoms of dementia.
CAQDAS = Computer assisted qualitative data analysis software.
CST= Cognitive stimulation therapy.
DCM = Dementia care Mapping.
IPA = Interpretative phenomenological analysis.
LREC=Local research ethics committee
MMSE = Mini mental state examination.
NRES = National research ethics service.
QOL= Quality of life.

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CHAPTER ONE

Introduction to the thesis

Introduction

Megan is gently led onto the dance floor by two volunteers. She looks lost, but her calm facial expression suggests that she is comfortable being here. Megan smiles as she starts to move her body gracefully to the music. She joins a circle of others and her smile broadens. She looks across the hall in my direction and beckons me to join her.

This PhD explores the experiences of a group of older people from diverse ethnic backgrounds, who like Megan, live with dementia. The research described in this thesis is concerned with how physical activity can provide the context within which people with dementia can engage certain innate embodied skills that have been resistant to the effects of dementia. I will explore how, by utilising these embodied skills, people with dementia can respond to the challenges of living with the condition. My study looks at how engaging in physical activities such as dance and exercise can have a positive impact on the well-being of people with dementia by helping them to maintain their identity, meet psycho-social needs and engage effectively with the world around them through their body. My research explores how it is possible for older people with dementia to thrive in social environments when they are supported and encouraged to act in a spontaneous manner. In this first chapter I will begin by introducing myself and explain my interest in dementia and physical activity. I will then explain why research in this area is important. I will go on to discuss the development of my research questions and the scope of this study. Finally, I will detail the layout of the thesis and preview the contents of the chapters within it.

Personal and professional background

I have my own complex personal relationship with physical activity. Competitive running, mountaineering and cycling have played an important part in my life since my teenage years. These activities are part of my identity, they help me to regulate my mood and they contribute greatly to my well-being. As I enter my 50s I am aware that my body is subject to the ageing process. My joints are beginning to stiffen, I am prone to injuries and during fell races I struggle to run as fast as my 21 year old son. Nevertheless, my body provides numerous opportunities for me to interact with the natural and social world in ways that I value highly.

I completed my first degree in social geography in 1984. Several years later I decided on a career in physiotherapy when working abroad as a volunteer with people who had profound learning disabilities. I have worked clinically as a physiotherapist since 1990 and for the last twelve years I have been employed in older people's mental health services in West Yorkshire. During my clinical practice I have regularly come into contact with people who have dementia and their carers. In the last few years I have also experienced the impact of dementia within my family. During this time I have been aware that as relatives we have found it difficult to talk openly about the effects of dementia.

Two years after completing my physiotherapy training I undertook a research secondment and gained an MPhil on the self-management of back pain which triggered my interest in research. In the early 2000's I undertook masters modules in research methods, exercise and diversity because I found studying stimulating and useful in the manner in which it informed my clinical work. I decided to enrol in a more structured course of study and five years ago I completed an MSc in public health and health promotion. My MSc dissertation described a small study exploring the role of physical activity in the management of depression. During this research project I interviewed older people recovering from severe depression about their relationship with physical activity and the role it took in their recovery. I was surprised by how strongly the people in my study identified with physical activity despite their advanced age and physical frailty. I found that for some participants, physical activity played a crucial role in their return to positive mental health. However, counter to my expectations, most participants had little interest in performing organised physical activity such as exercise classes, swimming sessions or walking groups. Instead

they preferred to undertake activities alone or with family and friends. Participants were keen to become physically active again because they wanted to regain their identity, function socially and enjoy themselves. This made me think about physical activity and how it is viewed by health care professionals. The promotion of physical activity had been part of my professional role since I had qualified. From the perspective of a physiotherapist, physical activity is usually equated with exercise and is mostly considered as a tool for rehabilitation and a way of maximising health. People are encouraged to be active on the grounds that it lowers their risk of contracting certain medical conditions, strengthens their muscles and maximises their independence. In contrast, little consideration is given to the social benefits of physical activity or how relevant it is to identity and well-being. Undertaking the MSc widened my perspective on what constituted "health" and what motivated people to engage in healthy behaviour such as physical activity. The studying and research that I had done led me to adopt a more holistic view of health to include well-being. I found myself re-evaluating my position as a health care professional; I became aware that my view of mental health had been narrow and biomedicalised. As I completed my MSc I began to look around for opportunities to study for a PhD in which I hoped to explore the relationship that older people have with physical activity in greater depth.

Identifying the research topic

Having successfully enrolled as a PhD student, the broad research question I began with was as follows; "What factors motivate older people to participate in physical activity and how does being active impact on their well-being?" Based on my initial reading and my own experiences, I suspected that social benefit and the pleasure of being active influenced participation in physical activity far more than the prospect of improved health. In order to develop my research questions I decided to visit several local over 50's exercise classes, participate in activities and talk to the people there about their views on physical activity. The people I spoke to told me that they came to the groups because they enjoyed them and the activities made them feel good. I experienced the social and physical effects myself; I had a feeling togetherness with those around me, the opportunity for social touch felt significant, the background music added to my enjoyment and enhanced my mood. I was aware that when combined, these elements exerted a powerful effect on my own sense of well-being.

As I continued to explore how older people engaged in organised community- based physical activity I witnessed the effects that participation in physical activity had on people with dementia. I spent the afternoon at a well-being café; a monthly event jointly run by the NHS and social services, designed to socially support people with dementia and their carers. A man with dementia sitting at the same table as me who had been silent and withdrawn for much of the afternoon became animated and self-expressive when dancing. The behaviour of others changed too; I was struck by the normalising effect that dancing had on the interaction between a couple I observed. When they had arrived and sat with others they had presented clearly as a person with dementia and their carer. However, as I watched them dance together they appeared as a contented couple enjoying themselves in shared activity. Through chatting with those around me I began to find out more about the relationship that the people with dementia attending the café had with physical activity in general. For example, individuals told me how they valued walking as means of sharing activity and satisfying a need for movement.

As my interest in focusing on dementia increased I attended a "memory walk" in a local park organised by the Alzheimer's Society. A large group of people with dementia and carers spent an hour walking together and mixing socially. The celebratory nature of the well-being café and "memory walk" felt at odds with the biomedical view of dementia that I had been holding up to that time. Influenced by my training and professional role as a physiotherapist in the NHS, I had previously viewed dementia through a biomedical lens as an illness associated with the decline of mental and physical function. I had considered dementia as a process which caused problems that I was expected to address. The fact that memory walks and well-being cafés seemed to exert a powerful therapeutic effect in terms of well-being without the direct involvement of health professionals resonated with my previous thoughts about the limitations of the biomedical approach to health and physical activity. I recognised that most of what constituted the experience of dementia took place outside the remit of the health services. I realised that dementia was a complex human experience involving all aspects of the lives of those affected and I became aware of my horizons widening.

Having decided to concentrate on dementia, well-being and physical activity it was inevitable that I would consider ethnicity. This is because I live and work in a city where the population includes large ethnic minority communities and I had been interested in the tensions and dynamics that this diversity entails since moving here twenty years ago. At times throughout my life when living in ethnically mixed communities in the UK and abroad I had considered my own ethnic identity. In my current place of work I was aware that some mental health and social services interventions targeted specific ethnicities and I had wondered about the implications of this approach. In order to explore this in relation to my PhD, I spent an afternoon at a second well-being café which was intended for people from Eastern Europe. Here the exercise and style of dance was performed in a culturally specific way that was very different to the activities at the café I had visited before. As I continued to develop my research ideas I talked with two Asian community support workers about dementia and the way that cultural factors influenced how the condition was viewed in south Asian communities. We discussed how engagement in physical activity may be influenced by ethnic factors and I was told that it was unusual for older South Asians to engage in physical activity. I became interested in exploring what happened in terms of well-being when people with dementia from different ethnic backgrounds came together and were encouraged to perform physical activity. I also realised that it was important to hear the voice of people with dementia.

Why research in this area is important

Research in dementia is important because the condition is common amongst older people. It is estimated to affect almost a million people in the UK (Alzheimer's Society, 2013) and represents a serious threat to the well-being of those effected (Luengo-Fernandez et al. 2010). Exploring physical activity and well-being is also important because they represent major themes in health promotion (Department of Health, 2011). Physical activity is thought to be beneficial for the mental health of older people in the general population (Angavaren et al. 2008). Furthemore, NICE (2011) supports the use of "physical exercise" for people with dementia. However, it is recognised that more evidence about the value of physical activity for people with dementia is needed (Potter et al. 2011; Prince et al. 2011). Similarly, little is known about how physical activity can enhance well-being for people with dementia. The Prime Minister's Challenge on Dementia (Department of Health, 2012) calls for

dementia friendly communities. Therefore research in activities that are potentially cheap, community based and which improves the well-being of people with dementia is potentially valuable. Finally, research addressing issues of ethnicity in dementia care is needed to inform the debate about ethnic specific dementia services (Daker-White et al. 2002; Iliffe and Manthorpe 2004; La Fontaine et al. 2007). In West Yorkshire, mental health promotion using well-being cafés and day centres in multi-ethnic environments allows this to take place. As I read more widely I realised that my research could contribute to knowledge on how physical activity was meaningful for older people with dementia from diverse ethnic backgrounds and be useful in terms of informing services for people with dementia. In order to address the topic I formulated a set of aims and research questions.

Study aims and research questions

The primary aim of my research was to explore how physical activity influences the well-being of older people from diverse ethnic backgrounds who are experiencing dementia. I devised two secondary aims. Firstly, to contribute to the debate regarding the most effective methodologies to employ when conducting research involving dementia within multi-ethnic populations. Secondly, to inform policy and provide practical recommendations for physical activity based activities for people with dementia. After careful consideration I devised the following research questions;

- What facilitators influence how older people with dementia engage in physical activity?
- What barriers influence how older people with dementia engage in physical activity?
- How do older people from different ethnic backgrounds with dementia engage in physical activity?
- What benefits do older people with dementia from diverse backgrounds identify?
- What role does ethnicity play in the experience of physical activity for older people with dementia?

Scope of the study

My study focused on older people with dementia living in the community. The research was located geographically in a northern post-industrial city in the UK and was conducted in "natural" settings. Participants accessed services such as day centres and well-being cafes at which they undertook supervised physical activity. I decided to explore the subjective experience of physical activity for people with dementia; how ethnicity influenced this experience and how being physically active was related to participants' well-being. The study was idiographic; it was concerned with their individual experience and therefore included small numbers of participants. The scale of the study gave rise to issues of generalisability which will be dealt with in chapter eight.

Structure of thesis

In this section I will describe how this thesis will be laid out and provide an overview of the contents of each chapter. In Chapter two I will discuss the theoretical foundations which underpin and define the concepts of dementia, physical activity, well-being and ethnicity. I will describe how dementia has mostly been defined by society as a disease of the brain which leads to cognitive deficit and problematic behaviours. I will discuss the consequences of this highly influential biomedical model of dementia. I will then introduce alternative psychosocial models which have been employed. These models recognise dementia as a social phenomenon as well as an illness. They consider how the process impacts on selfhood and use theoretical elements derived from symbolic interactionism and social constructionism such as positioning theory to explain the process. I will introduce the concept of excess disability which is associated with psychosocial models of health and which has been applied to dementia. I will note how the role of the body has been neglected in the field of dementia and I will explore the concept of embodiment which allows the role of the body to be recognised as a factor in the experience of dementia. I will then describe its origins in phenomenology and discuss how embodiment has been applied by a small number of researchers exploring the experience of dementia. I will propose that in order to address my research questions effectively, it was helpful for me to conceptualise dementia as a threat to both social and embodied selfhood. I will go on to discuss the application of an approach that combined these two models. I will discuss the concept of well-being,

describe the elements that constitute it and consider the factors that influence it. I will then move on to the concept of physical activity and describe the benefits it can offer for older people with dementia in terms of the promotion of well-being. Finally I will discuss what is meant by the term ethnicity, I will explain how it is a problematic concept and one which is difficult to operationalise, but I will conclude that it can be an important factor in how individuals experience dementia.

In Chapter three I will describe my review of the empirical literature relating to dementia, physical activity, well-being and ethnicity. I will discuss the methodologies used and identify significant findings which have emerged from studies. I will start by discussing the evidence relating to the subjective experience of dementia. I will note that people experience a number of losses as they develop dementia and that they adopt strategies to help cope with these losses. I will point out that people with dementia can be aware of the stigma associated with their condition. I will note that people with dementia can experience well-being and I will explore factors that influence well-being such as music and social factors. I will then discuss how the concept of embodiment has been applied to the experience of dementia as a means of exploring the response of individuals to cognitive loss. I will review studies that have addressed physical activity and dementia and note that in the literature there is a focus on physical activity as an intervention for the relief of symptoms. I will present the evidence relating to ethnicity and dementia that suggests that the experience of dementia can vary according to ethnicity in a number of ways. I will identify a number of gaps in the literature relating to the lack of diversity in study participants, the shortage of studies exploring unstructured physical activity and the absence of evidence relating to the influence of ethnicity on the manner in which people with dementia engage in physical activity. Additionally, I will note the lack of evidence regarding the subjective meaning that people with dementia attach to physical activity and how it influences their well-being. Finally, I will discuss the limitations of RCTs as a means of effectively producing useful evidence when employed in this area.

In Chapter four, I will focus on the methodology and methods of my own study and detail how I addressed my research questions. I will list the reasons why I decided that a positivist methodology would be inappropriate for my study and how I chose to

adopt an interpretivist approach. I will discuss the development of my ontological position in which I defined dementia as a threat to both social and embodied self. I will describe how this resulted in the recognition of both phenomenological and social constructionist epistemological positions. I will explain why I chose to adopt participant observation and semi-structured interviews as methods of generating data and what the advantages of using them together were. I will then introduce Van Manen's hermeneutic phenomenological approach to researching lived experience and how this provided guidance for me in terms of my approach and the interpretation of my findings. I will outline how I referred to the Mental Capacity Act (2005) in order to plan how to recruit participants for my study. I will then recount how I gained permission to access eight fieldwork locations. I will describe the ethical considerations I had to make and my attempt to apply the process consent method (Dewing, 2007). I will describe how I included 19 people with dementia and eight carers in my participant observation phase and recruited 13 people with dementia for my interview phase. In the following section I will outline the process of data analysis. Finally, I will discuss issues of validity, reliability, and reflexivity.

Chapter five is the first of my two findings chapters in which I present themes derived from my analysis and refer directly to my data. Segments of text containing data from participant observation and interviews will be indented. In order to differentiate between data derived from different sources, text originating from participant observation will be underlined. The names of both the study participants and my fieldwork locations will be pseudonyms. I will present themes relating to factors which influenced participants' engagement in physical activity. The themes I will present are contained within four categories. My first category will contain themes which represent participants' attitudes and beliefs regarding physical activity and the relationship that they had with physical activity. My second category will contain themes relating to social environment. My third category will include themes reflecting the influence of participants' relationships with their bodies. My final category will contain themes relating to the environmental factors that influenced participants' engagement in physical activity.

In Chapter six, I will present themes which describe the benefits that participants experienced as a result of engaging in physical activity. I will describe how I referred to a well-being scale devised by the Bradford Dementia Group (2005) to enable me to identify expressions of well-being associated with physical activity. In order to identify relationships between physical activity and well-being and highlight which combinations of factors maximise benefits I will present findings in the form of a typology. This typology will contain four categories. Themes within these categories reflect a range of participants' experiences from full participation in physical activity resulting in clearly expressed well-being to lack of participation in physical activity and clearly expressed ill-being.

In chapter seven I will identify five key findings and discuss them in relation to the empirical and theoretical literature outlined in chapters two and three. This will enable me to identify the contribution that my study has made to dementia studies in the form of empirical knowledge, methodology and the application of theory.

In chapter eight I will draw my thesis to a close. I will relate my study findings back to my research questions. I will then present a synthesis of my findings which will relate to the manner in which physical activity was useful in promoting the well-being of most of my participants. I will go on to relate my study findings to dementia policy and practice and make recommendations for future research. I will discuss the strengths and weaknesses of my study. Finally I will make some concluding remarks.

Summary of chapter one

In this introductory chapter I have introduced myself, explained how important physical activity is to me in terms of my own well-being and described my interest in the wider social aspects of health. I have given an account of the development of my research topic, I have described my adoption of dementia as my topic and I have explained why it is an important field for research. I have identified my research questions and outlined the scope of my study. I have then previewed the contents of the chapters contained in this thesis. In my next chapter, I will look at how dementia is conceptualised and how questions relating to the lived experience of dementia well-being and ethnicity are best approached through the use of alternative models of dementia.

CHAPTER TWO

Theoretical foundations: conceptualising dementia, well-being, ethnicity and physical activity.

Introduction

In this chapter I will define and discuss a number of concepts; dementia, well-being, ethnicity and physical activity. Together, these concepts will form components of my research questions. In the first half of the chapter I will begin by defining dementia in a biomedical manner and discuss how the dominance of the medical model which underpins this definition has effected how society views dementia. I will then argue that other views of dementia based on alternative models are needed in order to successfully explore the multi-faceted nature of the dementia experience. I will introduce alternative models of dementia and suggest that combining several theoretical models is helpful. In the second half of the chapter I will introduce the concepts of well-being, ethnicity and physical activity. Having defined these concepts, I will explain their relevance to dementia and discuss how I related them to dementia in order to address my research questions.

The biomedical conceptualisation of dementia

Currently, dementia is thought to directly affect approximately 800,000 people in the UK (Alzheimer's Society, 2013) and represents a considerable threat to the physical health and well-being of older people (Luengo-Fernandez et al. 2010). It is considered to be an under-diagnosed condition, with 43% of people experiencing the condition in the UK never receiving a formal diagnosis (Alzheimer's Society, 2013). Dementia is generally defined in a biomedical manner as an acquired irreversible impairment of intellect, memory and personality which can be due to a number of causes and which develops gradually (Richman and Wilson, 2004). The diagnosis of dementia is generally undertaken through history taking, physical examination, cognitive assessment and mental state examination (Newhouse and Lasek, 2006). The Mini Mental State Examination (MMSE) is commonly used in the UK and North America (Folstein et al. 1975). According to ICD 10 (World Health Organisation, 1999), in order for a diagnosis to be made the following criteria must be met; a deterioration in memory which is most evident in learning new information, together

with a loss of other cognitive abilities such as judgement and information processing. There must also be evidence of a change in social behaviour and a decline in motivation and emotional control. These signs and symptoms must have been present for at least six months during which time the individual's awareness of their environment is preserved (World Health Organisation, 1999). Dementia may ultimately result in death as the individual loses the ability to resist infection (Koopmans et al. 2006). There is considerable variation in the rate of decline between individuals, with the time from diagnosis to death lasting from five to fifteen years (Jacques and Jackson, 2000).

Dementia is usually classified in terms of its underlying cause (Richman and Wilson, 2004). The most common type is Alzheimer's disease which is caused by a neurodegenerative condition of the brain tissue involving the encroachment of neuritic plaques and neurofibrillary tangles (Snowdon, 2002). The second most common type is vascular dementia, which is the result of impaired circulation of blood to the brain. It is not uncommon for people to develop both Alzheimer's and vascular dementia simultaneously. There are many other less common types of dementia caused by neurological processes, infection and substances such as alcohol (Richman and Wilson, 2004). Dementia is staged according to severity (Reisberg and Franssen, 2006). In the UK individuals are described as having mild, moderate or severe dementia (World Health Organisation 1999, NICE, 2011) (see Table 2.1). However, these stages are not rigid and are subject to interpretation (Jacques and Jackson, 2000). Therefore, whilst a person scoring less than 10 on their MMSE will probably be diagnosed with severe dementia, the doctor making the diagnosis is likely to also consider the individual's pre-morbid level of function and their current ability to perform activities of daily life (Burns and Winblad, 2006).

Table 2.1 The Three Stages of Dementia based on ICD-10 (World Health Organisation, 1999).

Mild dementia – Moderate memory loss affects daily life, although this is not severe enough to be incompatible with independent living. The main function affected is the learning of new material. For example, the individual has difficulty in registering, storing and recalling elements involved in daily living such as where belongings have been left, social arrangements or information given by family members. Complicated daily tasks cannot be undertaken.
Moderate dementia - Severe memory loss makes independent living difficult, individuals retain only highly learned material. There is an inability to recall basic information about local geography, recent activity and names of familiar people. The individual is unable to function without the assistance of another in activities of daily living, including shopping and handling money. Within the home, only simple chores can be performed. Activities are increasingly restricted and poorly sustained.
Severe dementia - Severe memory loss leads to a complete inability to retain new information with only fragments of previously learned information remaining. The individual fails to recognise even close relatives. Individuals are unable to solve problems or make judgements (Jacques and Jackson, 2002). Carers need to take over tasks such as bathing and toileting the individual as they become incontinent. These functional deficits may result in a physical "burden" of care (Burns and Winblad, 2006). The individual may exhibit behavioural and psychological symptoms such as agitation, delusions, depression and aggressive behaviour (Byrne et al. 2006). Physical problems include raised muscle tone and motor dysfunction such as dyspraxia (difficulty translating intention into movement). Gait disturbances lead to unsteadiness and falls (Newhouse and Lasek, 2006). A person with severe dementia may eventually lose their verbal ability and will be unable to sit upright (Reisberg and Franssen, 2006). Eventually they may become bed ridden and at risk from muscle contractures (Vellas, 2006). Weight loss is common (Jacques and Jackson, 2000).

The Department of Health (2009) and NICE (2011) provide guidelines for management of dementia. Early diagnosis is recommended because it allows the underlying causes of dementia such as circulatory problems to be treated. The provision of a prompt diagnosis is also considered important so that information about dementia and sources of support such as the Alzheimer's Society are identified. Pharmacological treatments for the symptoms of dementia include acetylcholinesterase inhibitors and Mermantine for the cognitive dysfunction associated with Alzheimer's disease. Anti-psychotics are only recommended for non-

cognitive symptoms such as severe agitation and behaviours that challenge when the individual is distressed or at risk of harm. Non-pharmacological treatments such as cognitive stimulation therapy are thought to be beneficial in terms of cognition and quality of life (Spector et al. 2003).

Criticisms of the biomedical model of dementia

The way in which dementia has just been described in which a linear causal relationship between neuropathology and dementia is assumed represents the "standard paradigm" (Kitwood, 1989) or biomedical conceptualisation of the condition. This standard paradigm reflects how the condition has predominantly been viewed in the past (Kontos, 2003) and continues to be viewed (Luengo-Fernandez et al. 2010). The biomedical model which dominates society's view of health and illness is based on the following assumptions. The mind and the body are separate entities, disease is caused by an identifiable physical agent and the malfunctioning body can be repaired like a machine through the application of medical science (Nettleton, 2006). This model of health has been dominant in the industrialised world for last 120 years (Taylor, 2007) and has led to a number of consequences. Firstly, it has resulted in a medicalisation of society with medical science and the pharmaceutical industry attaining great power and influence (Illich, 1976). Doctors are in a position to exert moral as well as physical regulation of the body (Turner, 1992). Secondly, deviance from the norms of acceptable behaviour is construed as symptomatic of a disease (Harding and Palfrey, 1997). As a result of these factors, folk or lay models of health have been displaced (Nettleton, 2006). Thirdly, "patients" are disempowered and the body is seen as passive rather than active and intentional (Kontos, 2005). Fourthly, according to Taylor (2007), the improved capacity to identify and diagnose has not been accompanied by improvements in ability to treat conditions. This has led to unrealistic expectations regarding the efficacy of medical intervention (Toombs, 2006).

The consequences of a biomedicalised view of dementia

Adherence to a biomedical model of dementia which focuses on dysfunction of the brain and stresses the loss of normality has led to three consequences. The first consequence relates to the practical problems associated with a reliance on the biomedical model. For instance, differentiating between types of dementia type can

be difficult when formulating a diagnosis. Symptoms and physical signs are sometimes ill-matched. Many people who have been assumed to have Alzheimer's disease show no signs of plaques and tangles at post mortem, whilst many people function well despite there being evidence of organic changes (Harding and Palfrey, 1997; Snowdon, 2002). Furthermore, disease classification socially clusters people as similar and ignores the differences between them as well as missing the unclassified similarities (Bassett and Graham, 2007). There have been problems in the recent past associated with the use of medication for people with dementia. It has been recognised that anti-psychotics have been overused to a great extent which has exposed thousands of older people with dementia to potentially dangerous side effects such as an increased risk of stroke (Banerjee, 2009).

A second consequence has been an oversimplified view of dementia which ignores the complexities of the condition. It is claimed that the biomedical model has led to the management of dementia which focuses on the progressive loss of function which means that people with dementia are viewed in terms of what they can't do (MacRae, 2008). Emphasis is placed on testing deficits and placing individuals into categories and this is thought to de-humanise people and encourage society to view dementia in negative and simplistic terms (Dupuis et al. 2011). The separation of mind and body and the association of selfhood with cognition that is implicit in the medical model leads to the assumption that dementia results in a loss of selfhood (Kontos, 2004). There has been much debate in the literature about the extent to which self persists or diminishes during dementia (Caddell and Clare, 2010). Recognition of the de-humanizing effects of dementia diagnosis and management has resulted in calls for a humanisation of dementia and research which tests the likelihood of successful ageing and dementia (Braudy Harris and Keady, 2008). A further consequence is that other facets of the lives of people with dementia that contribute to the experience of being human, such as cultural and social factors have been overlooked (Kontos, 2003). For example, it has been suggested that social power and privilege have an important effect on one's experience of dementia but these phenomena have been neglected (Hulko, 2009). There is therefore a need for more research addressing social aspects of dementia.

A third consequence has been a neglect of the subjective experience of dementia. There has been a tendency for people with dementia to be viewed as passive recipients of care has resulted in a neglect of the highly individual, subjective and variable nature of dementia (Bond and Corner, 2001; Steeman et al. 2006). As a result, there have been calls for more research addressing the subjective experience of dementia for the last fifteen years (Kitwood, 1997b). The uncritical adherence to a purely biomedical model of dementia is less common now than it was in the past. It has been noted that dementia discourse has changed in the last decade or so, with a focus on the medical model gradually giving way to recognition of the individual experience of having dementia (Dalby et al. 2011; Lawrence et al. 2010). However, a continued emphasis on impairment has meant that people with dementia have been excluded from research because it is assumed that they cannot communicate their experience (De Boer et al. 2007). Whilst there has been increased interest in the experience of dementia using such narrative methods, most has been undertaken in the United States and the research has lacked diversity in areas such as culture, ethnicity and sexual orientation (Page and Keady, 2010). Meanwhile, calls for more biomedical research continue which include statements such as this; "With enough support our scientists can defeat dementia and halt this tidal wave of suffering" (Luengo-Fernandez et al. 2010, p.2).

Psycho-social models of dementia

The limitations associated with the "standard paradigm" or biomedical model of dementia outlined in the previous section have been recognised for the last twenty years and alternatives proposed. One alternative view defines dementia as a social phenomenon which involves a threat to the socially constructed self (Kitwood and Bredin, 1992; Sabat and Harre, 1992). This view owes a debt to the ideas articulated by symbolic interactionism. This section begins with a description of symbolic interactionism and the closely related concept of social constructionism and then discusses how interactionist theories have been applied to dementia.

Symbolic interactionism

Symbolic interactionism is a sociological perspective whose roots lie in pragmatism, a philosophical field concerned with how living things make adjustments to their environment (Hewitt, 2002). A leading figure in the development of symbolic

interactionism was George Herbert Mead (1863-1931) who was active in the 1920s and whose work was interpreted by Blumer (1962). The symbolic interactionist perspective focuses on individuals and how they interact with their social environment. There are three essential tenets to the symbolic Interactionist theoretical position: Firstly, people are conscious of themselves as objects (Blumer, 1962). This has several repercussions: it means that human conduct is self-referential; people take themselves, their feelings and their interests into account when they act. The ability to see themself as an object as others do allows the person to develop a self-image (Blumer, 1962). Being aware of oneself as an object implies that one's sense of self-esteem and therefore one's well-being is linked with self-focused feelings and is a product of one's activities and interaction with others (Hewitt, 2002). According to Goffman (1959) people generally present themselves in the best possible light during social interaction.

A second tenet is that people are active social agents who constantly interpret situations and align their actions with others in order to adopt roles (Blumer, 1962). This is because humans tend to strive for security and a sense of identity by participating in group life (Hewitt, 2002). This social conduct is situated rather than occurring in a vacuum which means that context is crucial. Being active social agents means that language and symbols are very important for humans; language enables us to interpret what is happening around us and people are highly sensitive to the nuances present in communication.

A third tenet of symbolic interactionism is that the concepts of self and identity are important. A person's "selfhood" can be the described as the set of characteristics which define their unique humanness. Selfhood comprises a number of attributes, identities and social personae that the individual constructs and expresses through behaviour and language in both a conscious and pre-reflective manner (Blumer, 1962; Sabat, 2002). From the symbolic interactionist perspective "self" refers not only to an object that can be the focus of attention by the person themselves and by others but also the process of creating it (Manis and Meltzer, 1967). People take on roles and act on the basis of their definition of the situation they find themselves in (Goffman, 1959). Selfhood is therefore situated socially and made up of a number of identities that are constructed with the assistance of others. People "announce"

identities in social contexts and whether these persist is dependent on them being recognised by others and the person being "placed" accordingly. People have a multitude of selves which can be classified into three different types of identities (Hewitt, 2002). These classifications consist of situated identities, social identities and personal identities. All of which are dependent on announcement and placement by others. Situated identities are short-lived and fleeting, for instance shop customer or rail passenger. Social identities are longer lasting and locate people in social space, for example train driver or mother. Personal identities are much more enduring; the focus is more on biography and the distinctive characteristics of individuals, for example being musical. Sometimes unwanted identities can be ascribed to us by others, for example "deviant", "victim" or "mentally ill". Furthermore, some of these ascribed identities can be particularly powerful and mask the presence of more valued identities, for instance stigmatised identities (Goffman, 1997).

Social constructionism and positioning theory

The concept of social constructionism is closely related to symbolic interactionism. Social constructionism involves scrutinising the ways in which language is used to create social realities and explores what the implications of this process are (Berger and Luckmann, 1967). Positioning theory is a theoretical model associated with social constructionism which emerged in the 1980s and which focuses on the manner in which social identities and relationships are continually generated through conversation and conversation-like activities (Harré and van Lagenhoven, 1999). A position can be defined as a cluster of personal attributes articulated through discourse with others (Harré and van Langenhove, 1999). According to this model, aspects of a person's self emerge through social interaction in the form of dynamic and variable entities that are constantly constituted and reconstituted through discursive practices (Davies and Harré, 1990). In recognising the dynamic nature of social encounters in the formation of selfhood, positioning theory has provided an alternative to the concept of role and identity mentioned previously in this section which suggests a more static and formal aspect of a person's self (Davies and Harré, 1990).

Davies and Harré (1990) describe two types of positioning. Firstly, reflexive positioning in which individuals position themselves. Secondly, interactive positioning which involves one person positioning another. Individuals can position themselves or be positioned in a variety of ways. For example, as dominant, competent, submissive, confident or apologetic (van Langenhove and Harré, 1999). Positions are considered to be relational, which implies that for someone to be effectively positioned as powerful, others need to be positioned as powerless. Furthermore, the position held by an individual influences how they are treated by others. For instance, a person who is positioned as incompetent is likely to be treated as such by others around them. However, Davies and Harré (1990) point out that positioning may not be intentional, and that positions may be contradictory and not always clear cut.

In the course of social interaction an individual may attempt to position someone else in a particular way through interactive positioning (Davies and Harré, 1990). However, the other person may not want to be positioned and may reject that position and attempt to position themselves in a more desirable way (Davies and Harré, 1990). The act of positioning can therefore be seen as a means by which individuals cope with the social situations they encounter (van Langenhoven and Harré, 1999). The ability of an individual to effectively position themselves and others varies according to individual factors such as communication skills and motivation as well as social factors such as professional roles (van Langenhove and Harré, 1999).

Applying concepts from symbolic interactionism and social constructionism to dementia

Concepts associated with symbolic interactionism and social constructionism have been usefully applied to theorise the experience of dementia. Instead of the condition being viewed as the manifestation of a dysfunctional brain dementia is conceptualised as a social process. Dementia is viewed as a social construct and the word itself is seen to be loaded with meaning. Viewed through the interactionist lens, dementia is seen as a threat to the socially constructed self or as Kitwood and Bredin (1992) describe it to; "personhood". Viewing dementia as a social process helps us to recognise that the psychosocial effects of the condition such as lowered self-esteem, reduced feelings of autonomy, and the loss of a sense of personhood,

are products of the dysfunctional social interaction that often accompanies cognitive impairment (Sabat and Harre, 1992; Kitwood, 1997a). Kitwood and Bredin (1992) coined the phrase "malignant social psychology" to describe the process by which people with dementia can be invalidated, depersonalised and treated as dysfunctional during social interaction with others. Kitwood (1997a) identified 17 elements of malignant social psychology; treachery, disempowerment, infantilisation, intimidation, labelling, stigmatisation, outpacing, invalidation, banishment, objectification, ignoring, imposition, withholding, accusation, disruption, mockery and disparagement. It is thought that malignant social psychology is often engaged in unconsciously and without malicious intent (Sabat, 2002). Sabat and Harré (1992) noted that malignant social psychology leads to "excess disability" (Brody, 1971). Excess disability is the discrepancy which exists when an individual's functional incapacity is greater than that warranted by their actual impairment (Brody, 1971). The degree of excess disability relates to the social environment. For example, Sabat (1994) cites the case of disabilities relating to an individual with dementia which were reported at home by their carer were not present at day care.

Positioning theory and dementia

Steven Sabat has been influential in applying positioning theory to explore the social experience of dementia (Sabat and Harré, 1992; Sabat, 2002; Sabat, 2003). Sabat points out that most people who are considered by others to be healthy and cognitively intact may be able to resist being positioned in ways that they find objectionable but people with dementia are likely to find this difficult. Because of the problems they face with verbal communication, the stress and anxiety associated with dealing with the condition and their lack of social power they are disadvantaged in the social settings where positioning takes place. This means they lack the resources to position themselves favourably or re-position themselves in a more desirable way when unwanted positions are imposed (Sabat and Harré 1992). Sabat (2003) points out that certain aspects of positioning can have far reaching effects on people with dementia and their social relationships with others.

Sabat (2003) has argued that people with dementia are vulnerable to what he described as malignant positioning. Some of the positions imposed on people with dementia are malignant because they not only have a negative impact on how

people with dementia are viewed by others but also how they are treated and how people with dementia can view themselves. Sabat (2003) differentiates between explicit and implicit malignant positioning. He defines explicit malignant positioning as the way in which people with dementia are openly defined by others in terms of negative dysfunctional attributes despite the fact that people with dementia may also display intact attributes. Sabat provides the example of an individual caring for his wife who had Alzheimer's disease, who made the statement "They don't know anything anymore" when referring to everyone with dementia. Sabat points out that this generalisation was made despite the fact that the individual had limited contact with people who had dementia apart from his wife and in spite of clear evidence that people with advanced dementia can be self-aware and able to act coherently (Sabat and Harré, 1992). Implicit malignant positioning, on the other hand, reflects specific expectations that people have regarding all individuals with dementia regardless of their unique characteristics which can result in patronising behaviour towards them (Sabat, 2003).

Because people with dementia have difficulty in re-positioning themselves they are vulnerable to what Sabat (2003) describes as "story lines" which validate the disadvantaged position imposed on them. For example, due to the way in which the individual is positioned, restlessness or the avoidance of social contact is interpreted as a direct result of pathological neurological changes. This is despite the fact that acting in this way may represent meaningful behaviour which the individual may have engaged in throughout their life. Because of malignant positioning, carers may be oblivious to intact meaningful behaviour because story lines do not recognise the possibility that the person with dementia is capable of acting in this way. In this manner, attempts made by people with dementia to re-position themselves are interpreted as dysfunctional and symptomatic of dementia. As a consequence of malignant positioning people with dementia inevitably find themselves in social situations where problems caused by cognitive losses become the focus of attention and where they are unable to construct valued social identities because of lack of validation from others. These difficulties may in turn, compound the sense of loss they already experience as a result of developing the condition (Sabat, 2002).

The contribution of interactionist and constructionist views of dementia, which were developed in the 1990s, has been significant and has led to the recognition of social influences on the dementia experience. These influences include the importance of stigma (Steeman et al, 2006; de Boer et al. 2007; Moyle et al. 2007) the difficulties that people with dementia have in creating their identities (Small et al. 1998; Beard and Fox, 2008; Westius et al. 2010), positioning themselves effectively (Ryan et al. 2009) and maintaining a sense of self (Clare, 2003).

The embodiment perspective

I began this chapter by discussing how dementia is primarily viewed in biomedical terms as an illness which involves a progressive loss of brain function and which represents a threat to the cognitive self. I then presented an alternative view based on the tenets of symbolic interactionism which views dementia as a social construct that threatens the individual's socially situated self. Whilst recognising that dementia is more than a progressive brain disease, interactionist views of the condition share two limitations with the biomedical model. Firstly, the subjective lived experience of dementia is neglected and secondly, that the role of the body are ignored. In order to address these shortcomings, another theoretical view of dementia is needed in which the lived experience of dementia can be explored and the role of the body is recognised. A model addressing these short comings, which was based on the concept of embodiment was proposed in the 2000s and has become an emerging field within dementia studies (Martin et al. 2013). Kontos (2004) and Phinney and Chesla (2003) pointed out that we are embodied creatures and the symptoms of dementia are partly an expression of our embodied nature and not simply the symptoms of illness. Because so many of the ideas comprising the embodiment perspective originate in phenomenology I will begin this section by introducing this field of philosophy.

The Origins of Phenomenology

Phenomenology is a philosophical tradition that has greatly influenced qualitative research methodology in the social sciences (King and Horrocks, 2010). It has informed a diverse family of approaches (Langdridge, 2007). Phenomenology originated in the work of Edmund Husserl (1859-1938) who suggested that the focus

of enquiry should be on how phenomena appeared to human consciousness. Husserl directed this investigation at what he termed the "lebenswelt" or "lifeworld" which he defined as the lived world (Langdridge, 2007). In order to achieve this Husserl developed the "phenomenological method" which stipulated that the investigator must set aside or "bracket" their assumptions about the phenomenon they were investigating in order to describe the "essence" of the phenomenon stripped of the cultural and personal preconceptions of the researcher. Husserl called this process epoché and the act of bracketing is a key tenet in the tradition known as transcendental phenomenology. Husserl's ideas were developed by other influential 20th century philosophers; Martin Heidegger (1889-1976), Jean Paul Sartre (1905-1980) and Maurice Merleau-Ponty (1908-1961). Heidegger's claim that rather than possessing a body, humans are embodied beings was particularly influential (Leonard, 1994). These three philosophers shared an interest in questions exploring the nature of human existence. Whilst recognising the value of Husserl's approach they were sceptical about the possibility of the investigator achieving epoché. This was because they thought human existence to be so intimately entwined with aspects of the world they inhabit that it is impossible to step outside it or bracket. Existential phenomenologists and researchers adopting their ideas are less concerned with essences and more focused on exploring and interpreting aspects of their subject's "lifeworld".

Concepts underlying the embodiment perspective

The term embodiment reflects an approach rather than a formal theory. It is concerned with the body as experienced by the subject, and how human beings relate to the world around them as embodied entities. Embodiment was a central theme within twentieth century phenomenology. There are three central tenets of the embodiment approach. Firstly, that the body is the locus of experience. Rather than being an object in the world, the body is the medium by which our world comes into being (Leder, 1990). This is despite the fact that for most of the time we are unaware of the actions of our physical body. It is only when we become tired, or in pain that our bodies emerge into our consciousness (Leder, 1990). Secondly, there is a denial of the Cartesian mind/body split. In other words, instead of the mind directing the body, our bodies are "mentalised" (Leder, 1990). Thirdly, the body has its own ability

to interact with the world in a pre-cognitive manner. The implication of these tenets is that human selfhood is partly embodied (Kontos, 2004).

The concept of embodiment owes a debt to Heidegger who described the manner in which humans engage with the world as being "transparent", un-reflective, "ready at hand" and that much of our everyday activities are the result of smooth flowing habits rather than being directed by intentional mental state (Heidegger, 1961). Heidegger influenced Merleau-Ponty who was a key figure in developing the concept of embodiment. Merleau-Ponty made the distinction between an individual's objective body as constituted by a physiological entity and their "phenomenal" body which represented the body as experienced (Merleau-Ponty, 1962). Like Heidegger, Merleau-Ponty claimed that people experienced their bodies tacitly, in terms of potential or the capacity to do tasks. In other words, humans are unaware of the physiological processes underlying activities such as driving a car or operating a type-writer. Furthermore, our bodies have their own inherent ability to apprehend and convey meaning (Merleau-Ponty, 1962). Bodies can express their nature in a manner over which we sometimes have little control (Toombs, 2006) and have the capacity to act in ways that surprise us (Laz, 2003). Another important figure in developing the concept of emdodiment is Pierre Bourdieu. Bourdieu (1977) commented that our pre-reflective body practices or "dispositions" are a product of our socio-cultural environment. He called this link between the social world and pre-reflective bodily dispositions "habitus". For example, our gait or aspects of social etiquette such as our table manners are determined by factors such as our social class, ethnicity and environment.

The embodied experience of dementia
Rather than a neuropathological process or a product of social interaction, dementia can be conceptualised as an embodied experience which threatens our embodied selfhood (Phinney and Chesla, 2003; Kontos, 2004; Hasselkus and Murray, 2007). Kontos' work in Canada has been influential (Kontos, 2003; 2004; 2005; Kontos and Naglie, 2009). Kontos proposed a concept of "embodied selfhood" with reference to Heidegger, Merleau-Ponty and Bourdieu. Kontos (2004) noted that whether or not they have dementia, people engage with the world through activity rather than through contemplation and reflection. Kontos (2005) wrote that the body is a

fundamental source of selfhood that doesn't derive agency from a cognitive form of knowledge. She commented that the body is not a medium for selfhood, it has its own ability to be active, intentional and purposeful which has little to do with cognition, in other words, the body provides the source of selfhood. Kontos (2004) pointed out that during the process of dementia, selfhood persists despite severe dementia because the self is an embodied dimension of human existence. Kontos defined two aspects of embodied selfhood. Firstly, a primordial or basic intentionalist aspect which is based on the work of Merleau-Ponty and which recognises that our body has a pre-cognitive sense of the world. Secondly, Kontos applied the concept of embodied culture or "Habitus" (Bourdieu, 1977) which suggests that pre-reflective body dispositions are linked to the social world. Kontos (2004) suggested that given the right circumstances, people with cognitive impairment can remain actively involved in the world through activity and engagement because their pre-reflective abilities remain relatively intact.

Phinney and Chesla are also researchers in the field of dementia, based in Canada, and who have applied the concept of embodiment. However, they have used it differently by focusing on the effects of dementia on embodied selfhood. Phinney and Chesla (2003) have written that dementia results in a breakdown of our transparent and unreflective engaging in the world in which "…the everyday grace of engaged activity is lost" (Phinney and Chesla, 2003, p296). Phinney and Chesla (2003) point out that when our cognition is unimpaired, the "ready at hand" workings and actions of our bodies are invisible to us and that we only become aware of them when something is amiss. When dementia develops, this transparency is rendered opaque, and the individual's "being-in–the-world" becomes fraught with difficulty. In this manner, the changes in a cognitively impaired individual's ability to perform tasks of daily life can be seen as the embodiment of dementia. Hasselkus and Murray (2007) take this view further and suggest that these impairments can be regarded as constituting the disease itself rather than representing the disabilities that have resulted from the condition. The degree to which "ready-at–hand" engagement with the world remains in dementia is subject to debate and may depend on the degree of cognitive impairment which the individual is experiencing.

Combining models of dementia in order to gain a more comprehensive view of the condition

Rather than replace the biomedical approach with an alternative, it is possible and indeed helpful to refer to more than one model of dementia. Researchers have incorporated different models of dementia in their work. Kitwood and Bredin (1992) suggested that the dementing process should be viewed as the product of interplay between neurological impairment which sets an upper limit to how a person can perform, plus personal psychology that they have accrued, plus social psychology that surrounds them. Sabat and Harré (1992) also acknowledged the underlying cognitive impairment of Alzheimer's caused by neuropathological changes whilst focusing on social interaction. It is important not to discount the biomedical model completely because knowledge of physiological processes aids understanding of impairments relating to dementia that may not be explained in terms of social process or embodied experience. Milwain (2010) discusses how damage to specific areas of the brain results in specific impairment. For example, damage to the occipital lobe as a result of vascular dementia may cause visual disturbances. Milwain (2010) points out that knowledge that fronto-temporal damage may lead to personality changes can help carers in providing appropriate support and can lessen the risk of labelling the person with dementia as lazy or selfish. Milwain points out that knowledge of physiological processes lessens the possibility that carers feel guilty for their inability to support the person with dementia socially.

Nevertheless, in this study, because I am concerned with the lived experience of people with dementia, the biomedical model is of much less relevance than the psycho-social and embodiment models. Furthermore, the concept of embodiment is crucial to this PhD because I am exploring how people with dementia engage in physical activity through their bodies. However, the concept of dementia being a socially constructed phenomenon is also vital because the physical activity that participants will engage in is enacted in a social context. Therefore the theoretical framework that I chose to adopt in order to explore dementia as a contextually situated phenomenon was a combination of interactionist and embodiment perspectives. Consequently, I will draw on the concepts of symbolic interactionism, social constructionism and embodiment in order to interpret my findings.

In the first half of this chapter I introduced dementia in terms of the biomedical model or "standard paradigm". The negative implications of viewing dementia primarily in biomedical terms were discussed. I described how the biomedical model has influenced the way in which dementia is viewed by society and has dominated its management. I discussed how this model focuses on threat to cognitive self and how it can explain impairment to a certain extent but that it is unable to explain how the social environment influences levels of disability or shed light on the lived experience of dementia. I introduced the concepts of symbolic interactionism and social constructionism and discussed the contributions made in the early 1990s by Kitwood and Sabat. I explained how in the psychosocial model, dementia is viewed as a threat to the socially constructed self. I pointed out that whilst the social environment was important, interactionist approaches neglect subjective experience and the role of the body. I explained how, in order for these aspects of dementia to be explored, the concept of embodiment which originated in the tradition of phenomenology has been applied. Viewed through the lens of embodiment, dementia is conceptualised as a threat to embodied selfhood rather than a threat to cognitive or socially constructed self. I suggested that recognition of all three views of dementia is important in order to understand the complex experience of dementia. However, I pointed out that for the purposes of my research the biomedical model was of limited relevance. I described my theoretical position as one which combined interactionist and embodiment conceptualisations of dementia that is informed by the concepts of symbolic interactionism, social constructionism and recognition of embodied selfhood. In the second half of the chapter I will introduce the other themes contained in my research questions; the concepts of well-being, ethnicity and physical activity. I will then discuss their relevance to dementia.

Well-being

Defining well-being

Ed Diener is a leading academic in the study of well-being and has commented that people have been wondering about what makes life good since the times of the ancient Greeks (Diener, 2009). Despite this focus of interest, defining what is meant by the term well-being is difficult because in the broader literature, the concepts of well-being, life satisfaction and quality of life are beset with contradictions and

inconsistencies (Cook, 2008). Although the terms well-being and quality of life are sometimes used interchangeably, Cook (2008) suggests that there are fundamental differences between them. Assessment of quality of life usually includes some objective measurement of factors such as health, income or functioning. In contrast, well-being has been defined as a more transient state than quality of life (Hasselkus and Murray, 2007). Furthermore, the degree to which one experiences a sense of well-being depends on an entirely subjective assessment of one's circumstances. Diener (2009) defines well-being as the extent to which a person considers their life to be desirable, pleasant and good. This is an important distinction because it implies that everyone has the potential to enjoy a sense of well-being irrespective of their health or physical environment.

It has been pointed out that neither well-being nor quality of life is the same as happiness (Raibley, 2012). Eckersley (2008) suggests that the concept of well-being goes beyond happiness to encompass having meaning in life, fulfilling one's potential and feeling that one's life is worthwhile. Myers and Diener (1995) suggest that the experience of high levels of well-being is associated with positive thoughts about one's life and positive emotions at the affective level. Low levels of well-being is associated with appraising one's life as unsatisfactory and experiencing unpleasant emotions such as anxiety, low mood and anger.

The components of well-being

Eckersley stresses the social components of well-being as follows; "Wellbeing results from being connected and engaged, from being enmeshed in a web of relationships and interests. These give meaning to our lives. We are deeply social beings. The intimacy, belonging and support provided by close personal relationships seem to matter most; and isolation exacts the highest price" (Eckersley, 2008, p3). Others identify different components of well-being such as possessing a positive sense of self-esteem and maintaining a sense of control (Health Scotland, 2009; Myers and Diener, 1995). A sense of spirituality is also considered an important influence (Bond and Corner, 2004). A further powerful source of well-being is engaging in meaningful activities (Csikszentmihalyi, 1990).

Flow theory and well-being

The concept of flow was introduced by Csikszentmihalyi (1990) to describe optimal human experiences. Flow states are highly pleasurable and occur when people become completely absorbed in what they are doing to the point where nothing else seems to matter. There is an energised focus on the task at hand and a distorted sense of time. Whilst awareness of self disappears during the activity a stronger sense of self emerges after the event. People describe the experience of flow as being harmonious and deeply enjoyable. Csikszentmihalyi (1990) describes a number of attributes associated with activities which if present result in the experience of flow. There must be a balance between skills and challenge, enough difficulty to stimulate but not enough to cause anxiety. Other components of flow include a sense of control over the individual's actions, the ability to concentrate on the activity, awareness of clear goals and the presence of immediate feedback. The result of these factors is that the task at hand becomes "autotelic", in other words, intrinsically rewarding and fun. There has been interest in the links between the experience of flow and subjective well-being (Myers and Diener, 1995). More recently work has been done to identify the optimal conditions for older people to experience flow (Payne et al. 2011). It has been suggested that flow experienced through active engagement in activities contributes to happiness in this age group (Collins et al. 2009). Raibley (2012) agrees that flow is an important component of happiness and indirectly associated with enhanced well-being. When considering how we know when people are happy, Raibley describes the following attributes; high spirits, good mood, feeling good in the moment and smiling.

Well-being and dementia

The psychosocial model of dementia has been particularly helpful in exploring well-being and dementia (Cook, 2008). This approach suggests that the well-being of someone with dementia is contingent on their social self or "personhood" being supported. The concept of personhood represents a standing or status bestowed upon a human being by another based on recognition, respect and trust (Kitwood, 1997a). The concept of personhood was central to Kitwood's view of well-being, who stated that the main task of dementia care is to maintain personhood in the face of cognitive decline (Kitwood, 1997a).

Figure 2.1 Kitwood's psychological needs for people with dementia (after Kitwood, 1997a)
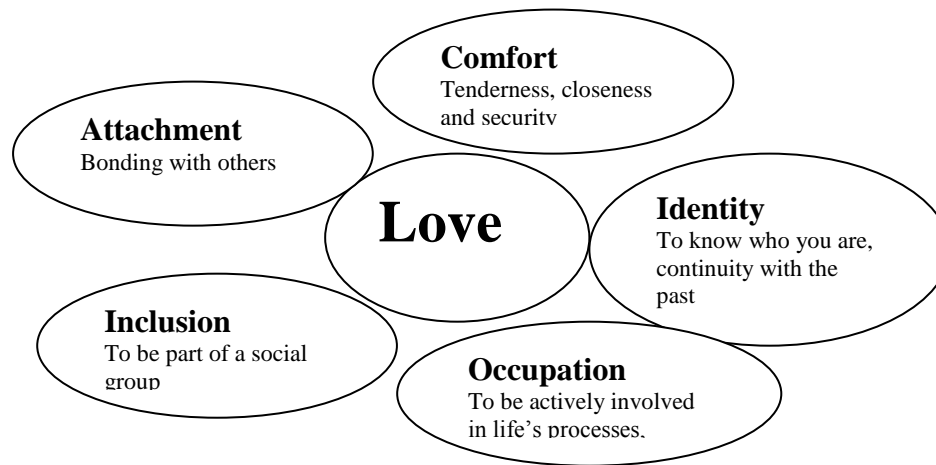
Kitwood & Bredin (1992) noted that people with dementia could experience relative well-being. They pointed out that the capacity to experience well-being is unrelated to the severity of cognitive impairment; people with very low scores in cognitive tests can show good levels of well-being whilst the minimally impaired may have high levels of ill-being. "Ill-being" refers to a state in which well-being is absent or lowered and is the result of an individual's five needs not being met (Perrin et al. 2008). When discussing well-being, Kitwood talks of a cluster of five closely connected and overlapping psychological needs and one all-encompassing central need for love. These five needs consist of; attachment, comfort, inclusion, occupation and identity (See figure 2.1). Kitwood stated that these five needs exist for everybody but they are more evident when the individual is under great social and psychological stress, for example when an individual experiences dementia. Without these needs being met, well-being is impossible (Kitwood, 1997a).

Kitwood has been extremely influential in the field of dementia care. In recent NICE guidelines on the management of dementia (NICE, 2011) the importance of relationships and interactions with others as a means of promoting well-being is recognised and the influence of Kitwood's (1997a) work establishing the principles of person centred care is noted. However, Kitwood's view of personhood is not without

its critics. Davis (2004) claims that emphasising the role of the carers in the disabling process and stressing their vital role in maintaining the personhood of their loved one is unfair and can lead to guilt. Davis (2004) suggests that personhood is lost during dementia and that to deny this fact is to undermine the legitimacy of carers who no longer recognise the person with dementia and prevents guiltless grieving.

Measuring well-being in people who have dementia

Both well-being and ill-being are considered measurable via an observational technique known as dementia care mapping (DCM) (Bradford Dementia Group, 2005). Dementia care mapping is based on the work of Kitwood & Bredin (1992) and is designed to show the degree to which people's well-being is upheld or undermined in the course of receiving care. The technique uses a number of well-being and ill-being indicators (Bruce, 2000) (see Table 2.2). According to Bruce (2000) conclusions regarding relative degrees of well-being and ill-being are suggested by the relative frequency of these groups of indicators. If people display both well-being and ill-being indicators they are likely to be alternating between well-being and ill-being. If they show few signs of either they are likely to be withdrawn and unresponsive. Significant displays of ill-being and few signs of well-being suggest that they may be experiencing distress. In contrast, large numbers of well-being indicators and few ill-being indicators suggest high levels of well-being.

Table 2.2 Well-being and ill-being profiles (See Bruce 2000)

Well-being indicators	Ill-being indicators
Can communicate wants, needs & choices.	Depressed or despairing.
Makes contact with other people.	Intensely angry or aggressive.
Shows warmth or affection.	Shows anxiety or fear.
Shows pleasure or enjoyment.	Withdrawn or listless.
Shows alertness and responsiveness.	Has physical discomfort or pain.
Uses remaining abilities.	Unresolved grieving over losses.
Expresses self- creativity.	Bodily tension.
Is co-operative and/or helpful.	Easily "walked over" by other people.
Responds appropriately to people/situations.	An outsider.
Expresses appropriate emotions.	
Has relaxed posture or body language.	
Reveals a sense of humour.	
Has a sense of purpose.	
Shows signs of self-respect.	

In this section the concept of well-being has been introduced and the possibility that someone experiencing dementia can experience well-being as suggested through the work of Kitwood has been recognised. In the next section I will introduce another important theme in my study; ethnicity.

Ethnicity

The concept of ethnicity

In this section I introduce the concept of ethnicity. After discussing how the concept has been defined in relation to its component parts I will explain why the concept of ethnicity is problematic. I will then outline the practical difficulties associated with applying the concept during empirical research. Finally, I will discuss how exploring ethnicity in the context of dementia is important despite these difficulties.

The term ethnicity is derived from the ancient Greek word ethnos, which is generally translated as "people" or "nation" (Jenkins, 2008). There has been much debate within the social sciences in recent decades regarding the meaning of ethnicity and how the concept relates to the associated concepts of race and culture (Fernando, 2010). Gunaratnam (2003) makes the distinction between race and ethnicity, stating that the term race evokes biological and genetic characteristics whereas ethnicity generally refers to cultural identity and kinship. However, in practical application the concepts of race and ethnicity coincide at times. For example, ethnic categories in the UK census include both national identity and a reference to racial characteristics in the form of skin colour (Office for National Statistics, 2009). Fernando (2010) describes ethnicity as a partly subjective psycho-personal concept (i.e. an identity) containing elements of race, shared meanings and patterns of belief, and a sense of belonging. Fernando (2010) comments that ethnicity is a confusing concept because it is comprised of components that are themselves ill-defined and muddled. For instance, people who have specific racial characteristics are assumed to possess particular culture and cultural markers such as religious affiliation. In this way, Fernando points out, Islam is associated with race. Nevertheless, despite this Fernando (2010) recognises that a racial element to ethnicity exists.

As well as being contentious in terms of the validity of its component parts, there has been debate regarding what the concept of ethnicity actually represents and how it is operationalised. The varying approaches that have been used to apply the term can be viewed in terms of a continuum. At one end, the "primordial" view sees ethnicity as an inherent, fundamental and unchanging aspect of human existence that is independent of social context (Gunaratnam, 2003). Located at the other end, is the "instrumental" or "situationist" view which has been influenced by the work of Fredrik Barth (1969). Barth pointed out that rather than existing independently of social processes, ethnic identity is generated during the course of human interaction. The situationist view therefore defines ethnicity as a dynamic, socially constructed phenomenon and assumes that ethnic identity is partly a matter of choice and can provide a potential resource for achieving wealth, power and status. Jenkins (2008) suggests that ethnicity is not something that one has, or to which one belongs. Instead, ethnicities are complex repertoires which people use, learn and perform in their daily lives. According to Jenkins, ethnicity is best thought of as a process of identification and a structure within which people construct a constantly evolving sense of themselves and the people around them (Jenkins, 2008). The view that ethnicity is a social construction that involves socially produced, heterogenous, fragmented and dynamic processes of being and becoming whilst retaining sufficient stability to sustain collective identities (Jenkins, 2008; Wetherall, 2009; Fernando, 2010) currently holds sway and this is the definition I chose to adopt for my study

Problems associated with researching ethnicity

There are a number of problems associated with the application of the concept of ethnicity. Firstly, the lack of consensus regarding how ethnicity is defined as a whole causes difficulties. The overlap between the different theoretical approaches mentioned above can create confusion regarding what researchers actually mean when they discuss ethnicity (Gunaratnam, 2003). This is because the various components that comprise the concept are dynamic and vary between countries, families and even individuals (Milne and Chryssanthopoulou, 2010). As well as shifting definitions of the central concept of ethnicity, Iliffe and Manthorp (2004) note that terminology relating to ethnic classification is not standardised and constantly changes. For example, the terms "Asian" and "mixed race" are ascribed different meanings. Furthermore, ethnicity as a category is in itself fraught with difficulty

because it masks the highly specific, complex nature of social groups. For example, in one American study, the "Latino" category was made up almost entirely from people who lived in Southern Florida whose families had migrated from Cuba (Sink et al. 2004). Fernando (2010) comments that the confusion around definitions relating to ethnicity is made worse by an increasingly heterogenous social world, in which populations constantly change in composition.

A second problem is that classifying people on ethnic grounds can lead to labelling and essentialism. In other words, the assumption that individuals possess qualities inherent in that particular group (Fernando, 2010) and that lived experiences are pre-determined by ethnic categories that are constructed as unchanging essences (Gunaratnam, 2003). For example, the assumption that an individual behaved in a specific way because he was a Rastafarian from Jamaica. Furthermore, in the present post-colonial context, ethnic identity is politically loaded and can therefore be particularly meaningful and sensitive for people (Gunaratnam, 2003). This is particularly significant for people in minoritized communities where ethnic identities provide a valuable means of resisting racism. As a researcher I need to take these points into account and be sensitive to these issues. I also need to critically reflect on what my own ethnic identity may mean to my participants. These issues are discussed in more depth in chapter four.

Thirdly, viewing human populations in terms of ethnicity has been criticised as seeking overly simplistic explanations. Concentrating on ethnicity can lead to stereotyping and assumptions of homogeneity that do not in fact exist. Terminology can be cumbersome and the racial component of ethnic classifications can result in certain groups being overlooked. For example, applying binary terms such as Black or White results in minorities within these groups becoming invisible (Aspinall, 2002). Assigning people to ethnic groups can conceal differences within the group relating to socio-economic status, education, migration and generational differences (Connell and Gibson, 1997; Iliffe and Manthorpe, 2004; Sink et al. 2004; Helzner et al. 2008). As a researcher I need to remind the reader of the diversity that exists within the ethnic categories.

Finally, the dynamic nature of the social world makes application of the principles of ethnicity difficult. Gunaratnam (2003) notes that a major challenge for researchers is the question of how to apply the concept of ethnic identity, without reifying/concretising dynamic processes into inflexible categories that quickly lose their meaning. The fact that experiences and attitudes vary according to one's generation means that what are viewed as the "ethnic characteristics" of specific groups will change thus making previous classifications obsolete (Iliffe and Manthorp, 2004). I recognise that whilst it is impossible to avoid the reification of ethnically based categories in research studies, the benefits outweigh the disadvantages mentioned above. This is because ethnicity can be a very important component of identity and can have a great influence on human experience, particularly in environments where people from different ethnic groups mix (Bhopal, 2007).

Ethnicity and dementia

The issue of ethnicity is important to consider in my study for several reasons. Firstly, because the experience of dementia is partly a social one and is therefore influenced by cultural and ethnic factors. Acceptance of the view that the experience of dementia is partly constructed socially implies that the cultural or ethnic factors will exert an influence. Secondly, there are growing numbers of people with dementia in the UK from BME communities. The Alzheimer's Society estimate that 11,500 people in the UK from BME communities are living with dementia (Alzhemer's Society, 2013). The proportion of people from ethnic minorities in the older population of the UK is increasing and this will inevitably lead to an increase in the number of people with dementia from these communities (Craig and Mindell, 2007). Thirdly, there has been some debate about how best to provide effective interventions for ethnically diverse populations (Daker-White et al. 2002; Iliffe and Manthorpe, 2004). This is partly because it is recognised that uptake of services is relatively low in ethnic minority communities compared with the wider population (Mukadam et al. 2011). Iliffe and Manthorpe (2004) point out that dementia services are often provided which target specific ethnic communities even though it is acknowledged that the best option involves high quality mainstream services which are sensitive to individual needs. Nevertheless, it is recognised that there is a need to be more sensitive to differences between ethnic minority groups and to look at which services are

effective for which ethnic groups whilst avoiding the risk of organising service provision on the basis of stereotypical categories of ethnicity (Mental Health Foundation, 2006). In recent NICE guidelines (NICE, 2011) it is recommended that health and social care providers should recognise the needs of people with dementia that are based on diversity, including ethnicity. However, this needs to take place in a person centred manner which recognises that individual life experience and identities influence their response to dementia as well as their ethnicity (NICE, 2011).

In this section I have introduced the concept of ethnicity. I have noted that the concept is ill-defined, lacking in precision, hard to apply and politically sensitive. I have suggested that despite the difficulties in operationalising the concept, ethnicity is a potentially important aspect of the dementia experience because it reflects the way in which people construct their identities and relate to others. In the next chapter I will discuss this concept further when I review the empirical literature relating to ethnicity and the experience of dementia. Now I turn to another key theme in the study; physical activity.

Physical Activity

The potential benefits of physical activity for older people

Physical activity is often defined as any movement of the body that results in energy expenditure above the resting level (Casperson et al. 1985). Engaging in regular physical activity is considered to be important for older people irrespective of their mental health needs because they are at risk from conditions associated with inactivity such as osteoporosis and hypertension (Young and Dinan, 2005). Low levels of physical activity and reduced mobility in older people are linked with social exclusion and loneliness which can have a negative effect in terms of mental health (Scharf, 2004). Exercise can help maintain functional independence as even the healthiest older people lose muscle mass and experience reduced joint flexibility as a consequence of the ageing process (McMurdo, 2000). Further benefits of being regularly active are thought to include maintaining cognitive function, reducing falls risk, and reduce cardiovascular risk (DOH, 2011). Because of these potential benefits physical activity is an important component of health promotion (Department of Health 2005; Naidoo and Wills, 2005). Currently the Department of Health

recommends that older adults should aim to be active daily and that over the course of a week the activity should add up to at least 150 minutes of moderate intensity in bouts of ten minutes or more (Department of Health, 2011).

Unfortunately, increasing the amount of physical activity that older people engage in is difficult. Simply advising them to be more active is ineffective (Hillsdon et al. 2002). Older people face a range of barriers related to their attitudes to physical activity (Stead et al. 1997) perceived environmental factors (Bowling et al. 2006) and their physical health (Iliffe et al. 1994). Bird et al. (2009) looked at physical activity levels in older members of ethnic minority communities in Australia and that found barriers such as inclement weather, transport and attitudes to being physically active were culturally specific. Bird suggested that whilst some of the barriers to physical activity in culturally diverse communities can be addressed by a common approach, some communities need specific strategies (Bird et al. 2009).

Physical activity has received a lot of attention from mental health professionals as well as sport and exercise scientists because of its association with mood elevation and improved cognitive function (Fox, 2000; Jones, 2004; Biddle and Mutrie, 2008). Theories have been postulated to explain the positive effects of physical activity on mood. They can be grouped into psychological, biochemical and physiological categories. Psychological effects of physical activity are thought to be particularly far reaching (Motl et al. 2005). Participation in physical activity can provide a distraction from negative thoughts (Peluso and de Andrade, 2005) and self-efficacy may be increased through the successful completion of tasks (Craft, 2005). It has been claimed that the positive effects are most pronounced when performing repetitive, predictable and relatively unenergetic tasks (Lane, 2005). Social interaction and a sense of belonging are considered important aspects (Mental Health Council of Australia, 2007), although people also report positive effects when exercising alone. Lawlor and Hopker (2001) commented that in the developed world, exercise is generally approved of by society and that participation in it can endow one with a sense of virtue.

Biochemical theories comprise the second group and are generally concerned with levels of neurotransmitters and the release of endorphins. In the former, exercise is

thought to raise the transmission of substances in the central nervous system in the same manner as anti-depressants. In the latter, the release of endogenous opioids is thought to impact on mood. However, the central role of endorphins has not been confirmed. Experiments using Naltraxone (a substance that blocks the effects of endorphins) have resulted in subjects still reporting improved mood following exercise (Peluso and de Andrade, 2005).

The final category contains physiological theories. It has been proposed that the increase in body temperature following physical activity has a relaxing effect (Koltyn, 1997). Similarly, the reduced muscle tension following activity and a sense of fatigue are also thought to have a calming influence (Webborn, 2002). It has been claimed that trying to identify specific cause effect relationships and optimum "dosage" of physical activity for maximising well-being is bound to be fruitless. This is because the mechanisms influencing an individual's mood are likely to be multi-factorial and highly individual given the complexities of human experience and the huge range of activities that fall under the umbrella of physical activity (Faulkner and Carless, 2006)

The relevance of physical activity for older people living with dementia

Physical activity is relevant for older people with dementia for two reasons. Firstly, they share the physical health risks of immobility with others in this age group. Secondly, their well-being is at risk due to dementia and physical activity may be helpful in countering this risk. For example, physical activity may assist in achieving flow states through engagement in meaningful activity, and social interaction. The importance of physical activity for people with dementia is reflected by current policy. Physical activity is on the agenda in terms of dementia policy and guidance. Recently, guidance from NICE (2011) states that health and social care providers should promote and maintain the independence of people with dementia through physical exercise. NICE (2011) also recommends that the therapeutic use of music and/or dance should be considered for people with all types of dementia who have co-morbid agitation. Finally, NICE (2011) states that exercise should be available for people with dementia who have depression and/or anxiety. In the next chapter I will review empirical evidence relating to physical activity and dementia.

Summary of chapter two

In this chapter I have discussed several models which have been used to conceptualise dementia. Dementia can be considered as an illness, a social phenomenon, or an embodied experience. These views reflect different facets of the same phenomenon. I pointed out that the biomedical model remains by far the most widely adopted and powerful, and that the way in which it encourages us to perceive dementia in an uncritical manner has had a number of implications. I explained that social interactionist and embodiment perspectives offer useful alternative viewpoints. This is because they are helpful in understanding the impact of dementia on identity, selfhood and well-being and why "excess disability" occurs. However, I concluded that it is important not to deny the physical existence of dementia. In the second half of the chapter I introduced the concept of well-being and discussed the contribution made by Kitwood who recognised that well-being was possible for people with advanced dementia given favourable social factors. I noted that Kitwood also provided a theoretical framework which can be practically applied to gauge levels of well-being and ill-being. I then discussed the problematic concept of ethnicity and stated that in spite of the difficulties associated with it, ethnicity is an important aspect of the dementia experience. Finally I discussed how physical activity has a role to play in enhancing well-being as well as physical health and is an important part of current dementia policy and guidance. In the next chapter I will present a review of the empirical literature relating to these themes.

CHAPTER THREE

The experience of dementia, physical activity, ethnicity and well-being; a review of the empirical literature

Introduction

In the previous chapter I discussed several models that have been used to represent dementia. I noted that the biomedical model of dementia remains predominant and influences society's view of the condition. I wrote that the biomedical model fails to explain much of the nature of the dementia experience and discussed why I chose to adopt a combination of interactionist and embodiment models for the purpose of my study. I defined the concept of well-being and suggested that physical activity had the potential to influence it. I then argued that having decided to view dementia as a socially constructed and embodied phenomenon it made sense for me to take the influence of ethnicity into account. In this chapter I will review the empirical literature in order to see how the concepts of well-being, physical activity and ethnicity have been applied by others in dementia research. Because my study set out to explore elements of the lived dementia experience, I will begin this chapter by discussing what studies have found relating to the subjective experience of dementia in general. This review will allow me to identify gaps in the literature that I subsequently have attempted to address through my own research.

Literature review strategy

I searched the dementia literature electronically in a systematic fashion. In order to provide an overview I began by searching the Cochrane library for reviews relating to dementia and physical activity. I then searched the following electronic databases; psycINFO, Medline and Cinahl. Three different databases were searched as they were likely to access evidence from different sources. I searched the databases by combining "dementia" with a number of other search terms. These comprised the following; "subjective experience/subjectivity/lived experience", "physical activity", "dance", "ethnicity", "well-being/mental health/quality of life" and "embodiment". In order to identify a manageable number of studies I limited my initial electronic searches to studies, reviews and editorial pieces published in the ten years preceding 2010. Citations were excluded if they were in a language other than

English. After all three databases were searched the results were compared and duplications were removed. Further relevant publications not revealed by these electronic searches were found as a result of reading the selected studies and noting references which appeared significant and related to my topic. This enabled me to identify relevant studies that were more than ten years old. I set up an automatic electronic search of the literature using NHS Information Resources which ran every two weeks and occasionally alerted me of newly published studies. I repeated my searches using this strategy towards the end of my thesis writing in March 2013. On this occasion searches were limited to publications from the previous three years. My final electronic search included papers published before 2000 and was undertaken to ensure that I had not overlooked any important older studies.

The experience of dementia; evidence from the literature

This chapter begins with a review of studies which have explored the subjective experience of dementia. This is important because well-being, ethnicity and physical activity are highly individual and subjective aspects of lived experience and in order for them to be contextualised they require setting within the wider dementia experience. Whilst it has been commented that the number of studies exploring the experience of dementia is growing (de Boer et al. 2007), it has also been pointed out that studies which explore dementia from the point of view of the individual living with it are rare (Phinney and Chesla, 2003; Steeman et al. 2007; Hulko, 2009; Robinson et al. 2012). Manthorpe et al. (2011) noted that carers still tend to be consulted more often than those living with the condition. Therefore, comparatively little is known about the experience of dementia and what meaning it holds for the people living with it (Phinney and Chesla, 2003; MacRae, 2008; Hulko, 2009; Manthorpe et al. 2011; Robinson et al. 2012).

There are several reasons why the subjective experience of dementia has been neglected. Moyle et al. (2007) suggest that the views of people with dementia are seldom sought because of the dominance of the medical model and the associated assumption that clinicians know best. Moyle et al. (2007) also point out that people whose social identities are devalued are often excluded from research. Manthorpe et al. (2011) suggest that a shortage of research in this area is partly due to the perceived barriers of ethical approval, informed consent and communication

difficulties associated with involving people with dementia. Another possible factor is the perception held by researchers that because people with dementia have a limited ability to communicate with spoken language, attempts to engage them in studies will inevitably lead to insurmountable methodological difficulties (Zank and Leopold, 2001). Such beliefs are unfounded; recent evidence suggests that people with dementia can be fully capable of taking part in research studies. For instance, Moyle et al. (2007) found that people with MMSE scores as low as five, which suggests considerable cognitive impairment, were able to complete questionnaires. Similarly, Clare et al. (2008) reported that the people with moderate to severe dementia living in nursing homes who participated in their study were able to describe their emotional responses to the care environment.

The subjective experience of dementia

My literature search found a small number of qualitative studies that explored the subjective experience of people with early to mid-stage dementia living in the community. One early paper was from the USA (Cohen 1991), five were Canadian (Phiney and Chesla, 2003; Bassett and Graham, 2007; MacRae, 2008; Hulko, 2009; O'Connor et al. 2010), two were Swedish (Westius et al. 2010; Robinson et al. 2012) and seven were from the UK (Clare, 2003; Harman and Clare, 2006; Langdon et al. 2007; Page and Keady, 2010; Wolverson et al. 2010; Dalby et al. 2011; Manthorpe et al. 2011). I also found two comprehensive reviews of qualitative studies addressing the lived experience of dementia (Steeman et al. 2006 and de Boer et al. 2007).

In this section I will discusses the methodologies used by studies and the findings described in the studies mentioned above. I will begin with reviewing the evidence relating to what it is like to develop dementia. Study participants with dementia report developing Alzheimer's disease as a complex transitional phenomenon (Robinson et al. 2012). Studies noted that people can find the onset of dementia stressful and may be fearful of losing their faculties (Clare, 2003; Manthorpe et al. 2011). The process of undergoing cognitive testing and then receiving a diagnosis of dementia can be very difficult to cope with (Pratt and Wilkinson, 2003; Clare, 2003). Cohen (1991) reported one participant with Alzheimer's disease reporting that being given a diagnosis had forced them to confront fundamental issues such as the nature of their

existence. Struggling to comprehend the nature of the disease that others have told them they have may be more of a problem than dealing with their cognitive symptoms (Cohen, 1991; Robinson et al. 2012). Evidence suggests that people with dementia have insight into their problems with cognition. Harman and Clare (2006) conducted semi-structured interviews with nine participants experiencing early stage dementia. They used IPA to analyse their findings and found that participants were fully aware of their cognitive difficulties and the fact that they would get worse. According to the studies reviewed by Steeman et al. (2006) social interaction is important in supporting individuals to cope with receiving a diagnosis. People may be unhappy being associated with terms such as "dementia" or "Alzheimer's" (Langdon et al. 2007). However, in MacRae's (2008) study some participants reported feeling relieved when they were given a diagnosis of dementia. Participants in MacRae's study said that they would rather be told that they had dementia than something that they perceived as even worse, such as a brain tumour.

The losses associated with dementia

Participants in studies addressing the lived experience of dementia have reported a number of losses. These reported losses included social roles and the status associated with them (Langdon et al. 2007). Other losses include a sense of competence, control and self-esteem, a loss of control, meaningful activity and relationships, physical objects and the ability to keep track of conversations (Steeman et al. 2006). Several of the ten participants interviewed by Wolveston et al. (2010) in their phenomenological exploration of hope among people with dementia spoke about feeling left out during social occasions. Participants in other qualitative studies have described the loss of memories and verbal communication (de Boer, et al. 2007). However, despite these losses people with dementia have noted that certain aspects of their selves have prevailed such as their sense of identity and attitude to life (Westius et al. 2010). For example, when discussing identity, none of the participants in MacRae's study which involved interviewing eight community dwelling Canadians in the early stages of Alzheimer's disease described themselves in terms of their dementia. They thought of themselves in terms of their family role, personality, and former occupation (MacRae, 2008).

Dementia as a dynamic and variable experience

Research suggests that the experience of dementia as described by those who are living through it represents a much more subtle and varied picture than that assumed by the general public (de Boer et al. 2007). A whole gamut of emotions may be experienced including anger, frustration, annoyance and embarrassment (de Boer et al. 2007). Evidence suggests that people's subjective experience of dementia can change over time. It can be influenced by complex factors and therefore be highly individualised (MacRae, 2008). Having dementia involves a dynamic process of personal adjustment; from initial resistance and attempts to manage to eventual acceptance and reconciliation (Cohen, 1991; Robinson et al. 2012). Participants in reviewed studies progressed through stages of acceptance of their dementia which were likened to a dementia "career" (Steeman et al. 2006, MacRae, 2008; Manthorpe et al. 2011).

The embodied experience of dementia

The concept of embodiment was introduced in the last chapter. In this section I will discuss empirical findings relating to the embodied experience of dementia. Phinney and Chesla (2003), Kontos (2004) and Bassett and Graham (2007) are amongst the few researchers that have adopted the embodiment approach to explore the experience of dementia. Phinney and Chesla (2003) used participant observation as well as interviews in their research which included nine people with mild to moderate dementia and which took place in a variety of settings where participants completed everyday activities. Participants in Phinney and Chesla's study experienced "being slow" as activities that which involved embodied skills that were previously smooth such as dressing, driving and conversation became disrupted. Phinney and Chesla identified three facets of the embodied experience of dementia. Firstly, "Being Lost" in which people were unable to find their way and were lost in a unfamiliar world of unrecognised objects. Secondly, "being a blank" which involved being in a world devoid of meaning wherein meaningful habits and practices fell by the wayside. Thirdly, "being lost in a world of activity" in which the individual's outer directed concern that in the past directed them towards meaningful goals was lost and activity became disorderly. In a similar study, Bassett and Graham (2007) used participant observation and interviews to explore how 58 people in the early stages of dementia engaged in activities of daily life. Participants in Bassett and Graham's study

described a loss of awareness so tasks were left uncompleted. They experienced a loss of attention so were unable to concentrate on the present together with a loss of anticipation which meant that they were unable to concentrate on the future. As a result, Bassett and Graham (2007) suggest that a person with dementia can be considered "lazy" because they fail to conform to society's expectations that people should complete tasks that they have started.

Pia Kontos is a key figure in the application of the concept of embodiment to dementia. She based her interpretation of the principles of embodiment on findings from a study carried out in a long term care facility for orthodox Jews in Ontario, Canada (Kontos, 2004). Kontos used an ethnographic approach, employing participant observation with residents as they went about their usual activities. Kontos' intention was to see how individuals with dementia inhabited their "life worlds". She noted that despite cognitive losses, people with dementia retained their concern for appearance, social etiquette and caring. Kontos found that gestural communication was an important manner of self-expression. Kontos concluded that the residents in her study were aware of their surroundings, engaged with the world in an embodied manner and interacted with coherence, purpose and meaning despite their cognitive impairment.

Strategies adopted by people with dementia to deal with the condition
Findings from these studies suggest that it would be a mistake to assume that people with dementia are passive victims of the condition. Participants with dementia in studies exploring their experiences do not necessarily accept the negative cultural meaning often associated with the "disease" (MacRae, 2008). They use strategies to deal with the challenges they face, although memory impairment may make it difficult for them to deal with the changes they encounter (de Boer et al. 2007). Clare (2002) makes the distinction between integrative and self-protective strategies. Integrative strategies aim to confront the perceived threat that dementia poses and self-protective strategies preserve the individual's identity. Examples of integrative strategies include **"**making the best of things" and participating as much as possible in activities, attending support groups, seeking social contact and maintaining a proactive stance (MacRae, 2008; de Boer et al. 2007; Beard and Fox, 2008). MacRae found that people in her study focused on what they could, rather than what

they could not do and noted that this tendency was in contrast with how the rest of society views the dementia experience. Clare (2003) conducted interviews with 12 participants with a diagnosis of early stage Alzheimer's and used IPA in order to explore the degree to which they were aware of their illness. Clare (2003) found that some participants developed a fighting spirit; they looked for positive aspect in their circumstances.

In contrast to the above, self-protective strategies include using humour, isolating oneself socially, normalisation of memory loss and maintaining hope in the future to cope with dementia (Langdon et al. 2007; MacRae, 2007). Spirituality was found to be helpful for six participants with mild to moderate dementia in a recent British phenomenological study (Dalby et al. 2011). Belief in a greater meaning to life and a relationship with the divine supported participants' acceptance of dementia and provided them with hope for the future. Participants in Dalby's study also reported receiving support through their faith community via prayer networks.

A limitation common to most available evidence on the experience of dementia is that most accounts belong to people who are white, professional, heterosexuals and do not include an analysis of privilege (Hulko, 2009). For instance, participants in MacRae's (2008) and Phinney and Chesla's (2003) samples were all well-educated middle class and White. In contrast, Hulko's (2009) grounded theory study included eight community dwelling older people with varying severity of dementia and a mixture of ethnicities and social classes. This lack of diversity in most studies is an important oversight because Hulko's study found that the subjective experience of dementia depended on the person's degree of privilege and marginalisation. Hulko found that for people who are already marginalised, dementia effects can be seen as insignificant. In contrast, for people who are multiply privileged such as professional, white males, dementia can seem like a living hell. Hulko (2009) suggests that this could be because the privileged are concerned with socio-emotional life whilst the marginalised are concerned with a less cognitively demanding instrumental life. Hulko concluded that leading a marginalised life can help people to deal with the effects of dementia.

The subjective experience of dementia: a summary

In summary, a small number of qualitative studies adopting participant observation and interviews have explored the subjective experience of dementia. Most of these studies have emerged in the last fifteen years and have used interviews and included community dwelling participants who were in the early stages of dementia. Several studies describe themselves as phenomenological and have used IPA (Clare, 2002; Harman and Clare 2006; Langdon et al. 2007; Dalby et al. 2011; Robinson et al. 2012). Hulko (2009) used a grounded theory approach. Page and Keady (2010) reviewed autobiographical accounts of the dementia experience. Several studies have adopted an ethnographic approach (Kontos, 2004; Beard and Fox, 2008). The concept of embodiment has been applied as a theoretical framework in several Canadian studies (Phinney and Chesla, 2003; Kontos, 2004; Bassett and Graham, 2007). Symbolic interactionism has also been a useful theoretical approach (MacRae, 2008). Studies suggest that the condition is a complex and dynamic process which involves much more than memory loss and behavioural or psychological symptoms (de Boer et al. 2007). Evidence also suggests that the subjective experience of dementia is highly individual and variable and that it changes over time (Steeman et al. 2006; de Boer et al. 2007; Manthorpe et al. 2011). An important finding from studies is that people in the early stages of dementia can manage to live with their condition and actively create meaning in their lives (MacRae, 2008; Hulko, 2009; O'Connor et al. 2010). Studies remind us that power and privilege have an important effect on one's experience of dementia (Hulko, 2009) and point out that future research should include more diverse populations (Steeman et al. 2006; Hulko, 2009; O'Connor et al. 2010). Having reviewed the literature that deals broadly with the subjective experience of dementia, I shall now concentrate on the empirical evidence related to well-being and dementia.

Well-being and dementia

Whilst Banerjee et al. (2009) comment that there has been a lot of interest in well-being and quality of life in the field of dementia in recent years, others have suggested that qualitative studies including the views of people with dementia have been scarce (de Boer et al. 2007). Nevertheless, there are a number of recent papers devoted to dementia and well-being from North America, Australia, and

Europe. These consist of both qualitative and quantitative studies. Qualitative studies have focused on the views of both carers (Hasselkus and Murray, 2007) and the experiences of people with dementia themselves (Katsuno, 2005; Phinney et al. 2007; Sixsmith and Gibson, 2007; Moyle et al. 2011). Quantitative studies have addressed Quality of life and wellbeing for people with dementia using surveys (Zank and Leopold, 2001).

Several studies have used mixed methods approach to explore quality of life and well-being (Cahill et al. 2004; Katsuno, 2005; Moyle et al. 2007). Moyle et al. (2007) used a quality of life scale specifically for people with dementia (QOL-AD), MMSE and a physical self-maintenance scale (PSMS) with 33 people with dementia living in care settings. Participants' views were captured during unstructured interviews. Moyle et al. (2007) found participants were able to comment on their quality of life in a meaningful way.

The capacity of people with dementia to experience well-being

A consistent finding from studies is that when asked to evaluate their well-being or quality of life, the views of people with dementia appear to be at odds with the negative view of the condition held by the rest of society (Cahill et al. 2004; de Boer et al. 2007; Hulko, 2009). Cahill et al. (2004) used a mixed methods approach in their study which explored the quality of life of 92 people with mild to moderate dementia. Cahill et al. (2004) found that most participants from a variety of European countries with moderate dementia reported experiencing generally positive moods, and seldom experienced negative affects such as depression or fearfulness. In a more recent study, Wolveson et al. (2010) found that half the ten participants with early stage dementia in their qualitative study described themselves as "happy". Similarly, in a study by Katsuno (2005) including 23 people with early stage dementia in the US using both quantitative measures of quality of life and questionnaires eliciting qualitative accounts of quality of life, it was found that participants were as satisfied with their lives as those in the wider population. In Katsuno's (2005) study, people with dementia rated their QoL more highly than participants living with other chronic diseases such as respiratory disease and cancer.

Maintaining a quality of life which is defined as good by individuals with the condition appears possible during much of an individual's dementia career (Page and Keady, 2010; Williamson, 2010). People in the early stages of dementia who have taken part in studies reported that they enjoy life despite having dementia (MacRae, 2008). Phinney et al. (2007) found that people with mild to moderate dementia continue to engage in leisure activities including social engagement. Furthermore, carers tend to underestimate the level of well-being that the care recipient experiences (Katsuno, 2005; Williamson, 2010). One explanation for this could be that individuals with more advanced dementia do not recognise the restrictions or deficits associated with their illness (Zank and Leopold, 2001). However, maintaining a sense of well-being is not universal; Zank and Leopold (2001) suggest that people with dementia show a great variability in their subjective well-being. Cahill et al. (2004) noted two cases in their study who described often feeling negative and experiencing ill-being.

It has been suggested that well-being is shared between the person with dementia and their carer. Hasselkus and Murray (2007) found that the sense of reciprocity experienced through shared identity can be satisfying for the carer and that it is misleading to view caring for someone with dementia as relentlessly burdensome. This study found that everyday shared activity was used by carers to monitor states of well-being and these activities greatly influenced the well-being of both themselves and the recipients of their care (Hasselkus and Murray, 2007) .

Factors people with dementia identify as influencing their well-being

When people with dementia have been asked about the factors that influence their sense of well-being a number of factors have emerged. I will now discuss these factors in turn.

The influence of stigma on well-being

Dementia remains a feared and stigmatised condition (Department of Health, 2012). A recent UK poll commissioned by the Alzheimer's Society found that in the wider population people are more afraid of dementia than any other condition (Alzheimer's Society, 2011). It has been pointed out that the media portrays people with cancer as battling the disease courageously but a different view of dementia is presented, in which the person experiencing it is more distanced and passive (Katsuno, 2005).

Beard and Fox (2008) commented that because dementia is a chronic illness associated with declining function, it is difficult to frame one's identity as a "survivor" unlike other more acute illnesses. When asked about their sense of well-being, people with dementia report that they are aware of the stigma attached to their condition and are concerned with how others see them (de Boer et al. 2007; Langdon et al. 2007). People with dementia describe experiencing social exclusion and devaluation (Katsuno, 2005). As well as coping with the stigma associated with dementia, the experience of cognitive impairment is made more difficult for older people due to the effects of ageism within society and in the services that they may access (Manthorpe et al. 2011). The difficulties relating to how dementia is viewed can lead to some people living with the condition attempting to resist the stigma of dementia and publicise their experiences (Page and Keady, 2010).

There is discussion in the literature about the degree to which people with dementia are comfortable sharing their diagnosis with others (Katsuno, 2005). Langdon et al. (2007) found that whilst people were happy to share their diagnosis with close friends and family they were more wary of disclosure to the wider world. Similarly, the degree to which having dementia had changed how others interact with participants varies according to studies. Harman & Clare (2006) found that others interacted differently to participants due to the presence of dementia. Similarly, people with dementia have reported experiencing social discomfort with friends and a tendency to avoid conversing with neighbours due to fear of embarrassment (Phinney et al. 2007). However, the participants in MacRae's (2008) study denied any such changes in their relationships with people around them and found that participants were not always afraid of disclosing their diagnosis to others.

Psycho-social factors and well-being
Social networks and family are thought to be integral components of well-being (Cahill et al. 2004; Katsuno, 2005; Beard & Fox, 2008). Wolverson et al.'s (2010) study exploring the degree to which people with dementia experience hope found that social contact had a positive influence. Psychosocial factors that have been identified as influencing well-being for people with dementia include a sense of belonging, being loved, being understood, and feeling accepted and valued (Steeman et al. 2006; de Boer et al. 2007; Moyle et al. 2011; Robinson et al. 2012*).*

Page and Keady (2010) suggest that the ability to reconstruct social identity during the onset and progression of the disease is important together with maintaining key social relationships and networks. Harman and Clare (2006) noted that the way in which medical staff interacted with people who had dementia could have a negative effect on their sense of well-being if they failed to speak to them and instead addressed their comments to carers.

Meaningful activity and well-being

Meaningful activity is considered to be an important influence on well-being (Sixsmith and Gibson, 2007; Perrin et al. 2008). However, the manner in which individuals with dementia perceive meaningful activity is poorly understood (Phinney et al. 2007; Harmer and Orrell, 2008). According to Vernooij-Dassen (2007), meaningful activity for people with dementia involves a sense of pleasure, connection, belonging, autonomy and self-identity. Participants reported that being absorbed in activity made them feel "normal" (Robinson et al. 2012). Harmer and Orrell (2008) conducted focus groups with 17 care home residents with dementia, staff and family carers. When discussing what made activities meaningful, participants with dementia identified enjoyment, reinforcing identity, feeling valued and experiencing a sense of belonging. It is suggested that everyday occupation is neglected in research due to it being part of everyday taken-for granted world (Hasselkus and Murray, 2007). Phinney et al. (2007) used participant observation and semi-structured interviews with nine community dwelling people with dementia in their phenomenological study of meaningful activity. Participants reported that they wanted to engage in as much activity as they could and also attributed meaning to activities that were enjoyable, connected them with others and gave them a sense of belonging.

Music and well-being

There is considerable debate in the literature regarding the value that people with dementia attach to music (Schwab et al. 1985; Cooke et al. 2010; Spiro, 2010). This is partly due to evidence suggesting that people with dementia may continue to play music and appreciate listening to it far into their dementia career (Pickles and Jones, 2006; Sixsmith and Gibson, 2006). Sixsmith and Gibson (2006) conducted interviews with 26 people with dementia in care homes and in the community and found that many participants remembered song lyrics and melodies despite severe memory

loss. Sixsmith and Gibson (2006) describe music as a non-verbal language that persists despite dementia while verbal language and speech are gradually lost. Similarly, memories associated with music have been found to survive the effects of processes of dementia (Pickles and Jones, 2006; Phinney et al. 2007). Pickles and Jones go as far as to hypothesise that individuals have a musical self which exists alongside their cognitive and socially constructed selves. This aspect of selfhood which is resistant to the effects of dementia is not based on reflection, social interaction or language and is sustained by interacting with music.

Music is thought to have the potential to impact the well-being of people with dementia in a number of ways. Most of Sixsmith and Gibson's participants experienced pleasurable emotional responses when playing or listening to music and some described enjoying it so much that they sometimes became "lost" in the music when engaging with it. Sixsmith and Gibson attributed this to the fact that that the experience of music is enjoyed at a sensory rather than intellectual level. Music is also thought to be associated with positive mood (Spiro, 2010). According to Spiro (2010), live music is more effective than recordings in prompting emotional arousal and social engagement for people with dementia. Sixsmith and Gibson (2006) suggest that music can enable people to participate in social activities that are enjoyable and personally meaningful because it provides social cohesion resulting from dance, and touch. However, Sixsmith and Gibson (2007) pointed out that encounters with music are not always positive; people can forget their connection with music. Tacit rules apply to the use of music such as what is acceptable to play at an appropriate volume which can be difficult for people with dementia to follow.

Despite widespread acknowledgment that music may have much to offer people with dementia, empirical evidence is currently equivocal. This lack of consensus reflects the various ways in which the experience of music and the ensuing outcomes have been defined. Whilst exploratory studies employing qualitative methods such as semi-structured interviews (Sixsmith and Graham, 2006) generally support the use of music in promoting the well-being of people with dementia, the evidence from clinical trials are less conclusive (Vink et al. 2008; Cooke et al. 2010). Rather than exploring the meaning that people with dementia associate with music, these studies are concerned with the relief of symptoms. In a recent Cochrane review of ten RCTs

published between 1993 and 2008, Vink et al. (2011) concluded that there was no strong evidence that music therapy was an effective intervention for alleviating social, behavioural and emotional problems of people with dementia. This was because the small sample sizes and short interventions used in the reviewed studies led to a high risk of bias and a likely overestimation of the "true" effect of the intervention. However, one RCT by Cooke et al. (2010) which included 47 participants with mild to moderate dementia noted that whilst they found little evidence of relieving agitation and anxiety, their live music sessions were effective in giving some of their participants a voice.

Other factors influencing well-being

Williamson (2010) cites physical health, a sense of independence, the ability to communicate, and opportunities to practice faith/religion as influences on well-being. Maintaining a sense of humour has been found to be important in the lives of many study participants (Beard and Fox, 2008; MacRae, 2008). Finally, in a study based in Australia which involved interviewing 33 people with dementia in long term care, Moyle et al. (2011) found that a lack of connection with the external environment and lack of opportunities to venture outside negatively impacted the well-being of people with dementia in their study. Williamson (2010) noted that many of these factors are not specific to people with dementia but apply to all.

Dementia and well-being: a summary

The volume of studies exploring the experience of dementia is increasing, with more research taking into account the viewpoint of the individual with the condition. However, according to Moyle et al. (2011) gaps remain in our knowledge about what factors are significant in making life meaningful for people with dementia. For instance, as previously mentioned, there has been a lack of diversity amongst study participants. In a meta-ethnographic analysis of accounts of dementia experience, Page and Keady (2010) observed that published first person dementia narratives are produced almost exclusively by North American, middle class, well educated people who have been involved in public service. Others point out a lack of diversity in terms of ethnicity and socio-economic status (Katsuno, 2005; Phinney et al. 2007). Furthermore, in contrast with research concerned with the subjective experience of early stage dementia which has included participants living in the community, most

research on well-being and dementia has been undertaken in care settings (Harmer and Orrell, 2008; Moyle et al. 2011) despite the fact that the majority of people with dementia live in their own homes (Alzheimer's Society, 2013, Phinney et al. 2007). Finally, as discussed earlier, engaging fully in meaningful activity may result in flow states which may exert a powerful positive influence on well-being (Csikszentmihalyi, 1990) but this has not been explored in the reviewed literature.

Physical Activity and dementia

In this section I will review the literature regarding physical activity and dementia. I will show that the dominant biomedical conceptualisation of dementia has influenced the way in which the potential benefits of physical activity have been investigated. I will also discuss the small evidence base relating to dance, well-being and dementia within which the biomedical approach has been less dominant.

There is considerable evidence that participation in physical activity leads to increased well-being in middle aged and older people in the general population (Lampinen et al. 2006; Litwin and Schiovitz-Ezra, 2006; Wray, 2007). When the processes involved in enhancing well-being are considered, a number of mechanisms have been suggested. Being physically active is thought effective because it can represent purposeful activity (Crone et al. 2005; Stahi et al. 2001). It is also thought that participation in physical activity enables older individuals to experience a heightened sense of their body and physical activity can be used as a means of counteracting a sense of "idleness" (Grant, 2008). In a review of 11 RCTs including people without known cognitive impairment, Angervaren et al. (2008) conclude that there are cognitive benefits resulting from being physically active.

Physical activity as an intervention for dementia.

I found a substantial number of studies devoted to physical activity and dementia. Physical activity has been considered useful for people with dementia for a number of years (Cohen, 1991; Bonner and Cousins, 1996). However, a consequence of the dominance of the biomedical approach to dementia has been that physical activity has primarily been viewed as a treatment intervention with the potential to alleviate specific signs and symptoms of the condition (Bonner and Cousins, 1996). Physical

activity is therefore most often considered as an alternative to pharmacological approaches which inevitably carry a risk of side effects (Thuné-Boyle et al. 2012). Studies have assessed the suitability of physical activity for older people with dementia. It has been established that people with dementia can successfully engage in standing and seated physical activity of a structured nature (Netz et al. 2007). A recent American study found that 22 care home residents engaged well will a strengthening program run three times weekly (Rogers and Jarrott, 2012). It is also recognised that musical accompaniment improves participation in exercise on the part of people with dementia (Mathews et al. 2001). I will now discuss the different ways in which physical activity has been considered useful in the treatment of dementia

The protective effect of physical activity

There is some empirical evidence that physical activity in the form of regular walking may protect people from dementia (Abbott et al. 2004). Large systematic reviews of RCTs (Angevaren et al. 2008; Leone et al. 2008) concur that physical activity has a protective effect for people at risk of developing dementia. Aarsland et al. (2010) conducted a review of 24 longitudinal studies involving people with vascular dementia and concluded that there was a significant association between physical activity and reduced risk of developing this form of the condition.

Physical activity and cognition

The efficacy of physical activity in the treatment of particular clinical features of dementia has been explored in studies. Firstly, physical activity has been considered as a potential means of improving cognition. However, despite evidence that physical activity improves cognition in the wider older population (Angevaren et al. 2008), the evidence is less strong when it comes to studies including people with dementia. Whilst individual RCTs claim that physical activity is beneficial in terms of improved cognition (Lautenschlager et al. 2008). Reviews of the literature state that there is insufficient evidence to conclude physical activity can result in measurable cognitive improvement (Forbes et al. 2008; Ortega et al. 2010; Littbrand et al. 2011).

Physical activity and the management of BPSD

A second possible benefit of physical activity as a treatment for dementia is the reduction of the behavioural and psychological symptoms of dementia (BPSD) such as agitation, behavioural disturbances and lowered mood (Fan and Chen, 2012; Thuné-Boyle et al. 2012). A number of RCTs have concluded that it is useful in this respect (Holliman et al. 2001; Woodhead et al. 2005; Rolland et al. 2007). Eggermont and Scherder's (2006) literature review of 27 trials published between 1974 and 2005 concluded that there was good evidence that physical activity in the form of walking helps to lift mood and improve sleep. Similarly, Teri et al. (2003) found that daily carer supervised physical activity reduced levels of depression in their RCT which included 153 people with Alzheimer's disease. Woodhead et al. (2005) who completed an RCT examining the effects of adult day care activities on BPSD noted that not just physical activity, but activities as a whole had positive benefits for people with dementia in terms of their behaviour. However, a recent systematic review (Potter et al. 2011) concluded that the evidence for physical activity improving the QoI and reducing depression in people with dementia remains limited due to the methodological weakness of trials.

Physical activity and the health and function of people with dementia

A third potential benefit of physical activity for people with dementia is that it can improve physical function and the ability to perform activities of daily life (Cohen, 1991; Teri et al. 2003; Rolland et al. 2007). A recent Taiwanese study found improvements in joint flexibility and physical health resulting from participation in yoga. These potential benefits are important because physical impairments are common among people with dementia and are associated with falls risk (Littbrand et al. 2011). In a well-designed French RCT including 134 participants, Rolland et al. (2007) found that flexibility, walking and balance exercises resulted in a less rapid decline in ADL scores in nursing home residents with Alzheimer's disease. Teri et al. (2003) conducted an RCT including community dwelling older people with Alzheimer's disease which concluded that home-based exercise combined with caregiver training improved the physical health of participants. Finally, Allan et al. (2006) suggest that physical activity can alleviate the autonomic symptoms such as postural hypotension that are common with Lewy Body dementia and dementia associated with Parkinson's disease.

Dance and dementia

In contrast to the amount of research undertaken exploring the therapeutic effects of physical activity on the symptoms of dementia, there is very little published research about the subjective experience of physical activity for people with dementia and how it influences their well-being. However, one area in which the benefits of physical activity have been considered both as a treatment and a means of enhancing well-being is in the field of dance. There is a small but growing evidence base relating to the use of dance with people with dementia. Dance is considered to be well suited to people with cognitive impairment because it provides a non-verbal way of taking part in creative, meaningful and expressive activity (Ravelin et al. 2006; Hamill et al. 2011). Much of the evidence comes from studies undertaken in Scandinavia and the UK. Hokkanen has published two quantitative papers which firstly describe a pilot study then a larger RCT including 29 participants based in a Finnish nursing home (Hokkanen et al. 2003; Hokkanen et al. 2008). Weekly Dance Movement Therapy (DMT) sessions lasting 30-45 minutes were undertaken over a four month period with individuals experiencing dementia. As with the studies involving physical activity mentioned above, dance is often viewed as a treatment for cognitive loss, the effect of which is potentially measurable using MMSE. Hokkanen's pilot study (2003) which looked at weekly dance and movement therapy sessions found that language abilities improved slightly although there was no change in MMSE scores or behavioural symptoms. The main study found that engaging in DMT for nine weeks led to moderate improvement in cognitive ability and a lessening of BPSD (Hokkanen et al. 2008). Another quantitative research pilot study has been published which has explored dance (Wu Tao) as a therapy for people with dementia in an Australian residential unit (Duignan et al. 2009). The study included six participants and took place weekly for four weeks. The researchers found that agitation declined during engagement in dance. Duignan et al. (2009) described a "lifting of the spirits" of both residents and staff.

As well as trials using quantitative methods, qualitative studies exploring the use of dance with older people with dementia have been published (Nyström and Lauritzen, 2005, Palo-Bengtsson et al. 1998; Palo-Bengtsson and Ekman, 2000; Palo-Bengtsson et al. 2002; Coaten, 2002; Ravelin et al. 2011; Guzman-Garcia, 2012). Nyström and Lauritzen (2005) set out to explore how seven older people with

dementia living in a care home communicated in the context of dance therapy during the course of ten videotaped dance therapy sessions. They found that although participants did not pro-actively interact with others, engagement in dance enabled bodily expression of emotion and experience and that movement replaced speech as a means of communication. Similarly, Whyte (2010) conducted an observational study including a dance group run on a Scottish dementia ward and commented that engaging in the activity led to people with dementia expressing themselves and communicating with others. Dance can therefore support non-verbal social interaction. Ravelin et al. (2011) conducted a study in which they explored the effects of watching four dance performances in a nursing home in Finland. Thirteen residents with dementia were involved and their responses videoed. Participants displayed signs of enjoyment, showed appropriate social etiquette by clapping and moved their bodies along with the performers.

Palo-Bengtsson has written three papers about how people with dementia and their carers experienced a monthly 45 minute dance session run in a Swedish nursing home. In this study a four piece dance band played music to which people with dementia and their carers danced waltzes, tangos and foxtrots. The sessions were videotaped and analysis undertaken using phenomenological methods. In the first paper Palo-Bengtsson concluded that dance supported personal identity and communication (Palo-Bengtsson et al. 1998). However, not all participants in the studies were capable of taking part. Palo-Bengtsson wrote about people with dementia presenting with a restlessness, "agony" or "irritability" which prevented them from participating (Palo-Bengtsson et al. 1998). It was noted that dance enabled study participants to re-connect with their bodies and engage in purposeful activity. For example, participants with dementia appeared to have increased awareness of their body and appear to forget their frailties. Participants who engaged in the activities rarely struggled to dance; they were aware of musical timings and displayed spatial awareness because they were operating at a pre-reflexive level (Palo-Bengtsson et al. 1998). When reflecting on their study, Palo-Bengtsson et al. (1998) noted that dance had led to spontaneous activity in a group of individuals that were usually led during their everyday interactions with others. Finally, participating in the session resulted in people remembering dances from the past (Palo-Bengtsson et al. 1998).

In the second paper the focus shifted to how caregivers experienced the same dance events (Palo-Bengtsson and Ekman, 2000). Palo-Bengtsson and Ekman noted that not all carers in her study enjoyed the activity. Caregivers sometimes struggled with the demands and there could be practical issues to deal with. For example, attempting to gather a mixture of male and female carers in order to make the activity feel more socially acceptable (Palo-Bengtsson and Ekman, 2000). Dancing sometimes resulted in a tension between the sexes which was an advantage for some and a disadvantage for others in terms of engaging in the activities (Palo-Bengtsson and Ekman, 2000).

In the final paper, the aim was to explore the emotional response to the social dancing described above and walking for people with dementia (Palo-Bengtsson and Ekman, 2002). The combination of music and dance created a positive atmosphere and led to heightened emotional reaction on the part of participants with dementia. Emotional reactions to walking were less apparent but mutual tenderness and intimate contact did occur during the activity (Palo-Bengtsson and Ekman, 2002). Carers in Palo-Bengtsson's (2002) study reported that whilst they did not always find the dancing comfortable, it generated a sense of togetherness and positive emotional arousal for those involved.

More recently, Hamill et al. (2011) evaluated a weekly circle dance group for ten people with dementia and their carers using participant observation and quantitative measures of quality of life, cognition and physical health. The study found that dancing resulted in the lifting of mood and a therapeutic bond between staff or carers and people with dementia. Improvements in quality of life scores took place for some participants. Qualitative studies have reported other findings, for example in an account of Coaten's research involving community based dance music therapy (DMT), he noted that dance could lead to the evocation of memories (Coaten, 2001). Studies have found that people with dementia may express an interest in dance that they did not previously possess. For example, the narrative of the wife of a man with dementia reproduced by Pickle and Jones (2006) describes how her husband engaged in dance enthusiastically despite showing little interest in the activity before he developed dementia.

Not all the findings in reviewed studies were positive. Guzman-Garcia's (2012) study explored the experience of Latin Ballroom dancing for people with dementia living in a care home. Guzman-Garcia (Guzman-Garcia et al. 2012) pointed out that sexual disinhibition was a negative effect that she has noticed during her research into "danzon" dance. In her systematic review, Ravelin et al. (2006) mentioned that there are potential consequences such as "sinful thoughts". Ravelin et al. (2006) pointed out the danger of promoting self-disclosure through dance when the person is not ready to go through the process.

Physical Activity and dementia, interpreting the evidence

The type of physical activity and the duration and frequency of its application varies in the literature and this makes comparison between studies difficult (Thuné-Boyle et al. 2012). Furthermore, papers are not always clear about what form the physical activity takes. For example Woodhead et al. (2005) refer to the intervention as "formal exercise/physical activity" without specifying details. The frequency of interventions also varies between daily (Teri et al. 2003), three times weekly (Holliman et al. 2001; Fan and Chen, 2012), twice weekly (Netz et al. 2007; Rolland et al. 2007), to weekly (Mathews et al. 2001). The physical activity featured in studies is mostly group exercise sessions of various lengths lasting for up to an hour. Exercises were undertaken either sitting (Holliman et al. 2001; Mathews et al. 2001) or in the case of Rolland et al. (2007), included walking, balance and flexibility exercises.

Reviews of clinical trials have commented that methodology is often poor. In Littbrand et al.'s (2011) review of 10 RCTs it was commented that quality was poor because diverse sample populations were exposed to multifactorial interventions. Other reviewers point out that studies often lack randomisation, control groups and rigorous blinding (Leone et al. 2008). Hamill et al. (2011) point out that the quantitative measures used in RCTs such as MMSE are unable to capture subtle changes in communication between people with dementia or the expressions of emotion that are important aspects of well-being. Similarly, when recounting her observational study employing mixed methods, Whyte (2010) commented that using the Well-being profile devised by Bradford Dementia Group (Bruce, 2000) in order to score levels of well-being during circle dancing failed to reveal meaningful results.

Attempting to score well-being on the basis of a large number of indicators in a brief ten minute dance session proved difficult. Whyte decided to concentrate on the "quality of the moment" and when closely observing and recording the actions of participants, plentiful evidence of enhanced well-being was revealed in the form of expressed pleasure and emotion.

Limitations associated with RCTs in the field of dementia and physical activity

When I reviewed published studies that have explored the experience of dementia, physical activity, well-being and ethnicity, I found that the prevailing view of the condition based on the biomedical model of dementia has influenced the type of research undertaken. The focus of most research is directed at the relief of symptoms, and clinical trials generally and RCTs in particular outnumber qualitative studies. In this chapter I have also noted that there have been problems associated with applying RCTs in the field of dementia. Reviews of studies have pointed out that many published RCTs are of poor quality (Forbes et al. 2008; Vink et al. 2011; Thuné- Boyle et al. 2012). One cause of low quality in the RCTs identified by reviews is small sample size (Forbes et al. 2008; Potter et al. 2011). Trial size is crucial because if sample numbers are low, the trial may be underpowered and clinically important effects may not be detected (Tilling et al. 2005). However, large homogenous samples may be difficult to achieve when the experience of dementia is dynamic and highly variable. Identifying effects of physical activity in a meaningful way through an RCT may also be problematic given the highly individual and subjective response to physical activity that people exhibit (Faulkner and Carless, 2006).

RCTs have other limitations relating to their design. Cowan (2009) points out that researchers using RCTs can only study what is observable and measurable. Cowan notes that it is difficult to observe and measure stress, hope, emotion or the "feel" of an experience (Cowan, 2009). A further limitation is that RCTs by necessity have a narrow focus. For example, in a recent review of RCTs, Thuné-Boyle et al. (2012) called for trials in which physical activity is strictly defined as repetitive, planned and structured, and which is directed at the relief of BPSD. However, this would neglect the potential of unplanned and unstructured physical activity as well as the potential benefit of physical activity in terms of well-being. A study by Kovach and Henschel

(1996) found that it was when engaging in unstructured physical activity that people with dementia expressed well-being by behaving spontaneously and with self-expression. I concluded that in order to capture the subjective experience of physical activity and the potentially important effects relating to less structured activities, more studies adopting qualitative methods are needed.

Physical activity and dementia; a summary

There is a small evidence base suggesting that dance may be beneficial for the well-being of people with dementia. There are a larger number of studies looking at physical activity as an intervention for the signs and symptoms of dementia. There have been calls for more RCTs with greater numbers of participants and that the people with dementia in these studies should be homogenous in terms of disease severity, mobility and diagnosis (Forbes et al. 2008; Thuné-Boyle et al. 2012). It is argued that these steps will allow the optimal physical activities for people with dementia to undertake to be identified. However, there are methodological limitations to this quantitative/positivist approach in terms of capturing the effects of physical activity.

Studies within the general population suggest that when older people participate in physical activity they are likely to experience a sense of well-being but research exploring physical activity and well-being has not been carried out to any great extent in the area of dementia. Instead, the biomedical model in which the person with dementia usually presented as a passive recipient of "treatment" dominates research in this field. Studies adopting a biomedical view of dementia and which have used RCTs have found that physical activity may be useful in controlling the symptoms of dementia such as cognitive changes, difficulties with ADLs and BPSD. However, there remains a lack of evidence around what meanings people with dementia attribute to physical activities such as dance. Similarly, the possibility that physical activity may result in enhanced well-being for people with dementia due to the experience of flow (Czikczentmihalyi, 1990) has not been investigated. This may be related to the belief that flow is difficult to measure (Collins et al. 2009). The neglect of the subjective experience of physical activity in the field of mental health is not limited to dementia. Others have noted a lack of research into the meaning that people with mental health needs attach to physical activity. For instance, there is a

lack of evidence regarding how people with depression (Harris et al. 2006) and young men with enduring mental illness (Carless and Sparkes, 2008) experience physical activity. This lack of a subjective view is important because attitude to physical activity in general and perceived barriers in particular greatly influence participation in activities (Fox, 2000) and influence motivation for older people to participate (Wallace and Lahti, 2005).

There are other gaps in the evidence relating to physical activity and dementia. For example, with the exception of Woodhead et al. (2005) and Teri et al. (2003) who included community dwellers, participants in all virtually all studies are nursing home residents. There is very little in the literature about the experiences of people with dementia performing physical activity alone or with carers and what it is like for them to attempt to be physically active in the community. Littbrand et al. (2011) called for more research in this area including community dwellers with dementia. Forbes et al. (2008) identified the need for research which investigates the effects of barriers and facilitators on the adherence to physical activity for people with dementia.

Ethnicity and dementia

In this section I will review the methodology and findings of studies which have addressed the issue of ethnicity and dementia. As mentioned in the previous chapter, ethnicity is a problematic concept because it is difficult to define and when applied to populations inevitably imposes rigid categories on what is a complex and dynamic social process. Researchers who intend to explore ethnic facets of the dementia phenomenon have been advised to avoid essentialist views of ethnicity and remind us that ethnicity is only one component of identity (Iliffe and Manthorpe, 2004; Adamson and Donovan 2005; O'Connor et al. 2010; Botsford et al. 2011). The application of ethnic categories makes stereotyping social groups a risk. For example, the widely held stereotypes that care giving is unproblematic in South Asian families (Milne and Chryssanthopoulou, 2005) and that BME communities "Look after their own" (Janevic and Connell, 2001; Iliffe and Manthorpe, 2004; Adamson and Donovan, 2005). Nevertheless, I argued in the last chapter that ethnicity is important to this study because I have adopted the view that dementia is a socially embedded phenomenon experienced in an embodied manner, which is

influenced by social factors which include ethnicity. Furthermore, the community based interventions at which people with dementia undertake physical activity inevitably have ethnic characteristics and sometimes clearly target specific ethnic communities.

According to Salway and Ellison (2010) health research has neglected the issue of ethnicity in the past. I found a number of published studies exploring ethnicity and dementia but this research has mostly taken place in the US and has focused on care giving issues (Hinton et al. 1999; Janevic and Connell, 2001; Vickrey et al. 2007). In contrast to the US, evidence regarding how dementia is understood and managed among ethnic minority communities in the UK is limited (Milne and Chryssanthopoulou, 2005; Mukadam et al. 2011). Most of the evidence relating to the UK focuses on South Asian and to a lesser extent African Caribbean communities whilst other minority ethnic groups such as Eastern Europeans are neglected (Botsford et al. 2011). As in the US, most British studies addressing dementia and including BME participants have explored the experiences of carers (Adamson and Donovan, 2005; Botsford et al. 2011) or have sought the views of the wider population (Mackensie, 2006; La Fontaine et al. 2011). In contrast, studies which address the lived experience of dementia in minority ethnic communities from the perspective of the individual with the condition are much rarer. I found two studies from outside the UK which explored the subjective experience of participants with dementia from non-white and non-western perspectives. These were the accounts of a group of Hong Kong Chinese (Mok et al. 2007) and a case study involving a woman with Canadian aboriginal heritage (O'Connor et al. 2010). Research which explores the experience of participants with dementia from ethnic minority populations in the UK is extremely scarce. In fact, my search led to a single study which interviewed people with dementia from White British, South Asian and Black Caribbean communities (Lawrence et al. 2010). I will now review the main themes that have emerged from the literature in the field of dementia and ethnicity.

The aetiology of dementia and ethnicity

Despite the suggestion by Iliffe and Manthorpe (2004) that the aetiology of dementia is for the most part unaffected by ethnicity, a small number of studies has found dementia prevalence rates in African-Caribbean and other minority ethnic

communities that differ from the wider population in the UK (Bhatnagar and Frank, 1997; McCracken, 1997; Adelman et al. 2009). There are several possible reasons for different prevalence rates in these communities.

Firstly, there may be different factors at play in the aetiology of the condition. British African-Caribbean and certain groups within the South Asian communities are thought to be at increased risk of vascular dementia due to high levels of hypertension and diabetes (Milne and Chryssanthopoulou, 2005). Differences in prevalence between ethnic groups on the grounds of aetiology have been noted elsewhere in the world. In Australia, studies have found that Aborigines are at greater risk of developing dementia related to alcohol and trauma than the general population (Pollit, 1997). Bhatnagar and Frank (1997) commented in their survey of south Asian communities in Bradford that in direct contrast to the wider population, Alzheimer's disease was much rarer than vascular dementia. In the US, Helzner et al. (2008) compared survival rates in terms of ethnicity and found that Hispanics had longer post diagnosis survival rates than Whites and African Americans. Helzner postulated that Hispanics may have a "survival advantage" due to health related behaviours or social factors. Sink et al. (2004) investigated the presentation of symptoms along ethnic lines in the USA and found higher reported rates of problematic behaviours relating to dementia in Black and Latino groups compared to Whites. In conclusion, there is evidence of minor variation in the aetiology of dementia on ethnic grounds.

A second possible reason for differences in the prevalence of dementia along ethnic lines may be associated with variability in the rate of diagnosis. McCracken et al. (1997) performed a survey of BME communities in Liverpool using the Geriatric Mental State Examination and found that whilst the prevalence of dementia in these groups was comparable to the wider population, the proportion of non-English speaking participants who were identified as having dementia by the screening tool was much higher. This seemed to be related to the fact that many non-English speakers could not identify the prime minister mentioned in the tool or recall their date of birth and so appeared to be disorientated. Bhatnagar and Frank (1997) performed a survey of the south Asian population of Bradford and concluded that standard dementia screening tools were unreliable for these groups because they

were culturally inappropriate. Beattie et al. (2005) explored the way in which people with dementia from BME communities in the Bristol area accessed dementia services. This qualitative study included interviews with black mental health workers who commented that diagnosing dementia in BME groups may be hard for doctors who lack the cultural or linguistic ability to recognise cognitive impairment. A third possible reason for variability in dementia prevalence between ethnic groups may be associated with demographic factors. Knapp and Prince (2007) noted that the prevalence of early onset dementia (below the age of 65) in BME groups is three times that of the population as a whole. They suggest that this variance is due to the younger age profile of these communities.

Ethnicity and attitudes to dementia

Stigma was mentioned in the previous section as an important influence on the well-being of people with dementia. Evidence suggests that this stigma can be manifest in ethnically specific ways. Attitudes to mental illness in general in the UK and dementia in particular is highly stigmatised in South Asian and Eastern European communities (Turner et al. 2005; Azam, 2010; Mackensie, 2006). It appears that stigma can also be expressed differently according to ethnicity. Lawrence et al. (2011) found that Black/Caribbean participants reported that the pejorative terms used in their community were "mental/crazy/mad" whereas White British participants associated dementia with different terms such as "Stupid/dimwitted/absentminded". MacKensie (2006) explored stigma associated with dementia in South Asian and Eastern European communities in a northern city in the UK. Mackensie (2006) noted that stigma constrains the lives of people with dementia and their families in both communities because it resulted in the concealment of the person with dementia. Mackensie (2006) suggested that the trauma experienced by many older Eastern European immigrants in the mid-20th century reinforced this tendency. According to Mackensie (2006), the concealment of dementia takes place in order to avoid inviting censure from members of the same community. Studies in the US have found similar variations in levels of stigma attached to dementia according to ethnicity. Care givers for people with dementia from African American, Hispanic American and Chinese American are more likely to keep the diagnosis of dementia a secret than White Americans (Vickrey et al. 2007). It is important to remember that stigma associated with dementia varies between social groups in ways unconnected with ethnicity. For

example, a dementia care worker interviewed in Beattie et al.'s (2005) study based in the Bristol area noted that stigma also varied within the white population and was particularly evident in closely knit rural communities.

As well as ethnic differences in the aetiology of the condition, evidence in the literature suggests that both the cause and effects of dementia can be interpreted in different ways depending on ethnic/cultural perspectives. For example, in South Asian communities, illness in general may be associated with punishment and dementia may be viewed as an act of god (Milne and Chryssanthopoulou, 2005; MacKensie, 2006). In one study, British Punjabi Indian participants attributed the signs of dementia to social, physical or emotional factors rather than the consequence of organic brain disease (La Fontaine et al. 2007). Mok et al. (2007) looked at experience of community dwelling Hong Kong Chinese with early stage dementia. Within this social group, attitudes to the condition were shaped by Taoism and Confucianism. This meant that participants held fatalistic views regarding their condition. In Mok's study, dementia was considered to be heaven sent and suffering considered a normal aspect of life. This view helped participants with dementia to come to terms with their difficulties.

Awareness of the medical conceptualisation of dementia varies on ethnic grounds. For instance, knowledge of the aetiology of dementia and possible interventions has been found to be limited in the South Asian population in the UK (Turner et al. 2005; La Fontaine et al. 2007; Lawrence et al. 2010). This finding is mirrored elsewhere in the world. For example, when talking to Australian aborigines, Pollit (1997) found that the concept of "dementia" was completely alien to them. In some BME communities, memory loss is considered to be a normal part of ageing (Turner et al. 2005). When considering possible reasons for these differences on ethnic grounds Turner et al. (2005) suggested that British South Asian culture is less influenced than the majority by western science. Lawrence et al. (2010) noted that viewing memory loss as normal was helpful for South Asian participants because it saved them from worrying about their cognitive loss and enabled the stigma of mental illness to be avoided. In contrast, the realisation that that they had a serious and progressive condition was a cause of fear for Black Caribbean and White British participants in this study.

Studies in the UK have found that the importance attached to dementia and assessment of its severity varied along ethnic grounds (La Fontaine et al. 2010). In La Fontaine's study, participants from Black communities assessed severity in a fictitious vignette on the basis of social support. In contrast White participants found the same scenario worrying on the basis that the protagonist's dementia put their independence in jeopardy. Lawrence et al. (2010) concluded that the different ethnic groups in their study were likely to hold different fears regarding their dementia because they conceptualised their condition and support differently.

Some studies which explore ethnicity and dementia have found that changes in cognitive function can be viewed in a positive way. In the US, Henderson and Henderson (2002) explored the interpretation of dementia in Native American culture and noted that it was different from the general population. In the Native American context, hallucinations were not seen as pathological; they were considered "supernormal" and provided access to the unknown. In the case study by O'Connor et al. (2010) which detailed a Canadian woman's experiences of developing early onset dementia, "Betty" reported that dementia had helped her to re-connect with her aboriginal ethnic identity. This cultural background enabled her to challenge the biomedical discourse and allowed her to think of dementia as an opportunity to grow and develop. Despite these differences between ethnic groups, studies suggest that some attitudes to dementia are unrelated to ethnicity. For example, the belief that forgetfulness is inevitable with advanced age and that the best way to deal with dementia is to get on and make the best of things (Botsford et al. 2011). British South Asians and Whites appear to share the view that dementia presents in terms of memory loss and personal care problems (Turner et al. 2005).

Ethnicity and the experience of dementia
In this section studies which have explored how ethnicity impacts on different aspects of the dementia experience will be discussed.

The influence of ethnicity on attitudes to dementia
Ethnicity as an influence on the experience of dementia has been neglected by researchers (Milne and Chryssanthopoulou, 2010; Banerjee et al. 2009; Lawrence et

al. 2010). Reasons suggested for this include the small size of certain communities, the stigma often attached to dementia in particular ethnic groups and low levels of diagnosis (Hulko, 2009). Three papers were found that dealt with the lived experience of dementia and which related the experience to ethnicity (Mok et al. 2007; O'Connor et al. 2010; Lawrence et al. 2011). Lawrence et al. (2011) found that White British participants were more likely to consider themselves as a burden on others. Mok et al.'s (2007) study in Hong Kong concluded that certain aspects of the dementia experience were much the same as in the indigenous white populations of the US and UK. For example; Chinese participants reported awareness of stigma and feelings of loss, which included the loss of valued meaningful activity. O'Connor et al. (2010) remind us that whilst ethnicity is an important aspect of identity and influences people's experience of dementia, there are other factors such as sexuality, socio-economic status and age which may be of equal or greater importance.

A recent study by the Alzheimer's Society including participants from ethnic minority communities concluded that there were differences in the well-being of people with dementia in the UK along ethnic lines (Williamson, 2010). It was suggested that well-being is strongly influenced by high levels of religious beliefs in older members of BME communities compared with the wider population. It was also pointed out that lower levels of well-being among Black women with dementia may be related to their greater risk of social isolation (Williamson, 2010; Lawrence et al. 2011). However, how much the experience of dementia is mediated by these factors needs further research (Williamson, 2010).

Dementia care practices and ethnicity
Attitudes to caring for people with dementia have been found to vary between ethnic groups in the UK. British Asians are more likely to view family and friends exclusively as carers whilst whites thought the state should provide care (La Fontaine et al. 2007; Lawrence et al. 2010). Adamson and Donovan (2005) found that that British African Caribbean and Asian carers' experiences may be influenced by a moral obligation to care, particularly for women. Participants considered caring for family to be culturally normal to the extent that they did not see themselves as "carers". Botsford et al. (2011) completed a study of Greek and African Caribbean carers in London and found that Greeks were family oriented whereas African Caribbean

participants were couple centred and did not want to burden their children with the responsibility of care.

In the US context, differences in care practices have also been found to vary between ethnic groups. White people with dementia are more likely than members of other ethnic groups to be looked after by their spouse and cared for in an institution (Sink et al. 2004). In contrast, people with dementia from ethnic minorities are much more likely to be cared for by their grown up children (Connell and Gibson, 1997; Janevic and Connell, 2001; Vickrey et al. 2007). American research has found that the perceived benefits of caring for someone with dementia also varies between ethnic groups (Connell and Gibson, 1997; Janevic and Connell, 2001; Sink et al. 2004; Vickrey et al. 2007). For example, Vickrey et al. (2007) found that Whites struggled to identify benefits for the caregiver whilst other groups were more positive (Vickrey et al. 2007). Similarly, other studies found that Whites described experiencing more stress as a result of caring for someone with dementia (Connell, 1997; Janevic and Connell, 2001; Sink et al. 2004).

Despite these differences, certain aspects of the experience of providing informal care have been found to be similar throughout ethnic groups in UK studies. Carers from all ethnic groups mention similar negative connotations of caring for someone with dementia. These include a degree of disruption to carers' lives, difficulty with child care and fulfilment of financial responsibilities (Adamson and Donovan, 2005). In terms of the care giving experience, American studies also found similarities between ethnic groups. For instance, carers from all groups express worry about the person with dementia that they care for and describe similar unmet needs such as more information (Vickrey et al. 2007) Similarly, carers from all groups express worry about the person with dementia that they care for and describe similar unmet requirements such as the need for more information (Vickrey et al. 2007).

The uptake of services and ethnicity
UK studies show that contact with dementia services can vary on ethnic lines. In a recent study based in London, Greek Cypriot families were found to be more likely to seek diagnosis than African Caribbean participants who had a tendency to receive their diagnosis as a consequence of a crisis (Botsford et al. 2012). Uptake of

dementia services in the UK is also lower in BME communities compared to the population as a whole (Mukadam et al. 2011). Various explanations for these differences in service uptake have been suggested. Daker-White et al.'s (2002) review of the literature on ethnicity and dementia suggested that variation in dementia service uptake may be due to attitudes to the condition. Medical services were not considered sources of help in one recent study including British Punjabi Indians (La Fontaine et al. 2007) because dementia not conceived in terms of a treatable illness. It has been suggested that people from "South Asian" communities in the UK are unlikely to seek services if they think dementia is a normal consequence of aging, if they don't see it as a burden or if they think the family should take responsibility (Turner et al. 2005). Uptake of dementia services from South Asian communities is also thought to be low because help from outside the extended family threatens the precarious balance between shame and pride (Mackensie, 2006; Azam, 2010). Daker-White et al. (2002) commented that for some minority communities dementia is not prioritised because other issues such as language difficulties, over-crowded living conditions and a precarious economic situation are of greater concern. Another factor suggested by Daker-White (2002) is the nature of services which fail to adequately meet the needs of people from BME communities. Service providers need to acknowledge culture and be culturally competent when designing services (La Fontaine et al. 2007). In the USA, both language difficulties and racial discrimination were described as barriers to services for Chinese and African American dementia caregivers (Vickrey et al. 2007; Hinton et al. 2004).

The question of access to culturally specific dementia services has been explored. Beattie et al. (2005) interviewed 61 health care professionals and paid carers for people with dementia from BME communities. Beattie found that participants generally assumed that people with dementia from BME groups should be cared for alongside others who shared their ethnicity in terms of language, food preference and favoured music. However due to low densities of BME groups and widely spread services, access to what were considered appropriate services was difficult. Furthermore BME specific mental health services could themselves be marginalised due to less qualified staff and having roots in community development rather than health services.

Ethnicity and dementia: a summary

The evidence base regarding the subjective experience of dementia in BME communities is very small. As previously discussed, the biomedical conceptualisation of dementia tends to neglect social aspects of the condition. Therefore, a lack of interest in possible differences in the experience of dementia on the grounds of ethnicity is unsurprising. Nevertheless, certain conclusions can be drawn from the literature on dementia and ethnicity. Ethnicity is an important factor to consider because certain communities are at higher risk and access to services is lower in BME communities. Culture and ethnicity can have a profound effect on how individuals make sense of dementia and on how people with dementia receive care. Levels of stigma and the manner in which stigma is expressed may vary between ethnic groups and this results in high levels of concealment in particular communities. More research is needed in which the person with dementia is consulted about their views on the relevance that ethnicity has on their dementia experience and what they think about interventions designed to cater for specific ethnic groups.

Problems associated with operationalising the concept of ethnicity persist. Studies have sometimes described the challenges of defining their ethnic categories due to the multitude of definitions and sampling frames used by others (McCracken, 1997). More than a decade ago, Daker-White et al. (2002) commented that many studies addressing ethnicity and dementia were fundamentally flawed because they assumed homogeneity within ethnic groups and this has continued in recent studies. For example, Lawrence et al. (2011) set out to examine the subjective reality of living with dementia from the perspective of people from ethnic minorities. Lawrence used ethnic categories in an uncritical way without recognising firstly, that the ethnic categories inevitably contained participants with a range of experiences and secondly, that ethnicity contributes only a part of the experience of dementia. Hulko (2009) recognised the danger of oversimplifying the impact of ethnicity on the dementia process. She commented that the subjective experience of dementia is predominantly influenced by power and privilege although she recognised that these factors may have some ethnic component.

Summary of chapter three

The few studies that have explored the experience of dementia suggest that developing the condition can be very stressful and that the process involves a wide variety of losses. However, research has also found that rather than accepting these losses in a passive manner, people with the condition may adopt strategies to cope with the effects of dementia. Furthermore, evidence suggests that well-being is possible despite dementia. People with dementia have reported that their sense of well-being may be enhanced through meaningful activity, social factors, spirituality, humour and music. Conversely, their well-being may be negatively impacted by stigma. The concept of embodiment offers a promising way of understanding the experience of dementia but up until now studies adopting this approach have been few and far between. Research in dementia continues to lack diversity in terms of the ethnicity and the socio-economic status of participants. While there has been discussion in the literature about the impact of ethnic factors on dementia this is also mostly of a biomedical nature. This research suggests that the aetiology of dementia may vary according to ethnicity. Attitudes to the condition, uptake of services and the lived experience of dementia may also vary along ethnic lines because of the way in which dementia can be socially constructed differently.

There has been discussion in the literature regarding the benefits that physical activity offers people with dementia. Most researchers have regarded physical activity as a treatment for the signs and symptoms of dementia and have adopted experimental methodologies which are ineffective in capturing the individual effects and subjective experience of physical activity for people with the condition. Dance is considered potentially useful in enhancing the well-being of people with dementia because it is associated with music and linked with positive effects on mood, social interaction and self-expression. However, what people with dementia think about undertaking physical activity remains under explored. A small number of studies suggest that the body can be crucially important for communication and self-expression when people develop dementia. Coaten (2002) suggests that in spite of severe cognitive loss, people can "be reached" by way of the body. Physical activity has the potential to allow this engagement to take place in a coherent manner. Applying the principles of embodiment may therefore be useful in understanding how

physical activity and dance tap into the pre-reflective abilities that people with dementia retain and how these activities influence well-being. Further research is needed that explores the meaning that people with dementia from diverse socio-economic and ethnic backgrounds attribute to physical activity. There is a shortage of research that addresses self-led and community based physical activity, that encompasses subjective well-being and which acknowledges the embodied experience of both dementia and physical activity. In the next chapter I will discuss the methodology and methods I decided to use in order to address some of the gaps in the literature mentioned in this chapter.

CHAPTER FOUR

Methodology

Introduction

In previous chapters I introduced my research topic, reviewed the literature and proposed research questions to address gaps in empirical knowledge relating to how people with dementia experience physical activity. This chapter is concerned with the selection and application of the study's methodology. Methodology can be defined as the general approach to studying a research topic (Willig, 2008). It represents a strategy which provides the logic by which the researcher attempts to answer their research questions (Mason, 2002). For Van Manen (1990), methodology also includes a consideration of what it is like to be human. In this chapter I will begin by describing the process by which my theoretical framework was developed. I will then give an account of how I selected two methods of generating data which were appropriate to this theoretical framework. I will follow this by discussing how I ensured that these two methods worked together within my theoretical framework. In the second half of the chapter I will detail how these methods were implemented. I will then describe the process of data generation, analysis and interpretation. Finally, I will explore issues of quality and reflexivity.

Establishing a theoretical framework to underpin my methodology

Willig (2008) suggests that researchers can demonstrate the suitability of their methodology by describing how they have dealt with several interrelated issues. Firstly, that they have selected an approach that has enabled the research questions to be answered effectively. Secondly, that they have considered ontological questions relating to their research topic and have clearly described their ontological assumptions. Thirdly, that they have thought about what kind of knowledge they plan to produced and identified epistemological positions that fit with their ontological stances. It is important that all the components that form the theoretical framework fit together coherently. In this section I will describe how I approached each of these issues in turn in order to construct my theoretical framework.

Paradigms in social research

The manner in which a researcher approaches their research questions is dependent on the paradigm within which they operate. The term paradigm has been widely used following the work of Kuhn (1962). Paradigms are socially constructed systems of belief and practices shared by communities of scholars. Paradigms regulate inquiry by providing lenses, frames and processes through which the creation of knowledge is accomplished (Weaver and Olson, 2006). Several paradigms have been theorised, these include positivism, post-positivism, interpretivism and critical social theory (Weaver and Olson, 2006).

Positivitism

It is argued that the dominant paradigm in the field of disciplined inquiry since the Enlightenment has been positivism or more recently post–positivism (Langdridge, 2007). The positivist paradigm is generally taken for granted in the natural sciences and remains dominant in the social sciences (Ashworth, 2008). According to Ashworth, positivism is based on three assumptions. Firstly, that there is a single unitary "real" world in which human phenomena display enduring and clearly defined characteristics. Secondly, that the world can be described in terms of measurable variables and that these variables relate to each other in the form of cause-effect relationships. Thirdly, that the logic which underlies the process of generating knowledge is deductive. This involves relating research to pre-existing theory in order to "prove" or "disprove" hypotheses through the use of experiments. When adopting a positivist stance, the researcher's task is to maintain objectivity and to remain detached and value free (Langdridge, 2007). Communication between subject and researcher during a positivist study involves the "transmission" of quantitative information (Lather, 2006). When considering paradigms I decided that a positivist approach would be ill-suited to addressing the research questions in my study. This was because my research questions were concerned with exploring and interpreting the subjective experiences of dementia, well-being and physical activity. I was aware of the view that the positivist paradigm neglects the significance and meanings that individuals attach to the phenomena being studied (Bowling, 1997). Furthermore, whilst it was inevitable that there were some pre-existing assumptions about what findings may result from the study, I had no hypothesis to prove or

disprove through the use of a deductive experiment. Finally, I recognised that human behaviour is unpredictable and subject to change.

Interpretivism

An alternative to the positivist or post-positivist paradigm is interpretivism. The interpretivist paradigm is based on the assumption that the meanings that people attach to their actions and the reactions of others are important (Weaver and Olson, 2006). In this paradigm the intersubjectivity between researcher and participant is recognised and encouraged. The generation of knowledge within the interpretivist paradigm is likely to be inductive rather than deductive and involve the development of new theory rather than the testing of hypotheses (Bowling, 1997). Interpretivism is associated with qualitative approaches. These involve generating and interpreting detailed descriptions of individual experience and focus on how people interact with the world around them (Litva and Jacoby, 2002). It is important to recognise that there is no single, unified qualitative approach; there are a number of different strands complete with a variety of philosophical underpinnings, methodological techniques and practices. However, certain common elements are shared. Data generated are usually in the form of language rather than being numeric (Creswell, 1998). In qualitative studies the researcher is central to the sense that is made (Banister, 1994). It focuses on human activity in the context of their everyday world rather than in an experimental environment (Van Manen, 1990; Creswell, 1998; Langdridge, 2007). Qualitative approaches are characteristically exploratory, fluid, flexible and data driven (Mason, 2002). The methods used for generating data are flexible and sensitive to the social context in which it is produced rather than rigidly standardised within an experimental context. Qualitative research can therefore provide rich and in-depth descriptions of human experience and social processes (Langdridge, 2007).

I decided that my research questions were most likely to be successfully addressed if I aligned myself to the interpretivist paradigm and adopted a qualitative approach. This decision was based on a number of factors; as previously mentioned, my questions were concerned with exploring the lived experience of dementia and the meanings attached to physical activity by participants. I intended to focus on small groups of individuals who gathered at social settings which meant that my study was

naturalistic and idiographic (Reid et al. 2005). My participants were likely to present with a degree of cognitive impairment and engage with their environment in a manner that would difficult to predict. The use of an emergent study design (Denscombe, 2009) and the flexibility that a qualitative approach offers could therefore be helpful. I was aware that the flexibility of qualitative approaches extended to the research questions themselves. Willig (2008) points out that qualitative research questions are always provisional because researchers may find that the terminology and concepts of the question are not appropriate.

Criticisms and Limitations of interpretivism

Inevitably there are limitations associated with interpretivism. Denscombe (2009) identifies three repercussions of adopting the interpretivist position that he suggests can be uncomfortable for researchers. Firstly, due to lack of objectivity they are open to the charge of relativism on the grounds that if the researcher cannot claim that they have the right answer to their question then the possibility arises that other explanations are just as valid. However, in response to this charge, others argue that complete objectivity in social research is impossible and there is no correct interpretation of a social phenomenon (Mason, 2002), but this does not mean that all interpretations are equally valid. As an interpretivist researcher my aim is to employ a systematic and transparent process in order to construct an interpretation that is judged by others to be a credible one (Mays and Pope, 2006). Denscombe's second point is that a focus on subjectivity and recognition that the social world is extremely complex can lead to messy, contradictory and incomplete explanations. I would argue that the social world is complex, contradictory and messy and that it would be naïve to think otherwise. Furthermore, it is by adopting qualitative approaches that the researcher is able explore these complexities (Parahoo, 2006). Thirdly, Denscombe claims that because of its lack of statistical analysis and emergent design, interpretivist research can appear to lack rigour. When considering this issue I noted how others maintain that well run qualitative research is systematic and thorough and there are established means of maximising rigour (Lincoln and Guba, 1985; Patton, 1999; Mays and Pope, 2006).

Qualitative research has also been criticised on the grounds that the use of small purposively sampled populations results in findings that cannot be generalized to the

wider population (Parahoo, 2006). According to Lincoln and Guba (1985) this issue has been often raised due to the influential work of John Stuart Mill (1806-1873), who argued that the primary aim of positivist enquiry is to develop knowledge in the form of generalizable truth statements that can be used to predict phenomena in a wider context. I cannot claim that my findings will be generalizable because they are dependent on the particular interaction between me and my participants at a particular place and at a specific time. However, Lincoln and Guba (1985) point out that generalizability is problematic for all social research because human activity is never context free. As an alternative, Lincoln and Guba (1985) suggest the concept of transferability to represent the application of findings to other populations and contexts. The degree of transferability is a direct function of the similarity between the two contexts. Findings from one context can hold true for another context if there is a high degree of similarity between them. Because dementia is such a common experience, it is arguable that findings from my study have a degree of transferability to other groups of older people living in similar circumstances. I will return to the issue of rigour later in the chapter when I discuss questions of quality, validity and reliability.

Exploring the realities of dementia; the recognition of complementary ontologies.

Having identified my approach as being interpretivist my next task was to address issues of an ontological nature. Ontology is the philosophical study of the nature of existence and reality (Guba, 1990). Ontological questions consider the relationship between subject and object, mind and body and what there is to know (Willig, 2008). The first ontological question I was concerned with was how to define the realities of dementia. In the previous chapters I discussed several models of dementia. I noted that dementia can be conceptualised as a threat to the individual concerned in three different ways. Most commonly, dementia is seen as a pathological condition of the brain which represents a threat to normal neurological function. Secondly, I noted that it was less commonly viewed as a social experience involving a threat to the social self of the individual (Kitwood, 1997; Sabat and Harre, 1992). Thirdly, I described how dementia can be conceptualised as a threat to embodied selfhood during which the individual's pre-reflective relationship with their life world is at risk

(Kontos, 2004; Phinney and Chesla, 2003). These three conceptualisations of dementia can be viewed in terms of ontological perspectives (see Figure 4.1).

Figure 4.1 The threat of dementia; alternative ontologies.
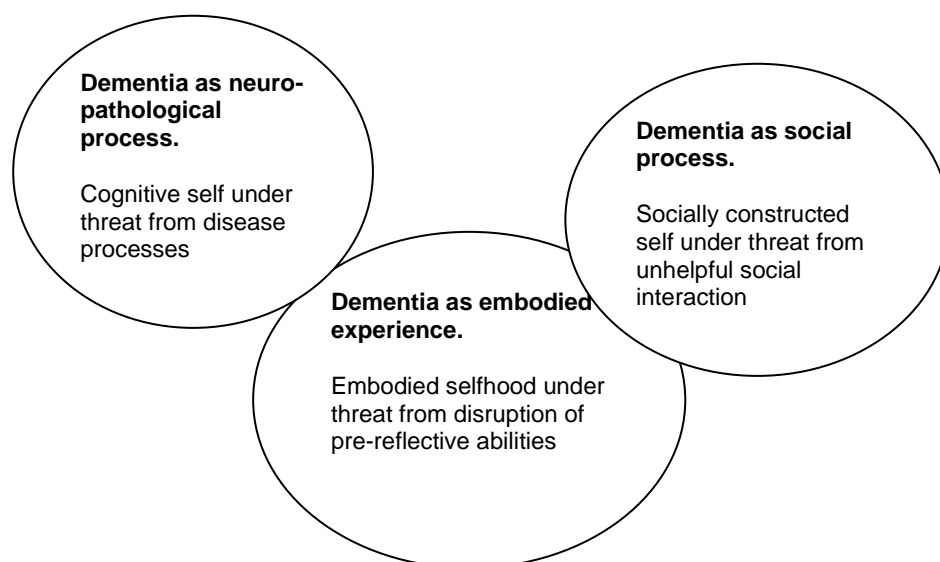
These three ontologies are not mutually exclusive; dementia is a multi-faceted phenomena. However, whilst I recognised the existence of dementia as a pathological process I had also become aware of the limitations associated with viewing dementia in this manner. Bearing this limitation in mind and acknowledging that the focus of my research questions was on lived experience, I decided to define dementia ontologically in two ways. Firstly as a social experience in which the individual's social self is under threat. Secondly as an embodied experience in which the individual's embodied selfhood is threatened.

My next ontological questions were addressed at physical activity, wellbeing and ethnicity and the manner in which the realities of these phenomena could be conceptualised. I noted that these phenomena all contained social and embodied elements and could therefore be conceptualised in terms of social and embodied ontologies. In order to encompass the complex and varied components of dementia, physical activity, wellbeing and ethnicity I therefore realised that I needed to adopt a broad ontological stance which took into account the socially constructed and embodied nature of the experiences that I was exploring. The ontological position that a researcher adopts is highly influential in terms of the rest of their methodology.

I will now discuss how the conclusions I described above were taken forward in order to develop my epistemological position and identify which methods were most suitable.

Epistemological choices; deciding what kind of knowledge to produce.

Epistemology is a field of philosophy associated with knowledge and what can be said about the world around us (Langdridge, 2007). Epistemology addresses questions about which type of evidence most effectively represents knowledge of the social world (Mason, 2002). Epistemological questions are concerned with the relationship between the researcher and knowledge they are attempting to produce (Guba, 1990). The researcher's ontological stance and research questions should suggest specific epistemological options (Mason, 2002). A researcher's epistemological position is grounded in their theory of knowledge and should acknowledge the principles and rules by which they consider social phenomena can be known and how evidence of social activity can be demonstrated (Mason, 2002). It may be appropriate to adopt a variety of complementary epistemological approaches within a methodological strategy. My task was to think about what epistemologies fitted coherently with my ontological definitions of dementia which defined the process as a social experience on the one hand and a highly individual embodied experience on the other. In the next section I will describe two epistemologies and explain why they are relevant to my ontological position, why they are compatible with each other and why they guided my choice of methods to generate and analyse my data.

Phenomenological epistemological positions

My recognition of two complementary ontological views of dementia suggested two epistemological positions. Firstly, a broadly phenomenological perspective which assumes that reality is highly subjective. I chose this because I wanted to explore the phenomenon of dementia in terms of subjective experience. Research adopting a phenomenological epistemological position explores the structures of consciousness in human experiences and the meaning that individuals attach to experience (Creswell, 1998). Knowledge is generated in order to find out how we experience the world as it appears to us rather than explaining the world. Because this epistemological approach is associated with the "feel" of a phenomenon, the type of

knowledge generated and considered useful is subjective. Whilst the focus is on capturing first person accounts of experience the role of the researcher in the generation and analysis of data is recognised (Langdridge, 2007). In relation to this research the phenomenological epistemology involves me co-constructing knowledge based on my participant's subjective experience of dementia.

Social constructionist epistemological positions

My second epistemological position was **"Contextual constructionist"** (Madill et al. 2000). Social constructionist epistemological positions assert that knowledge is constructed socially (Willig, 2008).This position suggests that there is no single reality that can be revealed through the use of the correct methodology. Instead, knowledge is local, provisional and situation dependent. A contextual constructionist position is associated with symbolic interactionism which suggests that people create their social world as they act within and towards it (Hewitt, 2002). Constructionist epistemologies acknowledge that both researcher and subject are conscious human beings who are sensitive to language and symbols and who are constantly interpreting and acting on the world around them within networks of cultural meaning (Madill et al. 2000). In the case of dementia, observable nuanced gesture, gestural communication; touching, social etiquette and speech are valid evidence of the way in which an individual with dementia is experiencing their life (Kontos, 2004). Various dementia studies have adopted this epistemology. For example, through the analysis of narrative discourse in autobiographies (Page and Keady, 2010) and when exploring aspects of embodied selfhood in the context of dementia (Kontos, 2004 and 2005; Kontos and Naglie, 2007). Adopting a social constructionist epistemology in the current study meant constructing knowledge that was shared socially with others; knowledge would be generated both with individuals and with groups.

Selecting methods for data generation

In this section I will describe how the choice of two methods was consistent with my theoretical framework. The term "method" can be defined as the procedures, strategies and techniques for the generation and analysis of data (Holloway, 2008, Mason, 2002). It was important for me to actively construct knowledge according to the principles associated with my epistemological position. I concluded that the best

way to explore what it was like for people with dementia to engage in physical activity was by watching it, doing it myself and talking to people about their experiences of doing it. In order to generate data I chose to adopt participant observation and semi-structured interviews. These methods are based on different ontological and epistemological foundations within a wider qualitative approach. Participant observation involves creating knowledge through interaction with others in a social environment and is therefore associated with a constructionist epistemology. Semi-structured interviews involve the co-construction of knowledge relating to subjective experience through dialogue and the method is therefore associated with phenomenological epistemologies. In the next section I will discuss these two methods in more detail and explain why they were well suited to my study.

Participant observation

Participant observation is one of several methods which involve the systematic, detailed observation of behaviour in natural settings (Mays and Pope, 1995). The method is associated with ethnography, a qualitative approach in which researchers explore the cultural dynamics of a defined social group by immersing themselves in the social environment (Mack, 2005). The use of naturalistic observation as a method in the social sciences was greatly influenced by Erving Goffman who used this approach from the 1950's until the early 1980's (Smith, 2006). Goffman recommended carefully scrutinising people's conduct in order to gain an understanding of the social processes that they are part of (Goffman, 1959). Participant observation is different from other observational methods because it involves the researcher becoming involved in the activities taking place while also observing them (Mays and Pope, 1995). The participant observer is generally open about their role and intentions as a researcher (Waddington, 2004). Data is usually recorded in the form of field notes that include the researcher's responses to what is taking place around them. Whilst video recording is widely used during observational research, I chose not to use this approach because I wanted to experience the activities myself and thought that handling a camera would limit my view and make participation difficult.

I chose to use participant observation because it has a number of strengths that suited my study. Participant observation enables the researcher to become familiar

with the cultural milieu of the setting (Mack, 2005). It allows the researcher to be unobtrusive and remain in the background from where social processes can be observed as they unfold (Bannister, 1994). Participant observation can reveal and overcome the discrepancies between what people say and what they do (Mack, 2005) and uncover behaviours of which participants are unaware (Mays and Pope, 1995). Because the method involves interacting with those around them in a social manner it can promote a trusting relationship between the researcher and participants (Waddington, 2004). There are several limitations to participant observation. Firstly, it is hard to document everything that is potentially important because the researcher relies on their senses and ability to memorise what they consider to be relevant to their research questions (Mack, 2005). It is therefore inevitable that some relevant detail will be missed. Secondly, the researcher may stimulate modifications in the behaviour of those around them (Mays and Pope, 1995). I decided that in order to minimise this by attending locations where I was performing my field work on a number of occasions and participating in activities as fully as possible. A further drawback is that gaining access to the social environment under investigation and becoming accepted within it can be time consuming (Mays and Pope, 1995). I considered this a price worth paying for my data.

Finally, it has been suggested that it may be difficult to maintain the balance between being an insider or an outsider. If the researcher becomes too much of an insider, they risk becoming so immersed in the process that the research agenda is forgotten (Mays and Pope, 1995). If they become too much of an outsider they risk being considered cold, detached and lacking in rapport by people in the field (Waddington, 2004). I considered that I was likely to present as both insider and outsider; I'm younger than those taking part in the study and I don't have dementia but I am likely to have other characteristics that are shared with some participants. I felt that the becoming so involved in activities that I would forget the research agenda was unlikely although I realised that presenting as cold and detached was possible and that this was therefore a further reason for me to participate as fully as possible. When writing about research which addresses ethnicity Gunaratnam (2003) points out that one should not assume that the findings are any more valid if the researcher is the same gender, ethnicity or class as participants. She comments that people

who are matched may face regional animosity, shared stigma and fear on the part of the participant that what they disclose may be shared within their community.

Semi-structured interviews

Interviewing is a core method of generating data in qualitative studies exploring physical activity (Biddle et al. 2001). Interviews can be defined in a broad sense as conversations that have structure and purpose (Kvale and Brinkmann, 2009), and which allow an in-depth exploration of the participant's view point (Rubin and Rubin, 2005). Performing an interview is an active process in which the researcher and participant produce knowledge together (Kvale and Brinkmann, 2009). Semi-structured interviews are conducted with loose structure consisting of open ended questions that define the area to be explored (Britten, 1995). I chose to use interviews because they can be useful in finding out participants' attitudes to physical activity and can help determine which aspects of a phenomenon are important to them (Rubin and Rubin, 2005). I would also be able to ask participants about the relationship they had with physical activity during the course of their lives. I was aware of the need to maintain flexibility because the participants in the current study were experiencing cognitive impairment and may have had difficulty in understanding my questions.

Inevitably there are disadvantages and limitations associated with this method. The process of transcription can be very time consuming (Britten, 1995). Generating meaningful data from interviews is dependent on the participant's ability to distinguish aspects of their own thoughts and ideas and effectively communicate these (Boeije, 2010). This can be problematic as people do not know everything about themselves, they may not want to share everything and they are not capable of putting everything into words (Boeije, 2010). There are further disadvantages associated with interviewing. It is hard to include non-verbal communication, body language, irony, tone of voice and intonation (Kvale and Brinkmann, 2009). These limitations are particularly pertinent for people with dementia who may have problems with recall and difficulty with verbal communication

Combining participant observation and semi-structured interviews to explore the experience of dementia and physical activity.

This section is concerned with the advantages of using two methods and the consideration that was undertaken to ensure that they were theoretically compatible. I decided that a combination of participant observation and semi-structured interviews would be the best way to explore my research questions. This decision was based on the following reasons. At a pragmatic level, participant observation would enable me to identify suitable participants for interviewing (Mack, 2005). I was aware also that people are more likely to be comfortable talking in an interview if they were familiar with the interviewer (Rubin and Rubin, 2005). Participant observation therefore provided an opportunity to develop a trusting relationship with participants I was hoping to interview.

At a methodological level, using more than one method enabled me to undertake methodological triangulation which involves checking the consistency of data generated by different methods (Patton, 1999). I would be able to see whether participants stated views regarding physical activity matched how they presented when performing it. Using participant observation immediately followed by interviewing can help to maximise the benefits from each method. For example, participant observation would enable me to identify aspects of social experience and processes that I could then explore with participants during interviews. Because I would be seeing the participant that I had interviewed again when I next undertook a participant observation session I could reflect on what they had told me as I watched them perform physical activity. I could also reflect on data generated using interviews and focus my attention on relevant aspects of the observed environment to see if what participants told me fitted with what I was seeing and experiencing myself (Mack, 2005).

Using two methods instead of one would therefore help me to create a more complete picture of a complex experience. Bannister (1994) points out that combining methods strengthens a study as all methods have different strengths and weaknesses and therefore support each other. In the case of my study, engaging in participant observations would enable me to communicate non-verbally with people

who may be struggling with speech. In contrast, by interviewing participants I could provide an opportunity for them to tell me what aspects of physical activity were important for them. Mason (2002) reminds the researcher of the need to justify the decision to use a variety of methods and recommends thinking through the implications of using data from different sources for the overall research design and for the strength of the argument the researcher intends to construct. I will now describe how I ensured that the two methods were complementary.

Ensuring integration between methods

According to Mason (2002), researchers who use a combination of different methods or approaches need to think about integration in several ways; technological integration, ontological integration, epistemological integration and integration at the level of explanation. I compared my two methods in order to assess their compatibility (see Table 4.1).

Technical integration

Firstly I considered whether the data produced was in a similar or complementary form. The units of analysis I would derive from participant observation were field notes relating to physical and social environment, observed behaviour of individuals and groups. Data derived from interviews would comprise transcribed speech reflecting individual perspective. I decided that whilst the two forms of data were different they were complementary as they were both produced through me as the research instrument. I also reflected on the fact that the content of both sets of data was somewhat blurred because field notes from participant observation contain transcribed statements made by individual participants and data derived from interviews contain reference to observed behaviour.

Table 4.1 Combining participant observation and semi-structured interviews (after Mason 2002).

Participant observation	Semi-structured interviews
Advantages of participant observation	**Advantages of semi-structured interviews**
I can experience physical activity myself whilst blending into the background (Bannister, 1994). I can observe what people do in a natural environment (Mays & Pope, 1995). Well-being café or day centre social milieu can be explored (Mack 2005). I can observe embodied aspects of experience and non-verbal communication can be observed. This is particularly important when participants are cognitively impaired (Kontos, 2004).	I can explore attitudes, meanings and the significance that participants attach to phenomena (Rubin & Rubin, 2005). I can gain historical and background information relating to the lives of participants.
Practical considerations	**Practical considerations**
Interacting with participants socially allows me to build rapport with them and identify candidates for interviewing.	It allows me to address questions generated during participant observation stage.
Limitations of method	**Limitations of method**
It is difficult capture it all in a meaningful way (Mack, 2005). Presence of researcher can influence behaviour of those observed (Mays & Pope, 1995)	People could say anything. People do not always do what they say they do (Maggs-Rapport, 2000). It can be difficult to include tone of voice, intonation and irony and to capture non-verbal communication (Kvale, 2009). People with dementia may have difficulty expressing themselves verbally (Boeije, 2010).
Ontological perspective	**Ontological perspective**
Dementia, well-being, ethnicity and physical activity are social experiences. Interactions, actions, behaviour and the way people interact and communicate are therefore central.	Dementia, well-being ethnicity and physical activity are highly individual, subjective and embodied experiences.
Epistemological perspective	**Epistemological perspective**
There are multiple perspectives (Mack, 2005). Knowledge is socially constructed in specific social contexts (Madill, 2000). Knowledge of the social world can be generated by observing and participating in "real Life" situations. Associated with intractionist perspectives. Phenomenological perspective; aspects of lived experience co-constructed with researcher in social environment. Participant observation is associated with purposive sampling	Knowledge is the result of an exploration of the meanings that participants attach to experience (Cresswell, 1998). Knowledge is co-constructed between researcher and participant. . Aspects of socially constructed experience can also be explored through discussion with participant. Semi-structured interviewing is associated with purposive sampling
Role of researcher	**Role of researcher**
The researcher is active, participant, reflexive, interpreting. The researcher is the research instrument (Mays and Pope, 1995).	Researcher is interpreter, participant. Co-constructor of data. Researcher is research instrument (Britten, 1995)
Units of analysis	**Units of analysis**
Descriptions of individual and group actions	Statements reflecting individual perspectives

Ontological integration

Clearly the two ontological perspectives were different. In order to address this question I investigated how other researchers had combined methods based on different ontologies. Paulson (2005) used observation and interviews thereby combining phenomenological and social construction ontologies in her study looking at the cultures of dance. Both Paulson and Kontos (2004) refer to the work of Bourdieu (1977) and his concept of "Habitus" which includes socially instilled dispositions which are also embodied in a phenomenological sense. Paulson (2005, p229) talks about her study combining phenomenological and social constructionist dimensions "…in which the subjective experience of the ageing body may become embedded in particular cultures of fitness". I concluded that there were many occasions when combining ontologies similar to mine had been successfully undertaken.

Epistemological integration

I considered whether the different forms of data emerged from the same epistemology or at least from complementary epistemologies. Maggs-Rapport (2000) points out that the ethnographic/social construction epistemological approach is similar to interpretative phenomenology in several ways. Both are exploratory, the researcher is the data collection instrument, reflexivity is very important and both look for meaning in the data. But there are also differences, the ethnographic/social construction approach deals with shared knowledge and meanings. In contrast, interpretative phenomenology tries to uncover meaning which is embedded in the data that reflects lived experience.

Integration at the level of explanation

Mason asks whether different data sources and methods usefully contribute to a coherent and convincing argument in relation to the researcher's intellectual puzzle. To address this I set out my research questions and noted how the two methods addressed different aspects of each question (see Table 4.2). I concluded that a combination of participant observation and semi-structured interviews produced distinct but complementary types of data that together would effectively address my research question. Because the data produced was different I realised that I would

have to be careful during the analysis phase that I interpreted the data in an appropriate manner.

Table 4.2 Integration in terms of explanation: answering the research questions.

Research Question	Data source and method	Justification
What facilitators influence engagement in physical activity?	Participant Observation Interview	I can observe and experience facilitators. I can ask about how participants perceive facilitators
What factors act as barriers and facilitators regarding engagement in physical activity?	Participant Observation Interview	I can observe and experience facilitators of physical activity. I can ask about what participants perceive as barriers.
How do older people with dementia from diverse ethnic backgrounds engage in physical activity?	Participant observation Interview	Allows me to witness how fully participants engage with the activities? (What participants do**).** Allows me to ask about other forms of physical activity and ask about their past relationship with physical activity (What participants say).
What benefits of physical activity do they identify?	Interview	I can ask how participants feel about the benefits of physical activity.
What role does ethnicity play in the experience of physical activity for older people with dementia?	Participant observation Interview	I can observe aspects how ethnic factors influence participants' experience. Awareness of researcher's own ethnic identity can be experienced. I can explore paticipants' views on ethnicity.

In the first half of this chapter I have described my choice of an interpretive paradigm, my adoption of qualitative approach and selection of research methods. These decisions were based on my research questions and my conceptualisation of dementia, well-being, physical activity and ethnicity. I recognised complementary ontological and epistemological perspectives which suggested the use of different methods of data generation. I considered whether these two approaches were compatible and concluded that they were not only are compatible but added strength to the study. I will now discuss the theoretical basis upon which I decided data from the participant observation and interviews would be interpreted.

Theoretical guidelines for the analysis and interpretation of qualitative data.

Van Manen's hermeneutic phenomenological approach.

As mentioned previously, the paradigm within which I chose to operate was interpretivist and this approach is associated with generating knowledge through induction (Bowling, 1997). The process of induction involves exploring phenomena by observation and then theorising about them through a process of interpretation (Parahoo, 2006). In this study the co-exiting phenomena under scrutiny are dementia, physical activity, well-being and ethnicity. Interpretation is needed because qualitative data does not represent lived experience exactly (Boeije, 2010). Instead, it has been co-constructed during an interaction between participant and researcher. I needed to decide how to interpret the textual data which would emerge from my two methods. Aspects of Van Manen's hermeneutic phenomenological approach to reflexion provided guidance on this process (Van Manen, 1990). Van Manen (1990) suggests a structure of human science research focusing on lived experience comprising six steps (see Table 4.3) of which stages three to six were of particular value to me. Van Manen advocates hermeneutic phenomenological reflection based on thematic analysis. He does not specify how data is managed in the process of thematic analysis. He writes that his description of methodology and features of human research should enable the reader to select or invent research methods appropriate for their own research questions. I therefore had to decide how best to perform thematic analysis.

Table 4.3 Van Manen's Methodical Structure of Human Science Research (Van Manen, 1990)

1. Turning to a phenomenon which seriously interests us and commits us to the world. Setting out to make sense of a certain aspect of human existence.
2. Investigating experience as we live it rather than as we conceptualise it. Looking at the world by re-awakening the basic experience of the world. The researcher stands in the fullness of life and actively explores the category of lived experience in all its modalities and aspects.
3. Reflecting on the essential themes which characterise the phenomenon. Reflective grasping of what it is that renders this or that particular experience its special significance.
4. Describing the phenomenon through the act of writing and re-writing. To do research in a phenomenological sense is always a bringing to speech of something through the act of writing.
5. Maintaining a strong and oriented pedagogical relation to the phenomenon. Researcher must remain strongly oriented to the fundamental question and avoid becoming side tracked
6. Balancing the research context by considering parts and whole. The researcher must not lose sight of the entirety of the question being addressed.

Thematic analysis

Thematic analysis is a method of making sense of qualitative data in which the researcher identifies themes and patterns within it (Holloway, 1997). It involves analysing data according to commonalities, relationships and differences which exist across the accumulated transcripts and field notes (Gibson and Brown, 2009). The aim of thematic analysis is to present key elements of the data (Green and Thorogood, 2009). This approach is associated with phenomenological epistemologies but is widely applied by qualitative researchers. Green and Thorogood (2009) list the processes that researchers undertake in order to complete thematic analysis. Firstly, the transcripts and field notes relating to different cases or field notes generated on different occasions are thoroughly read and segments of meaning identified. These segments are formed by sentences or paragraphs that appear to contain specific meaning. Secondly, data from different cases are compared and meaning segments that recur are identified as themes. Thirdly, an indexing system is devised in which the themes are listed and given a specific code. Some of the codes contained in the indexing system may reflect specific research

questions. In the fourth stage, the data is labelled according to the indexing system. Labelling the data allows a copy of it to be cut up either physically or electronically and reconstituted according to themes. Researchers can then move backwards and forwards between the whole text and the thematic categories in order to generate new understanding. Researchers can reflect on the content of their themes with reference to pre-existing theoretical and empirical knowledge. In the case of my study I referred to symbolic interactionism and embodiment theories and concepts of well-being that I discussed in previous chapters. I will describe how I undertook thematic analysis later on in the chapter. When I considered how to interpret the data as part of the thematic analysis I turned to Van Manen's hermeneutic phenomenological reflective approach. I decided that Van Manen's suggested methods of isolating themes and reflecting on a text could help me interpret my data I will now describe elements of this approach.

Van Manen's hermeneutic phenomenological reflexion

In stage three of his methodological structure, Van Manen suggests distinguishing between essential and incidental themes. Essential themes are considered unique to the phenomenon being studied. This is done by free imaginative variation during which the researcher considers whether the phenomenon would be the same without the presence of the theme. Van Manen also advocates reflecting on "lifeworld existentials" which together pervade the lifeworld of all human beings. These consist of lived space (spatiality), lived body (corporeality), lived time (temporeality) and lived human relation (relationality). The hermeneutic process of interpretation suggested by Van Manen is circular and owes much to Gadamer (1997). Van Manen's approach attracted me for several other reasons. The flexibility of his method was suitable for a study which combines epistemological and ontological positions. For example, Van Manen (1990) recognises that participant observation is a valid approach for exploring participants' lived experience. There is no attempt at "bracketing", instead the concept of surrendering to the text is advocated. This fitted with my recognition that knowledge is constructed in a social environment where context is important. However, because of the inherent differences between data generated through participant observation and interview I realised that I needed to try and recognise the specific contexts in which they were created. In the following sections I will describe the manner in which the study was undertaken.

The issues of ethical recruitment and consent

Ethical considerations are important in research because those conducting it are required to adhere to the principles set out in the Declaration of Helsinki (World Medical Association, 2008) which stipulate that the dignity and well-being of participants takes precedence in studies. Actively protecting the interests of participants is particularly crucial during research including people with dementia. This is because individuals with impaired cognition may have difficulty both in making informed decisions and communicating their wishes. These factors place them at risk of exploitation.

It is recognised that two major challenges to involving people with dementia in research in an ethical manner are recruitment and the obtaining of meaningful consent (McKeown et al. 2010). In this section I will describe how I set out to meet these challenges in my own project. I will begin by introducing the Mental Capacity Act (MCA, 2005). I will discuss how it guides research with vulnerable groups and describe how I referred to it when considering my study design. I will describe how by referring to the MCA (2005) I recognised the need for capacity assessments and acknowledged the role of carers in decision making. I will then point out the limitations of cognitive based assessments of capacity and consent from carers. I will explain how potential participants with dementia who may lack capacity can be supported to actively participate in decision making through the use of the process consent model developed by Dewing (2007). Finally, I will discuss why in my study I planned a combined approach which followed the guidance of the MCA (2005) and included process consent.

The Mental Capacity Act (2005)

The MCA (2005) provides a statutory framework for the empowerment and protection of vulnerable people who may lack the capacity to make specific decisions and as such provides a guide for researchers working in the field of dementia. According to the MCA (2005), an individual is deemed to possess the capacity to make a particular decision if they demonstrate the following four characteristics. Firstly, that they understand the information provided which is relevant to the decision in question. Secondly, that they retain this information long enough to

enable them to make a decision. Thirdly, that they use this information as part of the decision making process. Finally, that they are able to communicate this decision.

When adhering to the MCA (2005) as a guide to the recruitment of research participants, a central element is the completion of capacity assessments by the individual conducting the study. The act specifies a two stage test of capacity which involves the assessor posing two questions. Firstly, is there a temporary or permanent impairment of or disturbance of the person's mind? Secondly, if so is the impairment or disturbance sufficient that the person lacks the capacity to decide whether or not they want to be included. Whilst a lack of capacity to give informed consent does not necessarily mean that an individual must be excluded from a research study, the design of any project including such individuals must satisfy certain conditions in order to gain ethical approval. Section 31 of the MCA (2005) states that there need to be grounds for believing that research of comparable effectiveness cannot be carried out if it only includes participants who have the capacity to consent and if the research has the potential to benefit the participant without imposing a burden on them. Additional safeguards are listed in section 33 of the MCA (2005) which relate to research participants who lack capacity. For example, the Act states that the interests of the participant outweigh those of the project or wider society. Similarly, if the participant appears to object to aspects of the project or expresses a wish to withdraw from study they must be allowed to do so without delay.

Clearly consent is required in order for someone to be included in a research study. If a potential participant is assessed as lacking in capacity, section 32 of the MCA (2005) states that the researcher must identify a person who is engaged in caring for the individual or is interested in their welfare to act as consultee and provide proxy consent on their behalf. The Act stipulates that reasonable steps should be taken to ensure that this person is not someone acting in a professional or paid capacity. If unable to find someone who meets these criteria the researcher must nominate someone who has no connection with the project. The MCA (2005) states that recorded information relating to consent should contain details of those involved in the decision process and the rationale behind the decision including such factors as previously held beliefs and values.

The Mental Capacity Act and my study design

The MCA (2005) was an important influence on the design of my study protocol (see Appendix 1). In order to meet the requirements for approval contained in section 31 of the Act, I set out to minimise the burden on participants whilst providing benefit for them. Admittedly this benefit would be indirect, in the form of improved knowledge of the experience of physical activity for people with dementia. To minimise the burden on participants I ensured that involvement in the project would involve minimal risk (see Appendix 2). The study was designed to avoid interfering with participant's freedom of action by focusing on pre-existing activities and making every attempt not to disrupt these. For instance, I planned to undertake interviews at the end of the session when activities had finished. Privacy would be protected through the use of pseudonyms for both participants and fieldwork locations and any data relating to participants stored in a secure environment.

In order to act in the best interests of participants I discussed the terminology I would use during the project with other researchers and workers in the field of dementia studies. When discussing my project with a researcher from a local university based dementia research team I was advised to avoid using the term "dementia" on first encountering potential participants. This was because individuals may be struggling to come to terms with their diagnosis or may not have received a diagnosis at all. I decided to use the term "memory loss" in the information sheets and during conversations unless participants were clearly comfortable with discussing dementia. I also realised that acting in the best interests of participants implied that their well-being should be prioritised at all times and that they must be withdrawn from the project immediately if they appeared to express a wish to do so.

I recognised that I was responsible for completing capacity assessments and recording them. I decided that with limited knowledge of potential participants I would be reliant on carers to assist me in completing capacity assessments and if necessary provide proxy consent if they chose to do so. In view of the MCA I would attempt to avoid seeking assistance for proxy consent from paid carers whenever practically possible. The MCA (2005) states that decisions which are made on behalf of people who lack capacity should be in their best interests. To ensure this I planned to seek the assistance of the staff and carers who were most familiar with

the potential participant and therefore best qualified to assist in assessing capacity and deciding whether consent for participation should be given.

Limitations of cognitively based capacity assessments and proxy consent.

Whilst I was aware that the MCA (2005) provides robust guidance on the ethical design and conduct of research I also knew that there had been considerable discussion in the literature about how to enable people with dementia to become actively involved in issues such as consent in a meaningful way (Hubbard et al. 2003; Dewing, 2007; Goodman et al. 2011; McKeown et al 2009). Research designs focusing on assessing cognitive based capacity and the use of proxy consent at the beginning of research projects have been criticised in the literature on several counts. Firstly, this approach can lead to people with dementia being excluded unnecessarily from decision making (Dewing, 2007). Secondly, it is argued that people with dementia may experience ill-effects from being considered for studies that require capacity to consent to be established (Sabat, 2005). Sabat discusses how the process of testing a person's capacity can result in them being labelled as incompetent and have an adverse effect on their self-esteem. Thirdly, it has been pointed out that an emphasis on formally assessing capacity and seeking proxy consent at the beginning of a project does not reflect the fluctuating nature of the dementia experience during which an individual's capacity to make decisions may vary (Dewing, 2007). On this basis, Goodman et al. (2011) state that there is a need to tailor consent processes to the individual and consider seeking consent to be a process that should be undertaken throughout the duration of research studies. Finally, the use of proxy consent from a carer or relative on the basis that they knew the potential participant before they developed dementia has been criticised. This is because evidence suggests that carers of people with dementia are often surprised by choices made by the person in question regarding their everyday lives (McKeown, 2010). These factors indicated to me that I should attempt to involve potential participants who lacked capacity in as many aspects of decision making as possible.

Process consent

The issue of how to support people who may lack capacity in making the decision to participate in my study led me to the process consent model described by Dewing

(2007). This provides an alternative to proxy consent by placing the person with dementia at the centre of the decision making process instead of the carer. Process consent is intended for people who lack the capacity to make informed decisions as defined by the MCA (2005) but who are able to communicate their wishes. The model recognises that consent communicated through behaviour and other non-verbal means is equally as valid as the expressed wishes of relatives or carers. Whilst Dewing describes the method as a pathway that consists of five elements, she states that the elements do not have to form a linear progression (see Table 4.4). At the core of this approach is the concept that the researcher should be continually asking themselves whether or not the participant is consenting to their involvement.

Table 4.4 The process consent method (based on Dewing, 2007)

Element 1. Background and preparation.   Gaining permission to approach person from staff or carers. This means consent for access before thinking about consent for the study. Finding out about the person's biography. How does the person present themselves when in a state of well-being?
Element 2. Establishing basis for consent.   During this stage the researcher is primarily establishing the basis for capacity for consent and how this has been achieved. Things to consider include, the person's usual self presentation, the person's usual level of ill or well-being. How a reduction in well-being can be triggered. How a decrease in well-being can be recognised. What behaviour/conversation may indicate psychotherapeutic need? How does this person usually consent to activities?
Element 3. Initial Consent.   At this point the researcher should feel confident to seek initial consent i.e. situation specific consent. The exact method will vary according to the individual and may involve showing them props such as recording equipment. Researchers should record how consent was given.
Element 4. Ongoing consent monitoring.   Here the focus is on ensuring that the initial consent is revisited and re-established at every occasion. This highlights the concept of consent representing a process. It is important to remember that consent is both transitory and situational. One way to increase robustness of process is to ask someone else to sit in and act as a validator. It is also important to make a note of the participant's well-being state at the end of every encounter.
Element 5. Feedback and support.   It may be necessary to feedback to carers or relatives. But this needs to be considered carefully due to issues of confidentiality. Discussion with other members of the research team is important.

Dewing (2007) acknowledges that using this model still entails asking permission from carers before approaching potential participants with dementia. However, she points out that this permission is for access rather than proxy consent. Dewing also

comments that gaining permission for access from carers enables them to be involved in the process and this enhances transparency. There are clearly limits to the process consent model. Once an individual's level of cognitive impairment reaches an advanced stage they are unable to participate meaningfully in decision making. However, Dewing comments that when this is the case the researcher always has the option of including or excluding people based on proxy consent. McKeown et al. (2010) states that it is quite possible to follow MCA (2005) guidelines regarding the assessment of capacity and the use of proxy consent and employ process consent as well. In fact, one of the principles of the MCA (2005) states that all practical steps should be taken to support people in making decisions before it is concluded that they are unable to do so. When designing my research protocol I followed the guidance of the MCA (2005) by including capacity assessments of all potential participants. If capacity was not apparent I would attempt to use Dewing's process consent method before seeking proxy consent.

Study settings and type of physical activity

The study was located in a post-industrial city in the North of England with a population of approximately 500,000. The city is home to a highly diverse population. Large numbers of people from Eastern Europe (particularly Poland and the Ukraine) migrated there following the Second World War. The city experienced a large influx of people from South Asia and particularly Pakistan in the 1950s onwards. The census of 2011 showed that 20% of the district population identified their ethnicity as Pakistani (Bradford Met Council, 2013).

Characteristics of well-being cafés

Networking through my contacts in mental health services led to me to identify a number of potential fieldwork locations where people with dementia performed physical activity. These consisted of four well-being cafés and four day centres. I also spent an afternoon walking with a participant and his family in a local park (see Table 4.5). The well-being cafés were community based interventions which took place once or twice monthly and which had been created to promote the mental health of older people. In total the well-being café network comprised 17 separate cafés that met in a variety of settings such as church halls and community centres.

Well-being cafés were run by several different organisations and were co-ordinated by a Community Involvement Project, a partnership between a local NHS Trust and the local authority. The well-being cafés were staffed mostly by volunteers. They provided social support and information and offered activities for older people. Cafés generally attracted between 20 and 30 older people to each meeting and most individuals attended with a carer, usually their spouse. Several of the well-being cafés targeted particular ethnic minority groups. I decided that two of these would be valuable field work locations for the study; St Cuthbert's Well-being Café which served the local African/Caribbean communities and the Smithson Well-being Café which was attended primarily by older people with Eastern European backgrounds.

Table 4.5 Field work locations, type of physical activity and ethnicity.

Fieldwork location	Characteristics of well-being cafés/day Centres.	Type of physical activity	Ethnicity
1. Stanford Well-being Café.	Monthly Well-being café. Most attendees have dementia.	Dance	White/British
2. Browgate Well-being Café.	Twice monthly Well-being café run by Alzheimer's Society. Dementia specific.	Dance	White/British
3. Smithson Well-being Café.	Monthly Well-being café. Attendee clearly identified as living with dementia.	Dance	Eastern European
4. Women's Action Partnership.	Day Centre providing exercise for older women. Two attendees self-identified as having memory loss.	Exercise group	Asian British/ Pakistani
5. Chellowfont Day Centre.	NHS/local authority day centre. Dementia specific day centre	Exercise group	Asian/British & White/British
6. Park's Day Centre	Local authority day centre. Dementia specific day centre.	Walking	White/British & Caribbean/Black British
7. High Grange Day Centre.	Local authority day centre. Four attendees identified as having dementia diagnosis.	Exercise group	Multi-ethnic
8. The homes of Simon and his family		Walking with family members.	White/British

Characteristics of day centres

In addition to the well-being cafés I undertook field work at four day centres. One of the day centres, the Women's Action Partnership (WAP) was an independent lottery funded community project. WAP was run specifically by and for women from local South Asian communities. A variety of activities and events took place at this centre. During my visits women attended for a couple of hours specifically to join the exercise group. The other three day centres were run by a combination of NHS and local authority staff. Two of these, Chellowfont Day Centre and the Parks Centre offered services specifically for people with dementia and included older people from a variety of ethnic backgrounds. The fourth centre, High Grange Day Centre provided services for older adults with and without dementia and included older people from varied ethnic backgrounds. Typically, people receiving services from these three centres would arrive in the morning and spend the day engaged in various activities. The day centres differed from the well-being cafés in the fact that they were staffed by paid employees.

Physical activity at the well-being cafés and day centres

Physical activity at the well-being cafés consisted mostly of dance. People attending were encouraged by volunteers to dance accompanied by professional entertainers who sang pop songs from the 1950s, 1960s and 1970s along to backing tracks. Sometimes musical instruments such as castanets and tambourines were distributed and people were encouraged to play along to the music. Physical activity in the day centres usually involved exercise sessions led by a member of staff or performed along to a tape or DVD. Sometimes props such as parachutes, balls and bowling games were used at the day centres.

Fieldwork

In this section I will describe how I gained access to the locations where I conducted my fieldwork (see Table 4.5). I will also discuss the process by which I recruited my study participants (see Table 4.6). I will then detail how I undertook participant observation and interviews.

Permissions and access to fieldwork locations

My first task was to gain ethical approval and permission to undertake the project. I gained ethical approval from the School Research Ethics Panel (SREP) at the University of Huddersfield (see Appendix 3) and the National Research Ethics Service (NRES). My NRES reference code was 10/H1202/14 (see Appendix 4). I then sought approval to carry out the research in the NHS from the Research and Development department of the trust where I was employed (see Appendix 5). This was because the NHS employed some members of staff at the day centres where I planned to conduct my research. I also gained written permission to access the well-being cafés from the manager responsible for the well-being café network (see Appendix 6). I gained an additional level of permission in the form of written consent from the Alzheimer's Society and a South Asian community group to access the South Asian and Browgate Well-being Cafés which provided services exclusively for people with dementia and their carers (see Appendix 7 and Appendix 8). Once my approvals and permissions were in place I discussed the details of my project with the managers responsible for running each of the well-being cafés and arranged to start my fieldwork.

Participant observation stage recruitment at the well-being cafés.

I began my fieldwork at the Stanford and Browgate Well-being Cafés. On my first visit to these locations I talked to staff about the nature of my research before the arrival of potential participants. We discussed the characteristics of those attending the well-being cafés and agreed how I would recruit individuals with dementia and their carers. I was told that the majority of individuals attending the Stanford Well-being Café and virtually all those visiting Browgate Well-being Café either had significant cognitive impairment or were carers. During these discussions staff suggested individuals who may have been interested in the study. As couples arrived at the well-being cafés I explained the reason for my presence to each of them in turn. I briefly described my study and distributed invitation letters (see Appendix 9) and information leaflets (see Appendix 10).

As I talked to individuals and carers I made an initial judgement of their level of interest in participating in the study. If I judged them to be receptive to discussing the study further I assessed their capacity to give informed consent as set out by the

MCA (2005) (see page 112). I assessed whether they had the capacity to understand the information that I conveyed regarding the project, whether they retained this information and whether they were able to use it to form a decision that they could then communicate. As a clinician working with people who have dementia I have considerable experience of judging capacity and seeking consent for interventions. If potential participants expressed interest and had the capacity to make an informed decision about joining my project, I invited them to give written consent for me to include them in the participant observation stage (see Appendix 11). Participants and carers were told that they could withdraw at any time. I also gained written consent from carers to participate in the project. I stored completed consent forms separately from study data in a locked drawer within a secure office.

Difficulties in applying the process consent model for inclusion in participant observation

I quickly realised that I would face difficulties both in attempting to gain consent from everyone present at the well-being cafés for inclusion in participant observation and undertaking process consent as planned in the protocol (see Appendix 1). This was an important methodological development that was due to a number of factors. Firstly, people that I approached appeared to find the information sheets and consent forms daunting and difficult to understand. This made the process of informing people about the study, assessing their capacity and then gaining consent more time consuming than expected. The large numbers of people attending the cafés compounded this difficulty and meant that I was unable to spend the necessary time with all present to establish the basis of process consent. Secondly, the social settings were more chaotic than I had expected. Couples continued to arrive throughout the duration of the café session by which time the physical activities had begun and I had started engaging in my participant observation. Thirdly, I reflected that the bureaucratic nature of the process I was attempting in which I distributed forms to everyone felt out of keeping with the informal ambience of the café. In fact, at the Stanford Well-being Café the manager asked me to avoid over-facing those attending with paperwork because she was concerned it would put them off attending. Difficulties in recruiting participants for studies according to plan is recognised in the literature. Goodman et al. (2011) describe recruiting people with

dementia from a number of care homes and note that this process is shaped by the individual cultures of the settings and the attitudes of care staff towards research.

I decided to avoid disrupting activities by restricting the numbers of people I approached to those I judged to be most interested in becoming involved through social contact and following discussions with staff. I also realised that I would have to alter the way in which I gained consent and rely more on carers for proxy consent whilst still recognising the principles of process consent. Therefore when potential participants were identified who lacked capacity, proxy consent was obtained from the carer and noted on the consent form. In all but one case at the well-being cafés, proxy consent was provided by the participant's spouse. I adhered to the principles of process consent by getting to know participants and how they normally presented whenever possible, involving them in all discussions and reminding them of my study on every visit.

At the Stanford Well-being Café I recruited three individuals with dementia and their carers, a carer who attended alone and the co-ordinator of the café network. At the Browgate Well-being Café I recruited two people with dementia and their carers. I also gained consent from one of these couples for me to accompany Simon, who had dementia, on walking in the community. The Smithson Well-being Café which was attended by a large number of people with eastern European backgrounds was the third location that I accessed. I discussed my project with those responsible for running it as I had at previous locations. It was apparent that compared to the well-being cafés I had already visited, there was a lower proportion of people attending with cognitive impairment. Rather than approach individuals I spoke to the group as a whole about my interest in physical activity. Together with staff I identified a suitable individual with dementia who I later assigned the pseudonym Bercik. Following discrete discussions involving Bercik, his daughter and an experienced staff member I assessed him as lacking in capacity and gained proxy consent from his daughter. I recruited 27 participants for participant observation, nineteen of whom had dementia. Consented participants are listed in Table 4.6.

Difficulties at two of the well-being cafés and the identification of day centres as additional fieldwork sites.

I experienced problems at two other well-being cafés for which I had gained permission to access. When I attended the South Asian Well-being Café I discovered that contrary to my expectations, physical activity was not undertaken and so decided that it was pointless to continue visiting there. In contrast, although the St Cuthberts Well-being Café which targeted African-Caribbean communities had a well-established exercise group, I found identifying suitable potential participants very difficult. The staff I consulted were unclear about the levels of cognitive impairment of those attending. They advised me that people within these communities rarely discussed their health at the café. It was suggested that there were high levels of stigma associated with mental health difficulties in African-Caribbean culture. I realised that my efforts to recruit potential participants could be viewed as intrusive and I therefore decided not to continue attending the St Cuthberts Well-being Café. Instead I considered finding other locations outside the well-being café network which included people experiencing dementia from ethnic minority communities.

I was aware that people with dementia from a variety of ethnic backgrounds attended local day centres at which physical activity was promoted and this led me to seek permission to undertake my research in four such locations. I was granted permission from a senior manager (see Appendix 12) to attend two local authority day centres (High Grange Day Centre and the Parks Centre). The day centre manager provided permission to access Chellowfont Day Centre, a combined local authority/NHS establishment (see Appendix 13). Finally, a manager provided permission for access to a women's centre (Women's Action Zone) (see Appendix 14). I informed both the university and the LREC that I intended to extend the project outside the Well-being café network and received approval from both bodies (see Appendix 15 and Appendix 16). My final fieldwork locations are listed in Table 4.6.

Participant observation stage recruitment at day centres.

At High Grange Day Centre and the Parks Centre I worked alongside staff to identify suitable study participants. At High Grange Day Centre, where I was informed only a minority of those present had dementia; I did not seek consent for participant

observation. Instead I used my permission to attend the group in order to experience the nature of the physical activity session myself and gain the trust of two individuals who I had been advised had cognitive difficulties and from whom I hoped to gain consent for interviews. At the Parks Centre I became aware of an individual who enjoyed physical activity and to whom I later assigned the pseudonym Jacinta. I approached Jacinta together with a staff member and after assessing her as having capacity and interest in the project, I gained written consent from her to join her when walking in the environment adjacent to the day centre with a staff member.

The third day centre I gained permission to access was Chellowfont Day Centre. Here I met individuals with dementia attending the centre and discussed the issue of capacity with an experienced senior staff member. After chatting informally with the twelve members of the group over the course of a morning it was clear that none of the group had the capacity to make an informed decision about participating in my study. After further discussion, the centre manager provided proxy consent for these individuals to be included in participant observation. My final fieldwork location was Women's Action Partnership (WAP). Here I gained permission to attend an exercise group for South Asian women. On my first visit I spoke to the whole group about my project. The member of staff responsible for leading the exercise at WAP gave me written consent to include her in participant observation. I used the participant observation at this centre to gain the trust of those attending and identify potential participants for the interview stage.

Table 4.6 Capacity and consent details of study participants

Fieldwork locations	Participant observation participants (individuals with dementia in bold)	Interview participants
1. Stanford Well-being café. Nine sessions of participant observation.	**Mary** (capacity) Hugh (Mary's husband). **Megan** (Lacked capacity. Proxy consent via husband) Philip (Megan's husband) **Marcus** (capacity) Belinda (Marcus' wife) Paul (carer). Marjorie (Well- being Café manager)	**Mary** (capacity)
2. Browgate Well-being café. Eight sessions of participant observation.	**Esther** (Lacked capacity. Proxy consent via husband) Benedek (Esther's husband). **Simon** (Lacked capacity. Proxy consent via wife) Doris (Simon's wife)	**Simon** (lacked capacity. Proxy consent via wife). **Olive** (capacity). **Jack** (capacity). **Cynthia** (capacity) **Barbara** (capacity)
3. Smithson Well-being café. Two sessions of participant observation	**Bercik** (Lacked capacity. Proxy consent via staff & daughter).	**Bercik** (Lacked capacity. Proxy consent via daughter)
4.Womens Action Partnership Three sessions of participant observation	Maya (Staff member)	**Fameeda** (capacity). **Najma** (capacity).
5. Chellowfont Day Centre Seven sessions of participant observation	**Ahmed**, **Martha**, **Fiaz**, **Mrs Begum**, **Ronald**, **Noreen**, **Jane**, **Gladys**, **Joe**, **Penny**, **Derek**, **Rose** (All lacking in capacity. Proxy consent via centre manager)	**Ahmed** (Lacked capacity. Proxy consent via manager)
6. The Parks Centre Two sessions of participant observation	**Jacinta** (capacity)	**Jacinta** (capacity)
7. High Grange Day Centre Six sessions of participant observation		**Stella** (capacity) **Alveta** (capacity)
8. The homes of Simon and family One session of participant observation	**Simon** (Lacked capacity. Proxy consent via wife) Doris (Simon's wife)	

As part of the recruitment process at all locations I attempted to verify study participants' diagnosis of dementia through discrete discussions with carers and senior staff. Although I had sought an amendment from LREC in order to access medical records (see Appendix 17) I decided not to do so. This decision was made on the grounds that to do so would be both intrusive and unnecessary as my initial approach had provided me with sufficient information.

Conducting participant observation

When performing participant observation I joined in with activities and mixed socially with participants and staff. I tried to be as open as possible about my study whilst avoiding any discussion about my physiotherapy background. Because consent is situational and on-going, consent monitoring took the form of participants at cafés and day centres being reminded at every visit about the research project and their verbal consent being re-established. After my field work visits I wrote up my field notes as soon as possible. These included my own responses to participating in the activities. I avoided referring to unconsented individuals when writing up these field notes.

Two episodes of participant observation involved accompanying consented individuals as they walked outdoors with carers or family members. This approach is similar to the participatory method described as "walking interviews" by Emmel and Clark (2009) to explore how everyday life is embedded in place. Emmel and Clark invited participants in their study to lead the researchers on a walk and be interviewed by them as they did so. During these interviews, participants were asked about the meanings that they attached to the locations they passed through. In my study however, instead of questioning my participants I shared the experience of walking and observed their responses to the activity.

Interview stage recruitment

The participant observation phase provided opportunities for me to identify individuals experiencing cognitive difficulties who would nevertheless be able to discuss their experiences in an interview setting. Participants were considered for an interview if they had attended a well-being café or day centre on at least four occasions, as verified by carers and staff and had either received a diagnosis of dementia and/or considered themselves to have dementia. In addition to the above inclusion criteria I selected potential interview participants on the basis of their ethnicity and the likelihood that they would provide valuable information about their experiences of dementia and physical activity. This approach is known as purposive sampling (Higginbottom, 2005). The rationale behind purposive sampling is not to generalise findings from the participant group to the wider population but to indicate common links or categories (Mays and Pope, 1995).

At the well-being cafés I approached individuals who I believed to have dementia, with whom I had developed a rapport and who I considered likely to be interested in being interviewed. This took place in the presence of their carer. During informal discussion I provided verbal and written information to help them understand the rationale behind my project (see Appendix 18). I encouraged potential participants and their carers to ask questions and told them that they could withdraw from the study at any time. During these conversations I made an assessment of their capacity based on their ability to process the information I provided and my professional judgment. Potential participants who were interested in taking part and who I had assessed to have capacity were invited to sign a consent form (see Appendix 19). I recruited five interview participants in this manner. Simon and Bercik however, were two potential participants who appeared interested in taking part but were assessed to lack capacity. Nevertheless, it was clear during discussions with them and their carers that being interviewed was unproblematic and therefore proxy consent was obtained from carers.

At the day centres I discussed potential participants with staff who advised me which of the individuals present would be receptive to discussing my project. I then approached these individuals in order to introduce my study and assess their capacity. I recruited four participants from the day centres who expressed interest in being interviewed and had been assessed as having the capacity to provide informed consent. I interviewed one individual at Chellowfont Day Centre who lacked capacity. I had approached Ahmed because we had developed a rapport during my visits, he engaged fully in the physical activity sessions, and I was seeking an ethnically diverse participant group. After I assessed Ahmed as lacking in capacity to provide informed consent, the centre manager provided consent on his behalf. However, in order to involve him as much as possible in the decision to take part and ensure his well-being during the interview, I spent time with staff establishing which verbal and non-verbal signals he used when communicating choices and familiarised him with the recording device.

I gained consent to interview a total of 13 people (see Table 4.7). Members of my interview group were aged 50 to 88 and included nine women and four men. I asked them to identify their ethnicity using to the options devised by the Office for National

Statistics for use in the census (ONS, 2009) (see Appendix 20). Interview participants identified their ethnicity as follows; seven were White/British, two were Asian British/Pakistanis, two identified as Black British/Caribbean, one was Polish and one Asian British/Indian. I was able to confirm the presence of a dementia diagnosis for 11 participants. The two Asian British/Pakistani women, Fameeda and Najma, were included because they reported experiencing memory loss.

Conducting Semi-structured interviews

Interviews were performed immediately after the activities at the day centre or well-being café ended. This was done in order to avoid disrupting the activities and to enable me to talk to participants about events that we had both taken part in the previous few minutes. Interviews took place in side rooms away from the activities of the day centre or café. Carers sometimes joined us in order to reassure the participant but in all but one case they left after several minutes. I prepared a list of open ended questions that were designed to address the research questions in order to keep "on track" (see Appendix 21). Each interview lasted approximately ten minutes. I used the principles of process consent to monitor how people reacted to being interviewed, applying my knowledge of how they were when in a state of well-being. When I noticed Ahmed's difficulties with communication and social discomfort as we began his interview I curtailed it as I considered that he had withdrawn consent. At the end of each interview I invited the carer back into the interview room or reported back to centre staff. This allowed me to give feedback regarding the process thus maximising transparency and ensuring that participants were comfortable with what had just taken place. I recorded the contents of the interviews on a digital recorder and transcribed the interview data during the evening of same day adding notes about how the interaction felt from my perspective.

Table 4.7 Interview participant characteristics

Psuedonym	Location	Physical activity	M/F	Age	Dementia diagnosis	Ethnicity
Mary	Stanford Well-being Café	Dance	F	76	Yes	White British
Stella	High Grange Day Centre	Group exercise	F	75	Yes	White British
Alveta	High Grange Day Centre	Group exercise	F	81	Yes	Black British/ Caribbean
Simon	Browgate Well-being Café	Dance and walking	M	73	Yes	White British
Olive	Browgate Well-being Café	Dance	F	74	Yes	White British
Jack	Browgate Well-being Café	Dance	M	80	Yes	White British
Cynthia	Browgate Well-being Café	Dance	F	72	Yes	White British
Barbara	Browgate Well-being Café	Dance	F	75	Yes	White British
Jacinta	The Parks Centre	Walking	F	60	Yes	Black British/ Caribbean
Bercik	Smithson Well-being Café	Dance	M	87	Yes	Polish
Ahmed	Chellowfont Day Centre	Group exercise	M	79	Yes	Asian British/ Indian
Fameeda	Womens Action Partnership	Group exercise	F	53	Self-identified	Asian British/ Pakistani
Najma	Women's Action Partnership	Group exercise	F	50	Self-identified	Asian British/ Pakistani

Data analysis

Preparing the data for analysis

Qualitative data analysis consists of two closely related processes; managing the data and making sense of it (Ritchie et al. 2003). For me, the process of analysis and interpretation had actually begun before data generation was completed. Reviewing the data during the fieldwork stage had enabled me to refine the questions that I

asked during interviews and sensitised me to events unfolding around me when performing participant observation. Kvale and Brinkmann (2009) suggest that transcription of interview data is an interpretive rather than a clerical task. This is because oral speech is different to written speech and there will inevitably be interpretation as it is translated into written form.

My first task was to prepare the data for analysis. I allocated pseudonyms for both participants and well-being cafés and day centres. I selected traditional, culturally appropriate names for participants from websites listing babies' names. After applying the pseudonyms I scanned field notes into pdf format ready to analyse. Multiple copies of interview transcripts and field notes were made so that later on I could cut them up into sections for generating themes whilst maintaining context by referring back to intact transcripts and field notes. I considered whether to use computer assisted qualitative data analysis software (CAQDAS). Green and Thorogood (2009) discuss the advantages and disadvantages of CAQDAS. They point out that CAQDAS are good for managing large amounts of data and that analysis can be more systematic and thorough than if done by hand. Analysis will have greater transparency as there will be a record of how coding schemes are developed. But there are disadvantages to this method. It can be time consuming to prepare and code the data as it is not always possible to import files directly. It can take a while to learn and set up new system for which there may be a financial cost. CAQDAS are not effective at including the minutiae of interaction such as pauses, intonation and emphasis. Finally, Green and Thorogood (2009) point out that some researchers consider that employing CAQDAS results in a loss of closeness to the data that they would otherwise feel when working directly with the transcripts or notes. I chose to handle the data directly, because I did not have unwieldy amounts to process. My fieldwork data was sometimes diagrammatic and I found that I had managed well without CAQDAS when handling interview data for my MSc dissertation.

The process of thematic analysis
As previously mentioned, the process of becoming familiarised with the data had begun with writing participant observation field notes and transcribing the interview recordings. When the fieldwork phase was complete and I had my transcribed data

in front of me I read and re-read it in order to become familiar with it. The second stage involved creating a coding scheme. In order to do this I read through the entire data identifying sections of data that appeared to be relevant to the research questions or were somehow significant to my topic and annotating sections of text in pencil. I identified themes common to several participants or that occurred frequently in the data and listed them, noticing that a hierarchy of themes and subthemes could be established. I devised descriptive labels that reflected specific themes and assigned numeric codes to these labels. For example, I assigned codes to labels associated with the theme "connecting with the world through the body". An initial coding template was developed in which a combination of inductive and a priori categories and themes were laid out (King, 2012). This initial template was used to index three interview transcripts and three participant observation field notes to see if it effectively included all relevant data. When parts of the data were not represented by a code the template was refined.

During the third stage I applied the codes in order to index the rest of the data. When I attempted to use the first version of the template to organise data on subsequent transcripts it became clear that further revisions needed to be made. For example, people spoke about the experiences of attending the intervention in a manner which did not include physical activity so a new category was established. At a critical point I decided that the initial layout of the template was not sustainable and it was redesigned. The initial few transcripts were then recoded accordingly. When I had coded all the data the initial coding template contained ten categories and approximately 50 themes (see Appendix 22). Some sections of the text were relevant to several themes and were therefore indexed with more than one code.

Stage four involved re-arranging the data according to its thematic content. I produced a copy of the coded data and then cut it up according to the codes. This enabled me to re-assemble the data according to categories and themes. I used paper of different colours to distinguish between the two data sources. This was done because I was aware of the potential to "triangulate" the two types of data. Time was spent reflecting on specific topics across cases e.g. "barriers to physical activity". I then turned my attention to interpreting individual participant's experience by referring to complete interview transcripts and participant observation field notes.

The iterative nature of the analysis process in qualitative research is well recognised (Ritchie et al. 2003). I referred back to complete segments of interview and observation data as I was aware of the danger of losing the context in which the data had been generated and that maintaining a sense of context is very important in qualitative research (King and Horrocks, 2010).

During stage five the data was interpreted. When looking at the template it was clear that certain categories had more levels of complexity and range of descriptive codes/themes than others suggesting a greater range and depth. It was also clear from the volume of data in each category that some themes contained much more data than others. When indexing and dividing the data some portions had been coded several times which suggested that they were particularly significant (Van Manen, 1990). The next step involved arranging the categories and themes in a manner by which the research questions could be addressed. The categories were written on post-it notes and an attempt to arrange them in a meaningful pattern was made. Categories were divided into two clusters. The first cluster contained themes relating to the aspects of participants' lifeworld and their relationship with physical activity were likely to impact on their engagement in physical activity. The second cluster contained themes relating to participants' experience of physical activity and the impact that being physically active had on their well-being. A typology containing four different groups of themes relating to the experience of physical activity was devised as part of the second cluster. Typologies are usually multi-dimensional classifications which allow a refined or complex portrayal of a phenomenon (Ritchie et al. 2003). This ranged from being successful and effective to exploring when physical activity fails to occur. My final thematic categories are listed in Appendix 23.

Interpretation of findings

The diagrams of the two overarching themes were used as a means of re-engaging with the data and interpreting the relationship between categories and themes. This constant shift in focus from the data in its entirety to the individual context of participant experience represents the use of the "hermeneutic circle" (Langdridge, 2007). I adopted free imaginary variation when reflecting on the data. This involved imagining how the experiences described in the data would be different without the presence of dementia. Van Manen's concept of "Lifeworld Existentials" (Van Manen,

1990) was used to aid reflexion when considering how the experience of physical activity was made up of various component parts. I referred to the well-being indicators devised by Bradford Dementia Group (Bruce, 2000) Symbolic interactionism (Blumer, 1962) and other social theories such as embodiment (Kontos, 2004) were used as lenses through which to view the emerging themes. Referring to this theoretical framework aided interpretation and was helpful in placing findings in context with the literature. Writing and re-writing the findings chapters in my thesis also formed part of the process of interpretation.

Issues of quality, validity and reliability

In this section I will describe how I attempted to maximise the quality of the study. It has been pointed out that questions relating to quality in qualitative research and the degree to which it constitutes reliable evidence are fraught with difficulties (Litva and Jacoby, 2002; Mason, 2002; King and Horrocks, 2012). This is because whilst the philosophical underpinnings of qualitative research are explicitly anti-positivist, the criteria usually used for evaluating research have been derived from the positivist tradition. Mason (2002) points out that even the term "evidence" suggests the possibility of an objective truth which clashes with the tenets of qualitative research. However, Mason claims that the concepts of validity and reliability may still be usefully applied to qualitative research if the usage of these terms reflects the principles underlying qualitative approaches. For example, the concept of validity can be used to reflect the extent to which an account accurately and plausibly represents the social phenomena under scrutiny (Litva and Jacoby, 2002). Whereas the term reliability can be applied in the sense of how effectively a study's methods produced the data that the researcher intended to generate.

I considered how best to ensure the validity and reliability, and therefore the quality of my study. The first thing I decided to do was to expose my study to independent scrutiny whenever possible. I therefore took every opportunity to present my work at meetings and conferences and sought the opinions of others regarding the coherence of my methodology. King and Horrocks (2010) point out that whilst there is no "correct" interpretation of the data, independent scrutiny can help the researcher to reflect on alternative ways in which the data can be interpreted. In the

later stages, I tried to be as open as possible to alternative interpretation of my data by discussing my interpretation of the data with members of the supervision team on a regular basis.

I referred to the literature to find out what aspects of quality were considered important in qualitative research. Mays and Pope (2006) suggest that quality can be enhanced by several techniques. Firstly, the triangulation of methods and approaches is considered important. My decision to use two methods to generate data was discussed earlier in the chapter. I used triangulation of sources (Patton, 1999) to explore the experience of specific participants. For example, I employed participant observation with Simon as he participated in physical activity in two different environments and then interviewed him in order to gain a variety of perspectives. A second technique is the creation of a clear "audit trail". This is a documentary record of the steps taken and the decisions made when working with the data. I planned to make enough data available for the reader to be able to judge whether interpretation was appropriate. A third technique is "respondent validation" which involves feeding researcher's interpretations back to participant to determine whether they recognise and agree with them. I interviewed Jack twice verifying that the interpretations that I had been making on the basis of his first interview were valid. Mays and Pope's fourth technique is "fair dealing". This involves ensuring that the research design explicitly incorporates a wide range of different perspectives. I spent time negotiating access to eight field work locations and attempted to include participants with as broad a range of ethnic identities as possible. A fifth technique, "attention to negative cases" involves actively seeking out evidence that contradicted the conclusions being reached by the findings and including this evidence. I interviewed Cynthia, aware that she had not participated greatly in physical activity and appeared indifferent to it. A final technique to ensure quality is reflexivity, this is particularly important and will be dealt with separately in the next section.

Critical reflections on the research process

Reflexivity involves being sensitive to the ways in which the researcher has had an effect on their study and how the assumptions that they inevitably harbour have impacted on data analysis and interpretation (Litva and Jacoby, 2002). King notes that reflexivity also plays an important role in reflecting on alternative ways of interpreting data (King, 2012). Two types of reflexivity are recognised; personal and epistemological. Personal reflexivity is achieved by the researcher thinking about who they are and how characteristics such as race, sex, and social behaviour influence how they are perceived by study participants and how the researcher has generated their findings (Britten, 1995). In contrast, epistemological reflexivity is concerned with how the design of the study and the method of analysis have constructed the data and eventual findings (Willig, 2002). I will now relate these two types of reflexivity to my study.

Personal reflexivity

I am a practicing physiotherapist and my perception of the way that physical activity was performed during the study was inevitably coloured by my biomedical background. My training focused on exercise rather than physical activity and stressed the importance of setting clearly defined goals, prescribing exercise as a form of treatment and identifying measurable physiological benefit. I was aware that my background influenced my view and initially made me think that many activities I encountered in the study were childish and trivial. When engaged in the fieldwork, the identity I tried to portray was that of a participating researcher and was different from the identity of clinician that I adopt during my physiotherapy practice. I reflected that aspects of my experience of fieldwork were particularly vivid for me because I felt vulnerable without my professional clinician's identity to protect me. Despite belonging to a profession in which physical contact with patients is commonplace, touching others socially can be difficult for me. Touch can be classified as "affective" when demonstrating affection and promoting rapport and "instrumental" when instigating a task (Caris-Verhallen, 1999). My every day work involves predominantly instrumental touch. In British culture we tend to limit touch to those we are close to and it can often have a sexual connotation (Burnard, 1997). Burnard describes people as being "high touchers" if they welcome physical contact whilst others who are repelled are classified as "low touchers". I reflected that I'm generally a low

toucher. At times I would recoil at the feel of my dance partner's sweaty hand. Nevertheless I persevered with dancing as I felt it was important to fully participate in the activities I was exploring.

My male identity influenced my interaction with others during the study. I felt uncomfortable at times dancing in small groups with other men. This was particularly the case when I knew them to be carers and not participants with dementia whom I could regard as I would a "patient" in order to defuse my social discomfort. I found dancing with women that I did not know also disconcerting. I felt the interaction was sometimes too intimate. I was aware that gender has implications in terms of power. The concept of gendered power (Connell, 2004) refers to the power that men inherently possess compared to women in Western society. However, I did not feel empowered as a man. Particularly when surrounded by assertive, boisterous and noisy African-Caribbean women at St Cuthberts Well-being Café. I felt very uncomfortable there when attempting to identify potential participants. The fact that one of the women there asked me what I was trying to sell made me think I was being viewed with mistrust. I felt a similar sense of disempowerment and transgression when I found that I was the only man in a feminised environment attending the group at Women's Action Partnership (WAP). Nevertheless, I felt comfortable when interviewing women during the study.

I was aware that I held mixed attitudes towards ethnicity which may partly reflect my experience of living in a city where tensions often exist between ethnic communities. I recognised that I had conflicting feelings about Islam. I assumed that older South Asian women were downtrodden, serious and would be wary of me as a man. I recognised that these assumptions led me to reach particular conclusions. For instance, that all the South Asian women were feeling uncomfortable when I witnessed them visiting one of the well-being cafés when I had little evidence for this. My stereotypical assumptions regarding older South Asian women were shaken later at WAP where I found many of the women there to be articulate, humorous, physically affectionate and accepting of me as a man. Several times when conducting fieldwork I became very aware of my own ethnicity when I found myself to be the only white person in a crowded building. When I was looking for suitable

locations for my PhD fieldwork I spent a day at a day centre run by and for local South Asian communities. Because the environment had made it hard for me to construct my social identity I had made a note of my experience:

> I was Invited to lunch and told that whilst it was being prepared I could join the men attending. I sat in room with eight middle aged/older men. Most had hennaed beards. When more men arrived I felt confusion about whether or not to shake hands. I felt that they shared the uncertainty about shaking my hand. I sat awkwardly. I noted unfamiliar body language that I could not interpret. The men chatted in Urdu, reading Urdu newspapers. The television was on, news in Urdu. I felt excluded and unwelcome. Hand drawn sketches of people on the wall confused me. I had assumed that figurative art was unacceptable in Moslem culture. I was sitting four miles from where I lived and yet I felt as if I was in a foreign country. I did not know how to be.

This experience had made me aware of the difficulties that participants in my study may be feeling when they found themselves in environments that were culturally unfamiliar and uncomfortable for them. These experiences alongside discussions with Jacinta about the racism that she encountered when first arriving in the UK helped to sensitise me to issues of ethnic identity and consider how ethnicity was socially constructed.

I am middle aged and generally comfortable with interacting with older adults. I work with older people and I enjoy talking to older people about their lives. Most of the participants in this study were the same age as my parents and I was made aware that I belonged to a different generation when a woman at one of the well being cafés commented "You're not one of us are you?" I was happy to distance myself from participants on the basis of age and maintain a self-image of myself as a relatively young person. I recognised that my attitude to older people was not always benign; one day I recorded in my field notes that I wanted to escape the decrepit shapeless bodies around me. I was too young to know certain songs and sometimes felt that I had been transported out of my own time. I considered myself as an outsider and was therefore shocked when during the initial stages of my PhD a

participant asked for my age and commented that a 48 year old would be considered old in the past.

Epistemological reflexivity

This type of reflexivity considers how assumptions about knowledge and the choice of research subject have shaped the research questions and conclusions. My choice of interpretivism placed myself at the centre of the study and this had implications in terms of data generation and interpretation. I was aware that it would be easy for me to make assumptions about participants' experience based on my own. For example, just because I had enjoyed particular activities did not that mean others also enjoyed them as well. Kvale and Brinkmann (2009) write that the interviewer has a monopoly on interpretation. Using participant observation and interviews entailed me taking responsibility for carefully considering how I made sense of my data. Densombe (2009) comments that in interpretivist research it is important to recognise that people respond to the knowledge that they are being observed and that their behaviour may change as a result. At Chellowfont day centre where there were only a handful of participants and staff, I wondered if aspects of activities were done for the benefit of the researcher. I considered this less likely at larger day centres and well-being cafés where the impact of my presence seemed minimal.

Summary of methodology chapter

In this chapter I have described how methodological questions assisted in the creation of a theoretical framework. I justified the choice of complementary methods of data generation. I described how I recruited my study participants, how I undertook my fieldwork and detailed how I analysed and interpreted my data. I then explored issues of quality, validity and reliability. Finally, I discussed aspects of reflexivity and applied these to my experiences of performing my study. In the next chapter I will begin presenting my findings.

CHAPTER FIVE

Study findings: Factors influencing participants' engagement in physical activity

Introduction

In the previous chapter I described how I established a methodology to address my research questions. I also wrote about how I recruited my participants and undertook my field work. I then recounted how I used aspects of Van Manen's hermeneutic phenomenological reflection to assist me in my data analysis and the generation of sub-themes and themes. I went on to describe how I arranged my sub-themes and themes into categories which I then placed into two distinct groups. The first group of categories contained themes related to factors which influenced participants' engagement in physical activity. My second group of categories contained themes relating to participants' experience of being physically active and the impact that physical activity had on their well-being.

In the next two chapters I will present my findings. In this chapter I will present themes contained within the first group of categories which related to factors which influenced participants' engagement in physical activity (see Figure 5.1). The first category listed in Figure 5.1; "The influence of participants' relationship with physical activity" contains themes relating to participants' attitudes and beliefs regarding physical activity. The three remaining categories contained in the table, "Social influences", "The influence of the lived body" and "The influence of the lived environment" mapped quite well onto Van Manen's existentials of relationality, corporeality and spatiality. These categories contain themes which reflect the significance that social interaction, participants' experiences of their bodies and aspects of the environment played in their participation in physical activity. Segments of text containing data from interviews and participant observation field notes will be indented. In order to differentiate between data derived from different sources, text arising from participant observation will be underlined.

Figure 5.1 Study findings: Categories, themes and sub-themes representing factors which influenced participants' engagement in physical activity.

The influence of participants' relationship with physical activity **"A readiness to engage in physical activity"** Waiting to engage. Motivated to be active. Ready to engage in physical activity **"A Passion for physical activity"** Positive attitudes towards physical activity, Exercise is enjoyable. **"Indifference or dislike of physical activity"** Dislike of gardening. Dancing is foolish **"The belief that physical activity is good"** Body benefits from physical activity & busyness. It's good for you. It feels good. Relaxation. It keeps the brain working. Medical advice. **"I'm a active person"** Busyness. Identity **"Getting older: I'm not as active as I used to be"** Acting my age. Feeling young. **"It's something I've always done"** Nostalgia for past activities
Social influences **"A contracting social world"** Not going out. Reliance on carer. Feeling lost and out of the social loop. The secrets out. Words failing me. **"Lack of social resources"** Lack of social support. Lack of transport. Not knowing where to go. Fear of strange places **"Being social is important to me"** Physical activity providing context for interaction. Engaging with others. Mixing with others. **"We're in this together"** Social support. Playful. Spontaneity encouraged. Pre-reflective activity. Humour. Competition. Co-operation. Breaking rules together. Encouragement. The dog needs a walk. **"Practical help and encouragement to participate"** Transport provided. Effective interaction with volunteers and carers. Routine. TV advice. Led by a leader adopting biomedical approach. Acceptance **"The importance of social ritual"** Knowing the" rules". Routine. Disengaging the brain and following the rules
The influence of the lived body **"Pride in the body"** **"Connecting to the world through the body"** The expressive body **"She hasn't forgotten how to dance"** Innate embodied skills **"Liberated bodies"** Bodies taking the lead. Loss of inhibition. Doing something new. Critical faculties suspended **"The restless body"** The out of control body **"Facilitating movement through the body"** Use of effective equipment. Spontaneous non-verbal interaction. **"Facilitating engagement through music and rhythm"** Rhythm supporting movement. Music helping things along. Disruptive music **"The frail body"** Getting older. Lack of motivation. Health/Depression. Tiredness. Weight loss **"Cognitive overload: engagement through the body disrupted "** Use of inappropriate materials (DVD, tape). Cognitive overload. Imposed rules. Struggling to follow the instructions. Struggling to keep up **"Breaking the ice: the inhibited body"** Self- consciousness. Culturally inappropriate environment/activity.
The influence of the lived environment **"Safe environments"** Celebratory ambience. Safe social environment. Acceptance by others. Multi-ethnic environment. Safe. Buzz in room. **"Familiar territory, ethnic identities supported"** Women only. Ethnically separate. Gendered/ethnicised. Safe. "Knowing the" rules **"Ethnic incongruities"** Unhelpful interaction with staff/volunteers. Not knowing the" rules" **"Difficult environments"** Chaotic and unplanned environments. Hostile/chaotic. Institutionalised. Gloom in room.

The influence of participants' relationship with physical activity.

My first category contains themes and sub-themes relating to the relationship that participants had with physical activity and the influence that this had on their engagement in it. I will start with presenting themes which reflect participants' attitudes and beliefs relating to physical activity.

"A readiness to engage in physical activity"

Participants usually engaged in physical activity readily when the opportunity arose and expressed enthusiasm as they did so. This suggested that the majority of participants had a positive attitude towards physical activity. For example, at Chellowfont Day Centre one day I noted the following:

> We all move into the activity room and I detect an air of expectation in the room. There is a lot of eye contact between myself and the two Asian men. Smiles are exchanged. Fiaz catches my eye and gives me a thumbs up. Ahmed looks around, alert and ready to engage (Chellowfont Day Centre).

Some participants were motivated to engage in physical activity fully despite evidence of physical ill-health such as unsteady gait. For instance, at Chellowfont Day Centre, Gladys appeared frail and had difficulty walking but stood and danced along with the others during the exercise group. She invested so much energy and enthusiasm in the activity that she toppled back into her armchair.

"A passion for physical activity"

Several of the participants expressed strong positive emotions when discussing their attitudes towards physical activity. This was particularly the case with Simon and Jacinta who were both keen walkers. Jacinta told me:

> "My first passion is to get out there and walk! And I mean a real walk. Not from here to town. You know, from here to Bridgetown and back (a hilly ten mile round trip). A really good walk." (Jacinta).

Simon was equally emphatic when he talked to me about how he felt when walking:

"When I go walking it's..it's just wow..it's ..it's just WOW!!" (Simon).

During their interviews most participants reported that they enjoyed engaging in physical activity both at the well-being café or day centre and elsewhere. Participants also expressed enjoyment and enthusiasm when engaging in physical activity. There were many occasions when I watched participants smile, appear alert and responsive and display relaxed body language as they engaged in exercise or dancing. One participant talked to me about her love of walking and reported that she regularly walked several miles to a nearby town. When I asked her why she enjoyed it so much she answered as follows:

"That's what I like. I like the lovely countryside as well. I don't like going out eating meals all the time. You, know, it's nice to be walking around and seeing things. I think I've climbed all the big mountains in the Lake District" (Olive).

Participants were often clear about what forms of physical activity they liked or avoided. Occasionally participants expressed equally powerful attitudes towards watching and talking about sport as well as participating in physical activity.

"The belief that physical activity is good"

As well as enjoying physical activity, some participants expressed the belief that being physically active bestowed a range of benefits. The benefits that participants identified were often associated with their health and could be somewhat vague. When I asked Cynthia about what she enjoyed about the dancing at the café. She told me that the dancing involved moving around "….which is good for you anyway". Another participant associated the positive effects of walking with maintaining the general health of her and her husband. Participants could be quite specific about the health benefits of physical activity. For example, Jacinta told me that walking helped her by keeping her brain going. Several participants believed that being physically active was effective in addressing specific physical problems. For example, several

participants told me that they believed that exercise made their joints feel better and reduced pain. Physical activity was also considered good by participants because it provided an alternative to being sedentary. For instance, Olive talked about not wanting to spend her time sitting. Another participant reported that he liked to keep himself mobile and that dancing at the Browgate Well-being Café enabled him to do this.

Several participants discussed how their belief in the benefits of physical activity had been influenced by health professionals. One participant stated that her physiotherapist had advised her to exercise, although she could not remember what the explanation associated with this advice had been. Another was told by her GP that exercise could benefit her by lowering her cholesterol and managing her hypertension. Alveta's belief that her shoulder would improve following exercise was based on the advice of her GP. As well as health benefits, one participant told me that she kept busy because she thought being physically active was good for the body, for aesthetic reasons:

> "I'm not being funny but I know if I look at myself in the mirror….I look better now than I did years ago - simply because I've been doing exercises" (Stella).

Stella told me that not only did she think physical activity was good for her, it was good for all and everyone should be encouraged and enabled to be active. Stella told me that she believed doctors should recommend activities such as swimming. When I commented to another participant that she seemed to be a big believer in exercise she answered:

> "Yes, I am believing that it is good. Everybody they need it, the exercise. Yes, everybody they need it. Not just only for fatty people…everybody needs it" (Fameeda).

"Indifference or dislike of physical activity"

Not all the participants valued physical activity. Some participants never joined in the activities at the well-being café. Several told me that they did not like dancing. One of these was Mary and when I asked her about this she answered as follows:

> "I'm not one of those who want to throw themselves into a dance. It's just that when it's Christmas, or anything like that you join in don't you" (Margaret).

At Browgate Well-being café, Cynthia did occasionally dance with her husband but in a quiet, restrained way. During her interview she was ambivalent about the dancing. She made it clear that she attended the event for social support and entertainment and the activities were of lesser importance. I will now present themes relating to participants sense of identity and the influence that this had in terms of engagement in physical activity

"I'm an active person"

Some participants described how they were active people and that the impulse to be physically active was an aspect of their identity. One participant reported that she could not sit down and described how she felt compelled to do more housework even though she was aware that her house had recently been cleaned. Another participant who sometimes found it hard to stop moving told me that she considered herself to be an active person and told me that she found "just sitting down" boring. Jack was another participant who described himself as being driven to keep physically active:

> "I'm not the kind of person who can sit down for a long time. I've got to be doing something. Even if it's going out sweeping the drive…I might only have done it yesterday" (Jack).

Similarly, Jacinta identified herself as someone who needed to be occupied.

"Well, I'm not one of those that sit still and does nothing. Er …no..I've got to do something. Yes, that's it. If I can't do anything it drives me crazy! (sigh) I have to get up and do my washing and ironing or something (laughs) just to do something! Isn't that awful!" (Jacinta).

"It's something that I've always done"
Several participants told me that physical activity was something that had always been very important to them. For example, Jack had been a professional footballer and played golf as a hobby, Olive talked enthusiastically about ballet lessons in her youth. Simon told me that he had been a keen walker since he was a boy:

"I mean even from being a lad I started up and I just went out and about. There were not many people around and I just walked out …" (Simon).

During her interview, Barbara reported a long standing enjoyment of dancing:

Alan - "Have you always enjoyed dancing?"
Barbara - "Oh yes."
Alan – So this isn't new for you?"
Barbara - "Because I used to move to music….you know what I mean….and that was my…was one part of me if you like" (Barbara).

Others were less enthusiastic about their past experiences of physical activity throughout their lives, whilst recognising that they had been fairly active for all of their life. For many participants therefore, being physically active contributed to their sense of identity.

"Getting older: I'm not as active as I used to be"
Several participants in my study reflected on the fact that they were getting older and how this meant they were less likely to be physically active. They expressed the view that being less active was inevitable as they got older. Barbara told me that she could not walk as far as she did in the past. When talking about the potential benefits

of exercise groups Stella commented that they were helpful because with advancing age:

"..you tend not to do things that you ought to do" (Stella).

Olive told me that she still enjoyed being physically active although she was aware that she can do less than previously:

"Oh, I certainly like walking but I think now I'm getting too old to er..climb the mountains in the Lake district. The ones over 3,000 feet. But I still like walking" (Olive).

Participants sometimes expressed pride in their age and what their older bodies were still capable of. Bercik is a striking example:

"I'm 90! But I feel I'm just a teenager!" (Bercik)

The manner in which Bercik engaged in physical activity reflected this perspective and will be described in more detail in the next chapter. In the next section I will turn to the remaining categories in figure 5.1. Themes relating to factors influencing participants' participation in physical activity are grouped into three categories. The category "social influences" reflects the way in which they interacted with others impacted their participation. The category "the influence of the body" relates to the significance of their bodies. The final category "the influence of the lived environment" contains themes relating to the influence of the environment on participants engagement in physical activity.

Social influences

I will start by presenting themes contained in the second category in figure 5.1 which relate to how participants social interaction influenced their participation in physical activity. I begin by presenting themes reflecting the difficulties that participants had in engaging in physical activity due to social factors.

"A contracting social world"

Many participants had fewer opportunities to be physically active because their social lives in general were shrinking through the effects of dementia. For example, Bercik told me that there was nowhere apart from the well-being café for him to go to interact with others. Several participants talked about their social world narrowing and only going out with their spouses and immediate family. This was partly due to their cognitive difficulties. The sub-theme "feeling lost and out of the social loop" reflects that participants could struggle to meet the demands of social interaction and be excluded from social interaction due to their cognitive difficulties. Their difficulties were also partly due to how others interacted with them due to their dementia. The sub-theme "The secrets out" reflects that participants sometimes were aware of the social consequences of developing dementia and knew that some of the difficulties they had interacting in social settings were a result of attitudes held by others regarding dementia. For example, Jack spoke at length about how people reacted to him differently when they became aware of his Alzheimer's diagnosis. Jack reported that the widespread prejudice associated with dementia could make life difficult for him:

> "People may judge you a little different if they didn't know as they would do if they know. In other words they might just be in a conversation and then somebody says "Oh yes, you've got early stages of Alzheimer's." Well, I should think then you may be out of it. Because you'd probably be looked on as not mental, but not capable of joining conversation" (Jack).

When Jack was asked if having Alzheimer's disease had stopped him from doing anything that he liked to do he responded as follows:

"Oh, I don't think its so much as..stopping…er …me. Or me stopping myself. I think its how people judge you and they know that. In other words I say to my wife, I say it's treating me like an idiot (laughs)" (Jack).

As a result of this, Jack reported that he made a point of not telling people that he had Alzheimer's disease and did not like his wife to tell people either.

"Lack of social resources"

Participants often lacked the social support that they needed to engage in physical activity. The consequences of lacking social support were particularly significant for Jacinta and Simon who had previously enjoyed walking either alone or with kindred spirits. Jacinta talked about the barriers she faced when she considered going walking;

Alan - "What about having someone to go on long walks with you?"

Jacinta - "Oh I'd love to! I'm *desperate* to find somebody to go for a walk. Even if it was for just one day a week".

Alan - "So is this something which is stopping you from doing more walking at the moment then?"

Jacinta - "Yes, because I've got nobody to walk with" (Jacinta).

Simon's wife reported that she had sciatica which prevented her from accompanying him on walks as she had in the past. Consequently, until recently Simon had regularly walked alone which had resulted in him getting into difficulties such as becoming stuck in a stile during snowy weather. Several other participants were lacking the social support they needed to engage in physical activity at a time when they needed effective assistance in order to engage in it. One participant reported that she had always enjoyed swimming but was not currently going because she was unsure if there was a pool in the city. Earlier she had told me that her friends had moved away and that she hated going anywhere "strange". The following themes suggest that social factors could facilitate participants' engagement in physical activity.

"Being social is important to me"

Several participants expressed awareness of their social needs and told me that they valued the opportunity to meet people at the day centres and well-being cafés. When asked why Jack attended the Browgate Well-being Café he replied:

> "I think it's mostly because you can associate with people, males and females" (Jack).

Participants welcomed the opportunity to spend time with others who had dementia. For example, one individual told me that she liked to mix with other people because they had shared problems associated with Alzheimer's. Another reported that she found it easier to talk to people when they shared the experience of dementia:

> "When you know somebody has the same as you, you tend to blend with them don't you…" (Mary).

Barbara spoke about the value of spending time with others who had dementia:

> Barbara - "I love this group because we're all the same".
> Alan - "What does that mean- "you're all the same"?"
> Barbara – "I think it means that I am quite happy….I can talk easily to people" (Barbara).

Whilst Barbara reported that she sought the company of others with dementia in order to talk to them, her interaction with others at the well-being café did have its difficulties. She admitted that she could not actually manage conversation very well. It was noticeable that she rarely spoke at the café. In the next chapter I will describe the manner in which engaging in physical activity at the well-being cafés and day centres enabled participants to engage socially with others.

"We're in this together"

Having someone for participants to share the physical activity with had a facilitating effect on engagement. For instance, one participant told me that she relied on her husband when walking to a nearby town. Another talked about her husband's support of her dancing when they attended the wellbeing café:

> "Donald's sort of never was a dancer, sort of thing. But he sort of jigs about a bit with me just to, you know, keep me company and that…" (Cynthia).

Simon who was passionate about his walking was reliant on his family to support him on his outings. I spent an afternoon with him and his siblings in order to share his experience of walking with his family. They had a regular routine which involved walking around the lake in a local park and then buying ice cream from a corner shop. I described the following interaction between them in my field notes recording how the support they provided was all-encompassing:

> We walk slowly along in a companionable fashion. Simon is quiet-although he occasionally initiates conversation. It's hard for me to follow what he's saying. However, the others seem to understand Simon's references to the past. They exchange light hearted banter, relaxed in each others company (Simon's walk).

Social relationships were not restricted to human interaction; two of the participants described how dog ownership facilitated walking. Jack told me that he regularly took his son's dog for a walk.

> "Then I might go right down as far as …well, in other words it's as far as the dog wants. It isn't a case of how far I want to go, it's how far the dog wants" (Jack).

Jack told me that walking the dog helped him to initiate conversation with others when out walking. Another participant talked about the memories he had of walking with his dog and the fact that this influenced where he went even though the dog had died a long time ago.

"I used to have a hod..a dog. And the dog…it were dead and I used to think about it all the time and I used to, you know..want to see him..and I know its silly but..you can't do that with animals like that but I used to go to the place where..up this road somewhere just up here and I used to go just looking for him and he wasn't there…" (Simon).

I now turn to social factors that had a facilitating effect on participants' engagement in physical activity at the well-being cafes and day centres.

"Practical help and encouragement to participate in physical activity"
Practical social support was important for most participants. For example, the fact that someone picked her up from her house in the morning and returned her at the end of the day enabled one interview participant to attend High Grange Day Centre and perform the exercise that she valued. At the well-being cafés and day centres, encouragement from staff or volunteers was an important influence on participants engaging fully in activities. The presence of assertive volunteers at the well-being cafés resulted in full participation in dancing. The approach with which individuals led physical activity groups varied between locations. The activity leader at the Smithson Well-being Café was particularly effective in leading a session:

> We are instructed to stand up, link hands and form a large circle. In the background two men play traditional Polish Music on an accordion and an electric organ. The leader tells everyone to kick one leg and then the other in time with the music. A light hearted competition develops to kick the highest. I watch Bercik who looks quite athletic high kicking his long legs with slightly bent knees (Smithson Well-being café)

Marjorie Peterson, the co-ordinator of the well-being café network, was particularly successful in getting people to get out of their chairs. She approached participants directly and took them by the hand, leading them onto the dance floor. When she was absent from the Stanford Well-being café the lack of leadership was noticeable. Volunteers there were unobtrusive, gentle and rather ineffectual.

"The importance of social ritual"

Participants were more likely to engage in physical activity if it included an element of familiar social ritual. For example, At Chellowfont Day Centre when we played skittles or threw hoops over a cone, people were invited to take turns and their efforts were rewarded by a round of applause. This non-verbal social ritual of the game seemed to help maintain participants' engagement in activities. Participants paid attention they appeared to recognise that something familiar was happening.

The influence of the lived body

In this section, I will refer to themes contained in the third category in figure 5.1 which relate to the influence that participants' relationship with their bodies exerted on their engagement in physical activity. Themes contained in this category suggest that the manner in which participants experienced their bodies played a significant role in their engagement in physical activity. I will begin by presenting themes that suggest that participants' bodies could contribute towards participants' self-esteem and provide a resource for self–expression and communication in the context of physical activity.

"Pride in the body"

Many participants referred to their body in a very positive fashion. It often provided them with a source of self-esteem. The following segment shows how a participant's body provided her with a valued source of self-esteem. I had been aware that Olive had experienced falls and had sustained injuries in the recent past and during her interview I was interested in exploring how she had coped with these. I asked her if she had any discomfort when dancing at the well-being café and Olive responded as follows:

> "No, funny…..now I'm alright. Just watch me dash up there" (Olive).
> Olive got up in an instant and virtually skipped across the room "No problems!" she exclaimed from the other side of the room. She then darted up and down a short flight of steps in the corner of the room and returned to her chair. Olive told me that she was good at things like that. She denied that there were any things that she could not do. Olive was

very proud of her ability to move without restriction. "You just moved across the room effortlessly" I comment. "Did you see me do that?" Olive answered proudly. "And you just flew up those stairs" I observed. "I just jumped up them didn't I?" Olive replied and went on to say "I can do that easily. I mean at home if I've lost something upstairs I just dash up the stairs, find it and come down". Olive then told me that she felt sorry for people who could not walk very well (Notes from Olive's interview).

"Connecting to the world through the body"

Earlier in the chapter I noted that many participants appeared to be motivated to interact socially with others but that opportunities to be socially active were limited by dementia. At the well-being cafés and day centres it became clear that participants' bodies enabled them to connect with others through self-expression. During her interview, a participant said that she enjoyed the company of others and recognised that there were ways of connecting with people non-verbally when mixing with them in a social environment.

Mary - "When you wave to somebody at the other side (of the café)…there's ways and means of..instead of just talking to people, isn't there?"
Alan -"Other means of..?"
Mary - "Well, communic..that's not the right word..I'll have to find a better..I can't find the word. You've got to get some way of speaking to people haven't you?" (Mary).

Participants may have had trouble expressing themselves though speech but they were able to do so through their bodies. There were many examples of participants communicating through their bodies. For example, At Chellowfont Day Centre, I watched a participant who had very little speech as his nurse made an unexpected visit. His face lit up and he immediately stood up to greet her, grasping her hand and shaking it with enthusiasm. Each time I visited Chellowfont Day Centre I was greeted in the same way; his handshake became more effusive each time we met. Towards the end of my series of visits he performed an elaborate hand shaking movement in the air when he saw me before offering me his hand, his face smiling broadly.

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During Simon's interview at Browgate Well-being Café he stood up during the interview, towering over me when struggling to discuss his experiences through speech. He seemed to demonstrate his difficulties with spoken communication through his body. The same thing happened during Olive's interview when we discussed how she used to attend ballet classes as a child. After a sentence or two she stood up and demonstrated the concept of ballet dancing through foot positions and a graceful walk across the room. She did something similar later when talking about being a primary school teacher:

> Alan - "Did you do physical activities with them?"
> Olive -"Oh yes!"
> Alan - "What sort of things did you do with the children?"
> Olive - "Well, we sort of walked around and we sort of got up and did, you know, things like… "(Olive stands up again and walks around the room moving her arms about to demonstrate her point) (Olive).

It was as if Olive had reached the point where she could no longer express herself in verbal language and had slipped into non-verbal gestural communication. In the next chapter I will discuss themes which suggest that physical activity provided participants with a context within which they could use their bodies in order to express themselves. For some participants, the resources that bodies provided were particularly important due to the difficulties they were experiencing as a consequence of dementia.

"She hasn't forgotten how to dance"

Participants sometimes displayed embodied skills which had resisted the effects of dementia and were employed in the context of physical activity. I spent several afternoons at the Stanford Well-being Café with Megan and her husband Philip. Megan lived in a nursing home and was brought to the café by her husband. She was unable to communicate verbally. I learned that they had been keen dancers in the past and Megan retained the ability to dance. This was noted by those around her.

> Paul, a carer who had been sharing a table with them leaned over to me whilst Megan and her husband dance gracefully past our table and said "She hasn't forgotten how to dance has she?" (Stanford Well-being Café).

This was not the case with all of the participants however. When I suggested to another participant that we dance together and then take to the floor she appeared to have difficulty with the concept of a group of us holding hands in a circle. She also struggled to keep hold of my waist during the conga which disrupted the pattern for the group.

"Liberated bodies"

For some participants, having dementia appeared to facilitate engagement in physical activity by enabling the potential of their bodies to emerge unhindered by self-consciousness. The theme "liberated bodies" reflects how some participants were liberated from the social awkwardness of dance or the concern that they were performing the correct movements. They occasionally showed complete lack of self-consciousness. For example, one afternoon at the Stanford Well-being Café I watched Marcus as he danced with a volunteer. He moved his extended arms around above his head as if he was directing traffic. He looked good and appeared to be enjoying himself. His wife pointed out that he had always been a reluctant dancer but now he was doing something new, he was freer and less inhibited than in the past. It was as if the experience of dementia had freed him from adhering closely to social conventions. Similarly, at Browgate Well-being Café one afternoon the singer was performing "achy breaky heart" and people stood in formation attempting a line dance. Simon was surrounded by volunteers attempting to perform the correct steps. He marched out of time with the others and sang at the top of his voice. He seemed oblivious to their efforts at conforming.

The sub-theme "Critical faculties suspended" reflects how participants could be freed from critically evaluating aspects of their environment and how this could enable them to engage in physical activity. At High Grange Day Centre an exercise DVD was used. I thought the jaunty folk music was terrible and did not match the activity at all. The exercises were conducted at great speed and were very hard to follow. I noticed that the movements of the people modelling the exercises on the DVD were

out of time with the music. However, participants seemed to have a different experience to me. One participant commented during her interview that she found the exercise DVD easy. Unlike me she did not seem concerned with its quality. She seemed unaware that the music was incongruous and the exercises impossibly difficult.

"The restless body"

At times participants presented as restless and in need of movement. Their bodies appeared to provide much of the impetus for engagement in physical activity. Mrs Begum was one of the more restless participants. While everyone sat in the lounge at Chellowfont Day Centre waiting for an exercise group to begin she would repeatedly rock in her chair and call out the same phrase many times. She would also repeatedly move her arms across her body and tap her foot when waiting for the exercise group to start. Once the physical activity started, these movements stopped. Participants sometimes expressed awareness of the importance of attending to the needs of the body. Simon was the most restless of the participants. His wife Doris told me that he regularly got up at four o'clock in the morning and went up and down the stairs a few times. This appeared to be something which was out of his control. Simon discussed this during his interview:

> "Stephanie can't understand it, yeah I can understand her. You know really I should go to bed and I don't..I go and I go, walk walk away..." (Simon).

For Simon, the fact that he was in motion when walking seemed helpful in some way:

> "I like to take Doris (Simon's wife) and really go anywhere.....I mean it's silly, but it's just that I. It's that I need really to be going places, you understand. I just walk and walk and walk and then when I get fed up of walking I come back and that's it. You know, I turn it around" (Simon).

Other participants displayed a physical restlessness when they attended the day centres and cafés.

> We wait at Chellowfont for a group to start. Mrs Begum spontaneously starts to move her arms across her body and tap her feet. I think she wants to move. But none of the staff are present. Several weeks later something similar occurs. The group activities have finished and while most of the participants sit quietly, Fiaz continues to move his arms across his body in the manner of the exercises (Chellowfont Day Centre).

The following themes relate to how participants' engagement in physical activity was often facilitated through the body.

"Facilitating movement through the body"

Engaging with participants in an embodied non-verbal manner at the day centres and well-being cafés facilitated engagement in physical activity. At Chellowfont Day Centre, the times when participants appeared most engaged in activities were when staff members began to behave in a spontaneous manner and interacted with participants in a non-verbal way through their bodies. In my field notes I described how a game involving a ball took place:

> A staff member returns the ball to Mrs Begum who immediately throws it back to her. They continue to throw the ball quickly backwards and forwards smiling at each other waiting for the other to stop or throw to someone else. The ball passes rapidly between them for a few seconds. Both seem fully engaged in what they are doing; they were equal (Chellowfont Day Centre).

Watching playful non-verbal interaction at Chellowfont Day Centre made me reflect on how playful interaction can be a valuable part of my own relationship with others. Several days after witnessing the events described above I found myself noting down the details of an interaction which took place in my own home:

I arrived home from work one evening and found my wife and my teenaged daughter Martha in the kitchen microwaving potatoes. Before I had a chance to greet them Martha took one out of the microwave and threw it to me saying "This ones yours!" I caught it and instinctively threw it straight back. For a few seconds we wordlessly tossed the hot potato backwards and forwards across the kitchen. I thought how satisfying it was to throw and catch the solid hot object. After several throws the game changed slightly, we began to pull faces at each other as we caught and threw. Then another part of the game emerged; each time we caught the potato we bent our knees as well as grimacing. As the game progressed we bent lower and lower with every catch. My wife became irritated by us and told us to stop being silly "You'll break something!" The prospect of breakages made the game even more pleasurable. We carried on in defiance for a few more turns, eventually bending our knees so much that we both fell on the floor laughing; together we had found a way of bringing the game to an end. I realised afterwards that I had not spoken since I had entered the kitchen. There had been no discussion or spoken agreement about what we were going to do. I had not been aware of deciding how to progress the game it had just flowed spontaneously, the rules had been tacit. Somehow we had connected with each other in a highly enjoyable and deeply embodied manner.

I concluded that playful non-verbal embodied interaction was likely to be common place and something which is easy to take for granted. I also realised that trust between those involved and a supportive environment were needed to enable this type of interaction to take place. At the Stanford Well-being Café the non-verbal embodied interaction between the participants and staff was a significant facilitator of engagement in activities:

A gentleman stands stiffly and erect whilst a member of staff takes his hand. She begins to dance, twirling him around. The gentleman responds by beginning to lift his feet. There is a flicker of rhythm. (Stanford Well-being Café).

Non-verbal interaction through physical activity could be facilitated by the use of props. At Chellowfont Day Centre participants were sometimes encouraged to pass a balloon between them:

> Joe bounces it on his head before using his knee and then his foot to keep it in the air. Ronald takes Joe's lead and bounces it on his knee before kicking it. The balloon passes between them and they both stand up and reach for it at the same time. There is a buzz of excitement in the room (Chellowfont Day Centre).

On another occasion Ronald responded positively when a ball began to be passed between members of the group:

> At Chellowfont one morning the exercise tape is over and a ball the size of a football is brought out. I am given the ball and I lift it and gesture with it that I am about to throw it to Ronald. His eyes widen and he lifts his hands above his head as a signal to me that he is ready. I throw the ball and he easily catches it and throws it on to someone else. Later on in the same game the ball comes to rest at the feet of a member of staff who is sitting next to Ronald. I see him reach over the top of her lap to retrieve the ball. He clearly wants to take the ball and continue to play the game with it. Having taken hold of the ball he then returns to his chair and throws it to someone else (Chellowfont Day Centre).

The use of a parachute at Chellowfont Day Centre effectively drew everybody into the activity. We all grasped the edge of the fabric and flicked the material which caused the ball on top to jump into the air. It rolled off the fabric next to Mrs Begum and she picked it up and placed it back onto the top. This felt significant to me; she was actively engaging. There were smiles when the ball hit the ceiling and dislodged a tile. We were working together collaboratively.

"Facilitating engagement through music and rhythm"

The use of music and rhythm aided engagement in physical activity through the innate ability of participants' bodies to respond to it. I witnessed many examples of music supporting movement from tapping fingers to dancing. This was captured in the sub-themes "rhythm supporting movement" and "music helping things along". At Stanford Well-being Café one afternoon I watched while people mouthed the words to songs and swayed. The entertainer was singing "Deep in the heart of Texas" and encouraged everyone to clap rapidly along with the music at specific moments. Marcus clapped in perfect time, others had more difficulty. At Chellowfont Day Centre music drove participation in the activity, everyone seemed to be moving part of their body, tapping their toes tapping, twirling wrists and flapping their arms:

> Most people make some attempt to move their limbs vaguely in the manner suggested by the commentary on the tape. A frail lady moves her shoulders and hands gracefully and expressively to the music. I reflect how I like the music and the way in which it directs my movements (Chellowfont Day Centre).

Other residents remained seated but clapped their hands, tapped their feet or moved other parts of their bodies spontaneously along with the music. At the well-being cafés, music was particularly effective in facilitating physical activity when it was used to create a party atmosphere.

> At Browgate the music was live rather than recorded. One afternoon we were invited to stand in a circle holding hands while the singer performs "NewYork, New York". We followed the example of the entertainer and began to move together; Step step, kick. Step step, kick! Most people managed to perform the expected movements. It felt celebratory (Browgate Well-being Café).

At WAP, the day centre providing services for south Asian women, the exercise group was run without music but the rhythmic way in which we all slapped our knees and clap our hands seems to help perform the activities. The exercise leader encouraged us to perform the movements by calling out "Slap slap, Clap clap". This

reminded me of the pleasure of childhood games and games that I had played with my own children. I experienced pleasure in the movement of my body, it felt easy. I felt included and found myself exchanging smiles with the women sitting next to me. The sub-theme "inappropriate music" reflects that music had to fit the mood and be culturally/ethnically appropriate or it could jar. One morning in December the staff members at a day centre put on Christmas music during a boisterous game with a balloon. Whilst the activity continued and participants engaged half-heartedly I conclude that on this occasion the music failed to support the activity in any sense. The exercise tape used at Chellowfont Day Centre featured a heavily accented American commentary exhorting us to perform line dancing moves. Most of the group attempted to join in but the three South Asian members of the group stayed seated. They usually engaged in all activities. I found that there was a limit to how aspects of participant's bodies facilitated successful engagement in physical activity. This section contains themes which suggest that at times participants had difficulty in engaging in physical activity due to their embodied nature.

"The frail body"

Engagement in physical activity was sometimes limited because of the effects of physical health ill-health on their bodies. For example, during the exercise group at Chellowfont Day Centre, one participant repeatedly indicated to me that his shoulder was painful. He seemed to have difficulty throwing and catching the ball. Several individuals attending well-being cafés told me that they were unable to dance because of joint and balance problems. There were other ways by which physical activity could easily be disrupted.

"Cognitive overload: engagement through the body disrupted"

Engagement in physical activity was sometimes limited by the presence of cognitive demands on participants which they were unable to cope with. They were unable to engage in the activity in a pre-reflexive manner. A mismatch between skills and demands was a regular occurrence during physical activity sessions at Chellowfont Day Centre. Sometimes the problem lay in the materials chosen on which the activity was based, such as the exercise tapes with unclear instructions.

> I sit next to Penny during the seated exercises. An exercise tape featuring a very heavily accented American voice is used. The voice has a drawling Southern accent. It instructs us to "scissor your legs!" and "pound your fists!" I'm confused by the instructions and I rely on watching staff members. Penny is also struggling to keep up. "I'm lost" She says "I don't know what I'm doing" (Chellowfont Day Centre).

During these episodes it appeared that physical activity could be quite a negative experience for participants.

"Breaking the ice: the inhibited body"

Engaging in dance could be challenging for both participants and staff/volunteers. This appeared to be related to inhibition and a sense of awkwardness. At the Stanford Well-being café I was aware that getting up and dancing was quite difficult.

> I get up and hold hands with four women and a man who are dancing in a circle (it is unclear who has dementia and who is the carer). I don't feel confident in getting up to dance. I don't trust my body to do the right thing. We shift our weight from one foot to the other. The hands that I hold feel sweaty. I sense it's a little awkward for the others as well as for me. Nevertheless there are lots of smiles and eye contact. I have a sense that there is social ice that needs to be broken (Stanford Well-being Café)

Sometimes at the cafés the people around me seemed slightly ill at ease and self-conscious. Some individuals with dementia never got up to dance. The cafés meet monthly and many of those present could have been meeting for the first time. At Browgate Well-being Café, I spoke to a participant about why she was not dancing. It was her first visit and she told me that she felt too self-conscious about losing her short term memory which meant that she forgot what people told her. I discussed the difficulty that people experienced with getting up and dancing with Marjorie Peterson who co-ordinated the cafés. I told her that I found it hard to get up and dance and she admitted that she did too:

"What if everyone I ask refuses to get up and dance with me. How would that make me feel? But you need someone to get people going!" (Marjorie Peterson).

She recognised that it was hard and that people needed support in order to participate.

The influence of the lived environment

In this section I will refer to themes that are related to the impact of the environment on participants' engagement in physical activity. I begin by presenting themes which suggest that aspects of the environment could have a positive influence on participants' engagement in physical activity.

"Safe environments"

A supportive social environment clearly had a facilitating effect on participation in physical activities. For example, Browgate Well-being Café provided a safe environment for Megan to wander freely:

> Megan is silent except for responding to the greetings of others with a brief "hello". She wanders around the hall between groups of dancers. Her husband watches from the side. She goes right up to the singer and stands in front to him. He carries on singing while showing his acceptance of her by taking hold of her hand. Eventually she moves away and continues to walk among the dancers. People greet her and her face lightens with a smile. From time to time she starts to dance but quickly stops. For a while she disappears from the hall and her husband gets on to his feet and starts to look for her but she quickly reappears, there are volunteers around to make sure nobody leaves the building alone. I think about how safe/caring and supportive the environment is (Browgate Well-being Café).

"Familiar territory: ethnic identities supported"

Social environments that were culturally/ethnically familiar to participants made engagement in physical activity easier. For example, at the Smithson Well-being Café which catered for people with eastern European backgrounds, activities included dancing with a handkerchief and kissing members of the opposite sex to the accompaniment of traditional Polish music. Bercik who was Polish commented that he felt "normal" when performing physical activity there. His identity was supported by a culturally familiar environment. On the other hand, the Browgate Well-being Café reflected White British ethnic characteristics; "doing the locomotion", Hokey Cokey and dancing the conga involved men and women performing familiar dances together. Whilst not unknown, kissing was much rarer here. In contrast, the South Asian exercise group at WAP was attended by women only and reflected another shared set of experiences. There were no other men apart from myself present. All the women except Maya who ran the exercise group were wearing traditional clothing. The women who attended were clearly at ease. There was laughter and physical affection amongst the twenty or so women who sat in a circle. The women were invited by the instructor to handle the exercise equipment "…like rolling chapattis". Inevitably, at every intervention, elements of physical activity were more familiar to certain participants e.g. dancing was familiar to several White British women participants, who had done it for much of their lives.

"**Difficult environments**"

On the other hand, an unhelpful physical environment could make the performance of physical activity difficult for participants. At High Grange Day Centre the exercise group was run in an oblong open plan area where there were constant distractions such as members of staff continuously passing through the area. The layout of the room was unhelpful. The television was situated in the far corner and when I asked a woman sitting next to me if she could see the television properly she told me that looking at it made her neck ache. At the Stanford Well-being Café dancing was made difficult by the small cramped room. I felt as if I was squeezed up against the entertainer's equipment.

Summary of chapter five

Most participants were motivated to engage in physical activity and expressed positive attitudes towards it. Participants reported that they enjoyed it and they considered it beneficial. For some participants having dementia meant that they could be less critically aware of activities. Being physically active was significant for some participants because it was an integral part of their identity. A minority of participants expressed indifference to physical activity. Social factors influenced participants' engagement in physical activity. Social factors could represent a barrier to engagement. Participants reported a shrinkage in their social world which was related to dementia and this could make being physically active difficult. Participants needed social support to perform this and this was not always forthcoming. Familiar activities and social ritual supported engagement in physical activity. Social facilitators of physical activity were also apparent. Participants were motivated to spend time with others and valued the opportunity to mix with others who had dementia. Engagement was facilitated by practical support and encouragement when staff allowed people with dementia to take the lead rather than directing them.

The manner in which participants related to their bodies could be an important influence on engagement in physical activity. A number of facilitators relating to the body emerged from the study. Participants often valued their bodies highly and physical activity provided an opportunity for them to feel good about themselves. For some participants, the restlessness of their bodies facilitated engagement. Embodied skills were resistant to the cognitive effects of dementia. Bodies provided a resource for communication and self-expression which could be used in the context of physical activity. Dementia had a liberating effect on some participants; the disinhibition they experienced resulted in full engagement in physical activity. Having dementia could be an advantage in other ways when performing physical activity; physical health problems were forgotten. Other factors also influenced participants' engagement. The use of music and rhythm could facilitate engagement because they tapped into embodied skills which meant that participants could respond pre-reflectively to it. Equipment supported physical activity by physically connecting participants. A number of barriers to physical activity relating to body were identified. Some participants had difficulty engaging due to physical frailty. During dance

participants could experience inhibition which made it hard for them to engage in an embodied manner. Free engagement in physical activity in a pre-reflective embodied manner was also disrupted by factors such as cognitive overload.

Aspects of the physical environment exerted an important influence on engagement. Safe social and physical environments which supported participants' ethnic identities facilitated engagement in physical activity. Chaotic, cramped environments disrupted engagement in physical activity. It is important to note that the ethos at well-being cafés (particularly the café run by the Alzheimer's Society at Browgate) was different from the day centres which were mostly run by the NHS and social services and which inevitably felt much more clinical. The different approaches influenced the ambience of the cafés and day centres. I will discuss the implications of these varying approaches further in chapter seven.

In this chapter I have presented my findings which related to factors influencing participants' engagement in physical activity. Whilst I found that most participants wanted to engage in activities they were subject to number of factors which influenced their engagement. Participation in physical activity could be fragile and easily disrupted. In the next chapter I will discuss the findings relating to the effect that performing physical activity had on the well-being of participants.

CHAPTER SIX

Study findings: participants' experience of physical activity and well-being

Introduction

In the previous chapter, I presented themes originating from my data which were contained within my first group of categories and which related to factors that influenced participants' engagement in physical activity. I began by presenting themes which reflected participants' relationship with physical activity. My findings suggested that most participants held positive beliefs regarding physical activity, expressed positive attitudes towards it and were well motivated to engage in it when the opportunity arose. I then presented themes which identified a number of factors which influenced the degree to which participants engaged in physical activity. These factors were associated with the social and physical environment and aspects of participants' relationships with their bodies.

In this chapter I will present the rest of my findings. Figure 6.1 contains my remaining categories, themes and sub-themes. The upper section of Figure 6.1 contains the second group of categories which emerged from my data analysis. These contain themes that reflect participants' experience of physical activity and the impact that this had on their well-being. My first category, "Engaging in activity" contains themes representing the benefits resulting from participants' engagement in the process of physical activity. My second category, "Connecting with others" contains themes related to the benefits resulting from participants interacting with others through physical activity. My third category, "Feeling good" contains themes associated with participants' enjoyment and improved mood relating to engaging in physical activity. My fourth category, "Supported identities" contains themes suggesting that engaging in physical activity provided opportunities for some participants to position themselves effectively and construct social identities.

Figure 6.1 Categories, themes and sub-themes representing the influence of physical activity on participants' well-being.

The benefits of physical activity: components of well-being

Engaging in activity.
"A chance to burn energy"
Taking the opportunity to burn energy.
"Being in the moment"
Effortless engagement. Spontaneous engagement. Acceptance of others.
"Providing diversion and structure to social life"
Looking forward to attending. Dressing up. Sense of occasion.

Connecting with others.
"Making connections through physical activity"
Mixing with others who have dementia. Engagement with others. Retained social awareness. Affirmation of self from others.
"Having fun together"
The pleasure of competition. Humour. Playfulness. Breaking rules together. Making people laugh.
"**Being together through physical activity"**
Expressing intimacy. Acknowledgement of shared activity

Feeling good.
"Bodies feeling good"
Feeling great. Soothing
"Enhanced mood through physical activity"
Relaxation. Diversion. Feeling happy. Relief.

Supported identities.
"Empowerment through physical activity"
Being assertive. Doing something new.
"Constructing identities through physical activity"
Constructing gender identity
"Self-expression through physical activity"
Performance. Humour. Playfulness.

The experience of well-being through physical activity: a typology

"It's all coming together"
"Party time at Browgate Well-being"
Intoxication. Like a party. Using embodied abilities. Without inhibition. A buzz in the room. Touching others. Music and rhythm.
"Bercik takes to the stage"
Engaging without difficulty. Spontaneous engagement. Self-expression through physical activity. A performance. In the moment
"A glimpse of sunshine on a cloudy day"
Engaging with others. Expressing enjoyment. Communicating through physical activity.

"Doing it anyway"
"Being physically active their way"
Overcoming barriers. Being assertive.
"Mrs Begum takes control"
Being assertive. Breaking the rules

"Wanting to but not quite getting there"
"There's something stopping me"
Struggling to participate. Unmet need for physical activity.
"Unbroken social ice"
Passivity. It's too difficult

"It's just not happening"
"It's not for me"
Not interested. Indirect involvement
"Being left out"
Unmet need for physical activity. Ignored by others.

The lower half of Figure 6.1 lists the four categories which form a typology representing participants' experiences of physical activity. My four categories "It's all coming together", "Doing it anyway", "Wanting to but not quite getting there" and "It's just not happening" represent an additional level of data analysis and contain a synthesis of findings presented previously in order to form new themes and categories. I will explain later in the chapter why I decided to take this approach. Each category in my typology will contain themes which illustrate how the factors which influenced participation in physical activity interacted to varying extents and the consequences of engagement in terms of well-being. The contents of my four categories will vary from describing incidences where participants were highly successful in their endeavours to be physically active and well-being indicators are clearly evident, to situations when physical activity failed to take place and ill-being was clearly expressed.

Engaging in activity

The first category listed in Figure 6.1 is called engaging in activity. In my study physical activity provided the context within which participants had the opportunity to be occupied and engaged in activity. Engagement in activity clearly resulted in benefits in terms of participants' well-being. Several themes reflect how this took place.

"A chance to burn energy"

In the previous chapter I referred to the theme "The restless body" and described how several participants identified themselves as "busy people". Physical activity appeared significant for them because it provided them with a way of being occupied or busy. The theme, "A chance to burn energy" refers to the opportunity that physical activity gave several participants the opportunity to expend energy. For example, Jack told me that despite the fact that he was compelled to constantly find chores to do at home he never really felt tired. He reported that when he came to the well-being café he had energy and that dancing there was the best way to burn it off:

"You've got five days of built up energy. That's why I can't sit down much at home. I'll maybe go out and cut the grass or disappear in the garage doing something. I can't really sit down at home" (Jack).

Jack reported feeling a sense of relief after dancing with others for a couple of hours at the well-being café. Sometimes participants' reserves of energy remained undiminished despite extended activity. For example, I noted that participants sometimes danced at the well-being cafés for the entire afternoon without appearing to tire.

"Being in the moment"

One of the reasons why several participants found physical activity so pleasurable appeared to be that it provided them with the means to be completely immersed in the activity to the extent that they were in "the zone" or experiencing flow (Czikszentmihalyi, 1990). It first occurred to me that participants were experiencing flow when I went walking with Jacinta and Simon. When Jacinta and I walked together and she talked to me about the Caribbean, she seemed comfortable and at ease in a way that she had not appeared before we left the day centre. She used her hands and shoulders to gesticulate. Her tone of voice became varied and lively as she talked. She greeted people in the street. There were no signs of fatigue, she was engaged and energised. During our 75 minute walk in a local park, Simon also seemed alert and aware of his surroundings, fully engaged in the flow of the activity. Simon appeared relaxed, not exuberant as he had presented at the well-being café, nor was he stilted and struggling to communicate as he did during his interview.

"Providing diversion and structure to social life"

Some participants reported that physical activity could provide a useful diversion. Jacinta described how walking took her mind off concerns such as studying. Attending day centres and well-being cafés could also help provide structure for participants' lives. Several participants told me that they looked forward to coming to the well-being café. A participant told me that as soon as one session ended he started looking forward to the next. Similarly, when I asked Stella about her views of the High Grange Day Centre she told me:

"I enjoy everything here..everything…I look forward..when I leave at the end of one week I can't wait to come again" (Stella).

The themes introduced above reflect the benefits that participants experienced as a consequence of engagement in activity or "doing". I will now present themes which suggest a number of social benefits.

Connecting with others

In the previous chapter I noted that participants were aware of their social needs but often had difficulty meeting them due to the effect of dementia on their social lives. The following themes reflect the opportunity that physical activity gave them to be included in social activities.

"Making connections through physical activity"

This theme contains elements relating to both spatial and relational connectedness. For example, some participants found that being physically active connected them to the world around them in a spatial sense. Several participants talked about the fact that walking allowed them to enjoy the countryside. One told me of her love of mountain walking in the Lake District. Another described a gentler attitude to being active. She told me that she valued what she described as "pottering in the garden" as an alternative to being be "stuck in all the time".

Physical activity connected participants in a social sense. The social benefits of physical activity performed with others were discussed by many participants. Several participants said that the most important part of attending the café was to meet people and the way that this happened was through dance activities. I found that physical activity could provide a catalyst for social interaction. For example, people with advanced dementia attending Chellowfont Day Centre generally did not initiate conversation with each other or even recognise the existence of one another unless engaging in physical activity. Nevertheless, I noted that on one occasion two participants threw a large ball between each other for several minutes. They appeared completely engaged in throwing and catching the ball and working together. Physical activity had enabled them to connect with each other non-verbally.

Participants connecting with others through movement occurred on a regular basis. At the Stanford Well-being Café, Megan who had advanced dementia, stood in front of the entertainers who were moving their arms in time above their heads. As she mirrored their movements she appeared to be connecting with them through the actions of her body. I noted a similar occurrence when I observed Marcus as he danced with Marjorie Peterson who co-ordinated the well-being café network. They stood facing each other several feet apart with Marcus moving his arms above his head as if he was directing traffic. Marjorie reproduced his movements closely. This activity clearly had a positive impact on his well-being that afternoon. As he was dancing he caught my eye from across the room and waved to me and when I asked him later how he had got on that afternoon and he told me that he had enjoyed himself.

Similarly, at Browgate Well-being Café as I watched Jack shuffle slightly robotically around the dance floor, I noted that he engaged with everyone around him, smiling and pulling faces. Dancing had provided him with an opportunity to interact with others. The ability for participants to connect with others through physical activity was particularly evident during free flowing activities when people were unsure when they would need to respond to what was taking place around them and attention was focused on each other rather than on the completion of a task.

> We finish a game which involved participants taking turns to throw balls at a target. The new activity involves passing a large ball between members of the group. People become more alert. It is spontaneous and does not involve turn taking or scoring. I am given the ball and ask the group "Who wants it?" Jane calls out "Me!" while others raise their hands to indicate that they want it too. Ronald leans forward in his chair. This was a clear signal for him that he wants to be involved. (I know when Ronald is engaged because he leans forwards in his chair- when disengaged he sits back and cradles his head in his hand.) A game of catch begins with participants acknowledging each other for the first time that morning. "Do you want it?" Jane asks Ronald. There is a tendency for them to throw the ball back to me so I stand and walk away while the group continue to spontaneously throw the ball between

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themselves. This felt significant; participants were relating to each other without the interference of staff and sustaining an activity between them. (Chellowfont Day Centre).

"Having fun together"

Physical activity could provide the context for humorous non-verbal interaction which could be highly pleasurable for participants. At High Grange Day Centre I watched a game take place during which a parachute was stretched between people and a ball placed on top. The use of a parachute physically connected the members of the group and focused everyone's attention on moving together in a way that did not require spoken instructions. Participants and staff moved the ball around by flicking and lifting the fabric. Inevitably the ball would roll off the parachute at times which resulted in shared laughter. Performing physical activity together therefore provided an opportunity for light hearted and humorous interaction.

"Being together through physical activity"

Doing something with other people and sharing this experience appeared to be a source of well-being for many participants. I certainly felt a sense of inclusion when joining in the activities as I conducted my participant observation. At Chellowfont Day Centre I noted that it felt good to be standing in a circle with others listening to the tape instructing us to perform line dancing movements. I noted that there was an increased level of eye contact between us compared to other times at the day centre. At the Stanford Well-being Café I felt as if I should join in and dance although it would take a great effort on my part. As I did so I felt a sense of relief. I shuffled rather awkwardly from foot to foot but felt a real sense of togetherness with the people around me. It gave me a chance to connect with participants. At Stanford Well-being Café I noted the following:

We dance in a circle and I catch Esther's eye. Esther is virtually non-verbal at this point in time but she loves to dance. She gives me a wry smile. Her husband has told me that they have had a bad night. We exchange further nods and smiles, mutual recognition of what we are doing. (Browgate Well-being Café)

Esther's willingness to warmly engage with me as we danced together suggested to me that she was experiencing a degree of well-being despite the difficulties of the previous night. Megan was another participant who appeared to benefit greatly from engaging in dance at the well-being café:

> Megan is gently led onto the dance floor by two volunteers. She looks lost, but her calm expression suggests that she is comfortable with being here. Megan smiles as she starts to move her body gracefully to the music. She joins a circle of others and her smile broadens. She looks across the hall in my direction and beckons me to join her (Stanford Well-being Café)

Megan's behaviour and particularly the fact that she initiated contact with me in order to invite me to join her on the dance floor indicated a degree of well-being. Physical activity provided a context within which some participants could express themselves in a romantic, flirtatious or intimate manner. When I watched Megan and her husband dance together at the Stanford Well-being Café, I was reminded that they were a married couple as well as a person with dementia being supported by their carer. They held each other close and smiled at one another as they danced gracefully together. However, not all couples who attended the wellbeing cafes danced together. For example, despite Barbara's enthusiasm on the dance floor, her husband rarely joined her. I reflected that dance was not an activity that every participant enjoyed.

Feeling good

I found that engaging in physical activity could provide a sense of pleasure and enhanced mood for the participants.

"Bodies feeling good"

Most participants gave the impression that they gained pleasure from their body's engagement in physical activity. For example, Jacinta reported that her body felt good when she was walking and that she was free from aches and pains. She went on to tell me how much she enjoyed the physical sensation of being submerged in water when swimming. During Jacinta's interview I asked her how she felt after she had finished her physical activity. Jacinta described how she felt after a long walk:

"WON-DER- FUL! Abso-lutely wonderful! You can feel…yourself can't you? You're all nice and warm. So …and then, from there, home and into the bath" (Jacinta).

Another participant told me that her body felt good when she danced at the well-being café. At Chellowfont Day Centre I noted how I enjoyed the exercise tape because of the way it made my body feel. The voice instructed us to breathe deeply and slowly exhale. It was pleasant and soothing to raise my arms above my head and move them "like a willow" along with the others around me who all did the same. After the activities at the Smithson Well-being Café finished one day I asked Bercik how he felt. He denied feeling tired, telling me with a laugh that his arms and legs felt "fantastic". Unfortunately, the positive effects could be short-lived. One participant told me that she felt good after the exercise groups at WAP although as soon as she returned home she felt as if she was back "at square one". At Chellowfont Day Centre physical activity seemed to have a soothing effect for a short while on Mrs Begum. She stopped calling out and moving her arms when the exercise group started and became engaged in what was happening around her. However, when the group finished she began to lift both her arms up in the air again and repeated her phrase "Poo nam ree".

"Enhanced mood through physical activity"

As well as a sense of pleasure, several participants discussed how their mood was affected both during and after physical activity. Najma reported that she liked to walk outside and visit family and friends; doing so lifted her mood, relaxed her and made her happy. She told me that it "freshened" her "head". Barbara said that she felt "great" when she was dancing at Browgate, when I pressed her about how she felt great she responded that she felt happy. Other participants talked about the mood improvements that resulted from them being active. Jack described feeling "relieved" after dancing at the wellbeing café. Simon told me that he felt better after he had gone for a walk and Jacinta said that she felt relaxed after walking.

Supported identities

Sometimes participants' identities appeared to be supported during engagement in physical activity. Several themes reflect the significance that physical activity had on the way they constructed their identities.

"Empowerment through physical activity"

Participants in the study could be empowered following their successful inclusion in physical activity. Engaging in physical activity could provide them with a chance to redress the normal balance of power which existed between them and the staff caring for them. It gave the opportunity to lead the staff in certain activities. For example, one morning at Chellowfont Day Centre I noted that when music was put on the participants took the initiative. They began to sing and spontaneously clapped their hands. The staff responded by clapping as well; the participants had taken the lead and the staff were following their example. Empowerment is also reflected in the theme "Mrs Begum takes control" which will be discussed later on in the chapter.

"Constructing identities through physical activity"

Physical activities such as dancing could enable participants to construct social identities. Being physically active could make participants feel they were themselves. For instance, it was clear that Bercik engaged in the physical games and dancing at the well- being café with obvious enjoyment. During his interview afterwards he told me that the way in which he participated and his enjoyment of making others laugh made him feel "normal". Physical activity enabled participants to construct particular aspects of their identity. For example, at Browgate Well-being Café, Simon danced closely with the women volunteers forming the centre of the dancing group, flirting with each in turn. Dancing had enabled him to construct a gendered identity. Elsewhere at Stanford Well-being Café, Marcus' wife was very quick to get up and dance even if her husband was initially reluctant. She flirtatiously hit the back of his head as she passed, then leant up against his back as he remained seated. Dancing at the well-being cafés allowed expressions of sexuality in an appropriate non-problematic fashion. Dancing also enabled some participants to construct new identities. Marcus' wife commented to me that he had never been a dancer in the past. Similarly, when I commented to Jack's wife that he seemed to enjoy himself on

the dance floor, she told me that he had always avoided dancing until he started attending the well-being café.

"Self-expression through physical activity"

Physical activity offered the chance for participants to express themselves. At Chellowfont Day Centre, although often sitting silently, Ronald was quite capable of acting expressively in a spontaneous manner when given the chance. During one exercise group I watched while the ball trickled to a halt by Ronald's feet. He got up, took a step and kicked the ball playfully across the room. Dance also provided many opportunities for self-expression:

> Gladys is moving her body along to the music whilst still sitting in her chair. She's small and frail, one of the older members of the group. She has difficulty walking and often requires a steadying hand. Her movements are delicate, intricate and stylised. She's even twirling her wrists in the way that we do when following the exercise tape. Gladys' movements appear to reflect her feminine identity. I think she must have been a keen dancer in the past. (Chellowfont Day Centre).

After watching Ronald and Gladys move I concluded that most of the communication and self-expression that morning had been through the body and had taken place when performing physical activity. In this section I have presented a number of themes which suggest that participants experienced a wide range of benefits associated with their engagement in physical activity. They experienced a sense of well-being through the process of active engagement, from connecting with others, from the enjoyment of their bodies, from enhanced mood, and finally through the opportunity it provided for self- expression and the construction of their identities. It is apparent that the relationship between physical activity and well-being is a complex one. In the next section I will change my focus again in order to explore participants' experiences of physical activity and well-being through the use of a typology.

The experience of well-being through physical activity; a typology

Categories contained in the lower half of Figure 6.1 form a typology which represents participants' experiences of well-being through physical activity. Typologies are classification systems used to group social phenomena in order to describe and aid understanding of them (Berg, 2009). Typologies are usually multidimensional or multi-factorial, combining two or more dimensions so that a more refined or complex portrayal of a phenomenon can be identified (Ritchie et al. 2003). As mentioned previously on page 132, I chose to undertake further analysis of the categories and themes presented so far and generate further themes in order to develop a typology for three reasons. Firstly, whereas before I had considered the factors influencing engagement in physical activity and the ensuing benefits separately, I decided that these factors were closely related and should be considered both together and in the context of specific participants' experience. A typology would enable me to draw together these disparate threads and aid in the understanding of a complex social phenomenon. Secondly, a typology would enable me to illustrate the range of experiences that participants displayed and reported during the study. These ranged from full engagement in physical activity and high levels of well-being to low levels of engagement and lack of well-being. Thirdly, I decided that further analysis of my data and the development of a typology could draw to light what combinations of factors conditions facilitated well-being through physical activity most effectively. This would make the practical implications of my findings clearer.

In this section, reference will be made to elements of the well-being tool developed by Bradford Dementia Group (Bruce, 2000; Bradford Dementia Group, 2005). This tool was introduced in chapter two (p 49) and well-being indicators are listed in Table 2.2. Four categories describe the varying degrees to which study participants engaged in physical activity and experienced well-being as a result of this activity. The first category, "It's all coming together" describes how a combination of factors outlined in the previous chapter facilitated full participation in the activities and expressions of well-being were clearly evidenced. The second category, "Doing it anyway", contains themes relating to how participants were able to overcome barriers to full engagement in physical activity and how evidence of well-being was

displayed. The third category, "Wanting to but not quite getting there" contains themes referring to instances when participants were unable to overcome the barriers despite them appearing to be interested in being physically active. The final category, "It's just not happening" is comprised of themes describing circumstances when participants did not perform physical activity for a variety of reasons and whilst there was some evidence of well-being this could not be attributed to the physical activity.

"It's all coming together"

In this first category, participants were observed to engage well in physical activity and many of the well-being indicators were clearly identified through interview data and field notes. Participants engaged in activities in the manner intended by those running the intervention. Factors which facilitate physical activity are present and whilst factors acting as barriers may have been present they were overcome by the majority of participants. It was clear that the degree to which participants experienced well-being through physical activity varied according to location.

"Party time at Browgate Well-being Café"

At Browgate Well-being Café there was a high level of engagement in physical activity and clear evidence of well-being. My findings suggest that this was due of the presence of a number of factors. Firstly, the social and physical environment was supportive. The atmosphere there felt celebratory. The sound of laughter and exchanged greetings generally filled the hall. The party ambience was enhanced by entertainers singing along to backing tracks. The physical environment there was conducive to dancing. There was a large space in the centre of the hall where people were clearly expected to get up and dance. It was hard to have conversations with people due to the amount of noise and this favoured people who found verbal communication difficult. The fact that it was a mostly non-verbal environment had the effect of "normalising" relationships. Although I discovered later that some people with dementia there were experiencing considerable cognitive impairment, as a visitor it was not immediately apparent who they were.

Secondly, the volunteers and entertainers worked hard and were generally effective. On my first visit volunteers were putting thought and effort into their role. There was generally a group of five or so volunteers who facilitated engagement by inviting participants to join in. This made participation easy and legitimised physical contact with others. Thirdly, the type of physical activity readily facilitated engagement and promoted well-being. The familiar dance moves and music associated with activities such as the conga and "Hokey Cokey" provided clear structure. The activity was less intense; people were not facing each other in pairs as they so often did at the Stanford Well-being Café. My anxiety about dancing in pairs disappeared when dancing in a group. There was plenty of evidence of participants experiencing enhanced well-being. In fact, all of the well-being indicators were identified. The act of dancing bonded everyone together. Simon personified the powerful effect that some participants experienced at Browgate Well-being Café:

> I watch Simon and I am struck by the contrast between his behaviour at the café and his presentation at the interview. He was immediately on the dance floor. He was confident and assertive, clearly communicating with his body. He appeared comfortable, he was enjoying himself (laughing loudly), he seemed in a state of energised focus. He held the hands of those next to him aloft and sang exuberantly at the top of his voice, he appeared liberated. Simon was on his feet for almost 1hr 45mins. I thought how different he was dancing compared to his presentation during his interview; then he was serious, ponderous, restless, and struggling to communicate with words (Browgate Well-being Café).

There was a downside to the party atmosphere. Not everyone joined in and I reflected on the possibility that some participants may have felt outsiders. I noted on one visit that I was tired after a running a long race the previous weekend and definitely not in the mood for a party. I was being encouraged to conform and this made me want to resist. The sight of people behaving in an intoxicated manner; singing at the top of their voices and dancing boisterously with their arms held aloft sometimes left me feeling uncomfortable and I wondered if others felt the same.

"Bercik takes to the stage"

There were episodes during physical activity when aspects of participants' behaviour clearly reflected well-being indicators. For example, Bercik displayed evidence of deep enjoyment when a game with a handkerchief took place at the Smithson Well-being Café:

> Everybody is seated around a large circle. A man begins to play an accordion in the background signalling that it's time for the activities to start. A staff member dances in the centre with a handkerchief until the music stops at which point she presents it to Bercik. The musician plays a few bars of a wedding march. Bercik and a member of staff exchange kisses on both cheeks while saying "booshie booshie". Bercik stands a little stiffly. He is tall and long-limbed, his trousers pulled high; he looks fit and handsome. Instead of waving the handkerchief like the staff member has done he ties it around his neck. He performs a funny dance in the centre of the ring; shuffling his feet, sticking out his bottom and waving his arms. People respond with laughter. Then he drops dramatically to one knee and pauses. There is a moment of expectation. What will Bercik do next? The staff member stands and moves across the room to join him. She encourages him to dance with her which he readily does. Bercik is enjoying himself. He seems unselfconscious, his behaviour is met with tolerant amusement. (Smithson Well-being Café)

Many of the indicators of well-being were identifiable during Bercik's dance; he displayed pleasure, he made social contact with people, he was alert and responsive, he expressed creativity, humour and a sense of purpose, his body language was relaxed. As well as non-verbal expressions of well-being I was able to talk to Bercik shortly after the session finished which enabled me to ask him how performing the activities made him feel.

> Alan -"You seemed to really enjoy it in there."
> Bercik- "Yes, I enjoyed it, yeah."
> Alan- "Is there anything in particular that you enjoyed?"
> Bercik- (Laughs) "Messing about!" (laughs again)

Alan- "You seemed to be having a lot of fun"

Bercik- "Making people laugh"

Alan- "Yes?"

Bercik- "That's it. Nobody trained me, it's just in my mind like this" (Bercik).

Bercik appeared to benefit from a combination of a supportive social and physical environment, familiar music and activity and the result was a high degree of well-being.

"A glimpse of sunlight on a cloudy day"

This theme reflects the contrast that sometimes was apparent between participants' experience during physical activity sessions compared to other times of the day. At Chellowfont Day Centre I noted how participants expressed well-being during physical activity when at other times during the day such signs were largely absent. Participants expressed appropriate emotion, acted with a sense of purpose, made contact with others, and were alert, creative and expressed pleasure. However, the degree to which the physical activity resulted in evidence of well-being indicators was variable and expressions of well-being during physical activity could be fleeting. At the well-being cafes and day centres, the activities that were most effective in generating well-being involved staff engaging with participants on an equal footing. For example, when staff danced with participants by holding onto their hands in order to support and give encouragement, I noted that those involved watching each other intently and smiles were exchanged. I experienced the sense that everyone present was sharing an enjoyable activity together. There was a similar sense of shared activity and well-being when certain pieces of equipment were used and spontaneity was encouraged. For instance, the pleasure of passing objects to others:

> I throw the ball to Ronald and he immediately returns it. I send it back to him and it goes backwards and forwards, quicker and quicker. He smiles broadly. I carry on returning the ball until he decides to pass it to someone else which eventually he does (Chellowfont Day Centre).

Unfortunately, the moments during which physical activity resulted in clear evidence of well-being at Chellowfont Day Centre were brief. When the members of staff left

the room a sense of gloom could rapidly descend. Indicators of ill-being became evident; participants became withdrawn and listless, it was as if they retreated back inside themselves again. Furthermore, it should be noted that not every participant benefitted from physical activity.

"Doing it anyway"

This category contains themes relating to the manner in which some participants overcame barriers in order to engage in physical activity and this resulted in clear evidence of well-being indicators. In my study I found that participants could be successful in being active but not necessarily in the way envisaged by the staff organising the intervention.

"Being physically active their way"

At Chellowfont Day Centre the exercise tape was difficult to follow; the music was fast and constantly changing and the instructions were confusing. The participants performed their own movements regardless of what the tape instructed them, tapping their feet and moving their arms and legs along with the music. I noticed on several occasions that when the exercise sessions started Mrs Begum who tended to call out her phrase stopped and began moving her limbs whilst smiling to herself. On one occasion a CD was played featuring Christmas carols, while a balloon was introduced for participants to pass between them. This choice of music seemed incongruous to me; I felt that the music completely failed to match the activities. Nevertheless, Joe and Ronald boisterously kicked and batted the balloon between them with their hands, bouncing it into the air with their knees. Several times Joe knocked the balloon back to Ronald with his head. The balloon was sent around the room in this manner, occasionally hitting people's faces which resulted in laughter. Despite a lack of support and guidance from the staff, the two men engaging in this activity were both alert and responsive, they expressed appropriate emotion, displayed humour, interacted with each other, and showed pleasure, all of these suggest that well-being was being experienced. At the High Grange Day Centre, despite the terrible DVD, absence of encouragement and chaotic environment, participants still persevered in their attempts to perform physical activity and seemed to enjoy doing so. This was evidenced by participants tapping their feet, singing

along to the music and moving their limbs in approximately the manner suggested by the DVD.

"Mrs Begum takes control"

At times during physical activity at Chellowfont Day Centre, Mrs Begum displayed well-being indicators which appeared to result from her exerting her selfhood. For example, one day a game started which involved participants taking turns to throw several bean bags through holes in a scoreboard. Participants were instructed to remain seated as they did this. When it was Mrs Begum's turn, she stood and walked up to the board, in defiance of the staff. She then posted the bean bags rapidly through the hole before turning and walking back to her seat. She had been able to choose how to interact with the others present and communicate with them through her actions. She smiled broadly as she did this and then indicated to me that she wanted me to have a go too. Showing concern for others is considered an indicator of well-being. Mrs Begum was assertive on other occasions too; during an exercise session she emerged from the bathroom and joined the group half way through a game involving a large ball. We had been told to kick it between us. Taking control of the activity, Mrs Begum grabbed hold of the ball and threw it across the room. When it was returned to her she bounced the ball hard on the floor in front of her. It hit the ceiling and a light went out. The sound of laughter filled the room. These interactions contained many of the well-being indicators mentioned earlier, she was behaving with a sense of purpose; she was alert and responsive, she showed evidence of humour and enjoyment. I wondered if bouncing the ball in this manner reflected an element of anger or frustration as well.

"Wanting to but not quite getting there"

My third category contains themes reflecting episodes during my study when there was less participation in physical activity, less evidence of well-being indicators and some evidence of ill-being indicators. The ill-being indicators I identified included participants appearing withdrawn and listless and presenting as an outsider.

"Something is stopping me"

Jacinta reported that she was desperate to go on long walks but the barriers she faced prevented this from happening. Nevertheless she participated in shorter walks whenever she could and seized the opportunity of walking with me even if it was only a short walk around the block. Elsewhere, participants at Chellowfont Day Centre often appeared interested in performing physical activity but participation was derailed by the rule-bound and inflexible form that physical activities took.

"Unbroken social ice"

As previously mentioned, it appeared to be difficult for some participants to engage in dancing due to inhibition and insufficient supporting factors which may have helped them to take part. Many participants at the Stanford Well-being Café, did not dance, although they seemed to want to. People reacted to the music by moving in their chairs and clapping but often did not manage get on their feet like those attending Browgate Well-being Café. The social ice remained unbroken. At the Stanford Well-being Café the environment was cramped. The volunteers were gentle, unobtrusive and a little ineffective. There was no visible response from them one afternoon when a man danced alone exuberantly He was not supported in the way that Bercik was at the Smithson Well-being Café. Nevertheless, there were some benefits from the limited engagement in physical activity at the Stanford Well-being Café even if complete engagement in physical activity failed to take off. I watched Marcus and his wife mirrored each others movements as they respond to the music whilst remaining seated. When I spoke to participants about not actually getting up and dancing they commented that they had enjoyed watching others dance.

"It's just not happening"

This final category contains themes referring to episodes during which participants did not engage in physical activity. Participants not engaging in physical activity could coincide with them showing evidence of both well-being and ill-being. I will start by considering themes in which participants expressed well-being despite not engaging in physical activity.

"It's not for me"

Several individuals attending High Grange Day Centre did not conform with those around them; a small group carried on playing dominoes instead of joining the rest in exercising to the DVD. Similarly, one participant at Stanford Well-being Café never danced; she told me that she did not like it. But she did like to take part in organising the monthly well-being café and regularly assisted the volunteer at the table where people signed in. At Browgate Well-being Café, I chatted to a couple who did not dance. Through our conversation it became clear that it was the wife who had been told that she had dementia. They told me that they both had balance and joint problems. I asked if they still benefitted from coming. "Yes" The husband replied "It gets us out and mixing with others".

"Being left out"

Some people with dementia did not join in the physical activity and did not show any signs of well-being during the sessions but exhibited indicators of ill-being. I noted that Rose at Chellowfont Day Centre never took part in the physical activity sessions. Instead she spent all morning slumped in her chair, and was mostly ignored. She clearly displayed the ill-being indicators of being "easily walked over by others", "withdrawn or listless" and appearing an "outsider". Pauline, who also attended Chellowfont Day Centre, was one of the quieter participants and rarely participated in the activities. Like Rose, Pauline often presented as listless and withdrawn, and as an outsider during my visits. Twice during the exercise sessions, Pauline stood up, excused herself and left the room.

Summary of chapter six

In this chapter I have presented findings relating to participants' experience of physical activity and the effect that being physically active had on their well-being. I found that the relationship between physical activity and the well-being of participants was a complex one. The themes which emerged from my data suggest that participants benefitted from being physically active in a number of ways. It gave them an opportunity to be occupied through movement and this could be highly pleasurable for participants and exert a positive influence on their mood. Engaging in physical activity at cafés and day centres enabled participants to expend energy and afford a sense of relief. Engaging in physical activity resulted in a number of social

benefits. It provided a context within which they could connect socially and share enjoyment with others without the use of spoken language. Finally, I found that engaging in physical activity could empower some participants and enable them to express themselves and construct identities.

I then broadened my focus in In order to capture the nature of the relationship between physical activity and the participants' well-being. To do this I created a typology containing themes generated through a further process of analysis in which the participants' experiences were classified into four categories. The themes comprising these four categories suggested a wide variance of participants' experience. The degree to which participants achieved well-being through physical activity was dependent on a number of factors. Significant factors included a safe and uncluttered physical environment, effective support and leadership from those leading activities, familiar forms of physical activity, the use of appropriate equipment, and use of music and rhythm. I noted that participants could sometimes overcome obstacles and seize the opportunity to engage in physical activity. However, I also noted that achieving well-being through physical activity was often a fragile process, which was short lived and easily disrupted. Participation in physical activity could be prevented by lack of social support, inhibition, physical frailty and personal preference. In the next chapter I will discuss my findings in relation to the literature.

CHAPTER SEVEN
Discussion

Introduction

In the previous two chapters I presented a range of themes which were generated during data analysis and which formed the basis of my study findings. In chapter five I introduced themes which indicated that participants' attitudes to physical activity and their relationship with it were mostly positive. I then described themes which indicated factors that influenced their participation in physical activity. In chapter six I began by presenting themes which related to participants' experience of physical activity, the benefits that they experienced and the impact that physical activity had on their well-being. I then presented a typology which contained themes reflecting a range of participants' experiences of physical activity and well-being. This enabled me to explore the complex relationships between physical activity and well-being in a variety of settings and identify which combinations of factors had the greatest effect on participants' well-being. In this chapter I will begin by identifying five key findings which arose from a synthesis of the themes described in previous two chapters. I will then relate these findings to those reported by other studies and to the theoretical perspectives described in chapter two. This will allow me to identify the contribution that this study has made to the field of dementia studies in the areas of empirical knowledge, methodology and the application of theory.

Key findings

- Most participants were motivated to engage in physical activity and sometimes overcame considerable barriers in order to do so.

- Participants' embodied skills and abilities often provided them with a variety of resources with which they could counter the effects of dementia through engagement in physical activity.

- Participants' engagement in physical activity and the degree to which they experienced well-being was influenced by music and rhythm, the environment, type of activity, the effects of dementia and the nature of their interaction with others.

- Taking part in physical activity provided the majority of participants with a range of benefits which exerted a positive effect on their well-being. These benefits included, enjoyment, improved mood, occupation, connecting with others, self-expression, empowerment and an opportunity to construct social identities.

- Achieving well-being through engagement in physical activity was often a precarious and fragile undertaking for participants. Opportunities to be physically active could be limited and taking part in it was easily disrupted. Factors which made being physically active difficult for participants included a lack of social support, ill-health, an unhelpful environment and the nature of the available physical activity.

Discussion of key findings

I will now discuss each of the above findings in turn in relation to empirical and theoretical literature.

Most participants were motivated to engage in physical activity and sometimes overcame considerable barriers to do.

My first key finding relates to the degree to which participants were motivated to engage in physical activity. I found that most participants in my study were motivated to engage in physical activity regardless of their ethnic background. This motivation to be active appeared to be related to a number of factors. Positive beliefs and attitudes towards physical activity were often reported during interviews. My findings concur with other evidence from other studies that older people often think of physical activity in positive terms. Katz (2000) commented that in the context of old age, "activity" in all its forms is accepted by society as good and as a cultural ideal it inevitably conditions the beliefs of older people. Several of my participants expressed the view that being physically active was good for them. Maintaining physical health is thought to be important for many older people (Bond and Corner, 2004; Bowling, 2008). Others have found that older people in the wider population are well aware of the health benefits of physical activity (Crombie et al. 2004) and may think of physical activity as a means of warding off illness (Bullington, 2006). Several participants in my study regarded being physically active as an alternative to being sedentary which they regarded as boring. This finding concurs with Grant's

(2008) study which explored the meanings that older people in general attach to physical activity and which concluded that physical activity was a way to resist "idleness" which represented a threat to healthy ageing. It has also been pointed out elsewhere that being busy protects people from having time on their hands and the fear of oneself "vegetating" (Stahi, et al, 2002). My findings contribute to existing knowledge by suggesting that people from a variety of ethnic backgrounds with diagnosis of dementia share the positive views of older people in the wider community regarding physical activity.

Several participants reported that they had been advised to be active by health professionals on the basis that it was good for their physical health. The suggestion that people diagnosed with dementia continue to follow the advice of professionals extends evidence by Horne et al. (2010) who noted that advice given by health professionals to be physically active worked when it was related to physical health such as weight loss or for other physical health benefit. My finding implies that people with dementia may retain advice to be physically active and act accordingly.

Many participants had a well-established relationship with physical activity. They considered themselves to be active people. The participants who identified themselves as active individuals could be described as being "schematic" for physical activity. A self-schema is a cognitive structure based on an aspect of the individual's life to which they attach particular importance. It can be thought of as a form of "self-view" which has its origins in self-verification theory (Swann, 1983). I found that participants continued to view themselves in terms of their relationship with physical activity rather than an individual living with dementia. This mirrors other studies which have noted that people with dementia maintain other identities which are which were unrelated to dementia (MacRae, 2008). It was notable that participants in my study were sometimes motivated to engage in physical activity in ways they had shown no interest in before. This finding is similar to that of Pickle and Jones (2006) who described how someone developed an interest in dancing after they had begun to experience dementia. This implies that it would be a mistake for those involved in providing physical activity for people with dementia to assume that

an individual will not engage in an activity because they have not expressed interest in the past.

Participants in my study sometimes expressed the view that they felt compelled to be active. This urge to engage in movement seemed to be beyond their conscious control. Others have noted that bodies have an innate ability to express their nature (Toombs, 2006) and that this ability can be beyond our conscious control (Laz, 2003). One of my participants described how he would regularly spend time repeatedly climbing stairs at home at all hours of the day and night. The restlessness displayed by people with dementia is often described as wandering (Dewing, 2005) and has been noted to often take place at night (Volicer, 2007). Wandering has been conceptualised as a direct result of neurological damage to the brain leading to a drive to walk (Hope et al. 2001). Wandering is considered by some to represent a non-verbal but explicit expression that the person has a need for physical activity (Holmberg, 1997). On the other hand, wandering has been considered as an expression of unmet need, for things such as food or social contact (Lai and Arthur, 2003; Dewing, 2010). Whatever the cause, wandering is often considered a potential problem due to the risk of elopement, exhaustion and the possible experience of physical pain for the person involved (Lai and Arthur, 2003).

Dewing (2005) describes a debate within the dementia care field about whether the term is derogatory and the use of it leads to people being labelled. Dewing suggests that wandering should be viewed more positively as an activity and reminds us that most people engage in it at some point of their lives and that people living with dementia simply engage in particular types of wandering. It has also been noted that wandering like other forms of exercise has its health benefits (Lai and Arthur, 2003). Studies have found that wandering is particularly common among relatively young men who had an active "pre-morbid" lifestyle (Lai and Arthur, 2003). My participant Simon fits this profile very well. Walking and repeated stair climbing seemed to meet a need for movement. My findings contribute to knowledge of the restlessness associated with dementia by pointing out that Simon is both full aware of his behaviour and the fact that this behaviour is viewed as problematic by his wife.

Several participants were aware of their social needs and sought the company of others. Interacting socially is important for people because humans construct their social identities and sense of self by interacting with others (Hewitt, 2002). Social interaction is also considered as an important source of one's self-esteem (Goffman, 1959). Studies have found that connecting with others is a very important component in the well-being of people with dementia (Vernooij-Dessen, 2007; Katsuno, 2005; Wolveson et al. 2010; Williamson, 2010). This is also thought to be true for older people in general (Bond and Corner, 2001). Meeting the need for social interaction could be difficult for participants in my study because having dementia had resulted in a contraction of their social world. Participants were aware that they relied on others to access the community, struggled to interact through speech and could experience difficulties in their relations with others due to the stigma associated with dementia. Others have noted in the literature that people with dementia can become isolated in their homes (Cook, 2008).

My findings mirror other studies which have noted that people with dementia report feeling left out during social occasions (Wolveson et al. 2010), are at risk of feeling socially excluded and devalued (Katsuno, 2005; Steeman et al. 2006). My finding that most participants experienced a contraction of their social world concurs with Duggan (2008) who noted that people with dementia experienced a "shrinking world" due to restricted access to their neighbourhoods (Duggan, 2008). Phinney and Chesla (2003) described how the pre-reflective ability to participate in conversation can be derailed by dementia. What used to be accomplished without conscious effort had become difficult to achieve. A decrease in social interaction for my participants in these circumstances was likely as it is recognised that people will tend to avoid situations that impact negatively on their self-esteem (Goffman, 1959). The motivation for many participants to engage in physical activity appeared to be associated with a need for social contact. Social interaction through physical activity was important because they struggled to interact socially in a conventional manner. My study contributes to evidence that engaging in physical activity can afford a valued opportunity to mix socially with others.

I found that people in my study valued the opportunity to mix socially with others who had dementia. My findings concur with Pratt and Wilkinson (2003) who reported that people with dementia can find the opportunity to talk to others with the same condition valuable. According to Hewitt (2002) a consequence of being given a spoiled or "deviant" identity such as dementia is the tendency to identify with others who share the identity. When mixing with others, participants tended not talk to others at cafés and day centres, their interaction was primarily non-verbal. My conclusion that participants were partly motivated to engage in physical activity because it helped them interact with others in a non-verbal manner is supported by Phinney et al. (2007) who found that people with dementia report feeling social discomfort with others and avoid conversing with less intimate friends due to fear of embarrassment (Phinney et al. 2007). When writing about how people with dementia cope with the challenges associated with the condition, Clare (2002) suggested that they employ strategies to confront these threats and maintain their identities. My findings suggest that the motivation to engage in physical activity represents one of these strategies.

Participants' embodied skills and abilities often provided them with a variety of resources with which they could counter the effects of dementia through engagement in physical activity.

My second key finding relates to the significance of participants' bodies. Participants' bodies were often of great significance to them and this appeared to be because they could provide a resource with which individuals could deal with the cognitive difficulties and social disadvantages associated with dementia. Participants' bodies provided a resource in several ways. For example, the capability of their bodies to be active provided several participants with a source of pride which could make them feel good about themselves. This proposition is supported by the tenets of symbolic interactionism which suggest that people are thought to strive to attach a positive value to their self-image in order to enhance their self-esteem (Hewitt, 2002). Other studies have noted that the body can provide a source of self-esteem because it can provide an opportunity for older people in the wider community to feel good about themselves (Bullington, 2006). However, the capabilities of the body may be particularly valued by people with dementia because they may struggle to find other

ways of maintaining self-esteem due to losses relating to autonomy and independence (de Boer, 2007), the effects of malignant social psychology (Kitwood and Bredin, 1992) and positioning (Sabat and Harré, 1992).

A further resource provided by participants' bodies was the means to connect with the world around them. Participants' bodies provided them with the ability to express themselves and communicate with others. This was important for participants because most of them struggled with communicating through speech and several did not talk at all. Participants communicated non-verbally through touch, through the use of facial expression, by acting out what they wanted to describe during interviews, and through gestures such as hand shaking. My findings are supported by others. The body's ability to apprehend meaning and communicate is thought to persist despite cognitive loss (Kontos, 2004). Kontos (2005) noted that the body was the primary method by which cognitively damaged people engaged with the world because other methods were impaired. Similarly, Hubbard et al. (2002) commented that people with dementia attending a day centre used touch, gesture and body posture to communicate in meaningful ways. My findings provide evidence that physical activity provided a context within which self-expression and communication through the body was supported.

My finding that participants engaged in all manner physical activity in an expressive manner echo Whyte (2010) who found that participation in dance groups on a dementia unit resulted in self-expression and communication between people with dementia and others. The link between dance and self-expression is widely accepted. Nyström and Lauritzen (2005) pointed out that movement during dance symbolises thoughts, experiences and emotions as they are translated into movement. Nyström and Lauritzen's study involving people with dementia engaging in group "dance therapy" found that participants had the capacity to use a range of communication styles in dance. They concluded that body movement as communication is particularly important for people with dementia because of the limitations they experience in other forms of communication. My findings extend the evidence provided by others by noting that communication and self-expression took place in other forms of physical activity as well as dancing.

I found that participants' bodies could provide a resource in the form of a repository of embodied skills which could be used in the context of physical activity. Participants were able to maintain rhythm when exercising to music, they could throw and catch objects without difficulty and dance skilfully. These pre-reflective skills had been unaffected by the cognitive impairment associated with dementia. My findings are supported by Kontos (2004) who noted that in the right circumstances people with dementia can remain engaged with the world through their bodies because their pre-reflective abilities remain relatively intact.

Participants' engagement in physical activity and the degree to which they experienced well-being was influenced by music and rhythm, the environment, type of activity, the effects of dementia and the nature of their interaction with others.

My third key finding relates to a range of factors which influenced how participants engaged in physical activity and the extent to which they experienced well-being. I found that the use of music and rhythm facilitated engagement in physical activity and could magnify the well-being associated with the activity. This finding concurs with Kontos (2004) who undertook participant observation in a nursing home for people with dementia and who noted that during concerts and sing-alongs people in her study responded to music by standing up and dancing alone or with others. Others have found that music is an essential factor in creating an atmosphere when working with people with dementia (Palo-Bengtsson and Ekman, 2002) and enables social cohesion (Sixsmith and Gibson, 2006). Studies have noted that music supports movement through rhythm and suggest that it is effective for people with dementia because it does not have to be processed at a conscious level (Nyström and Lauritzen, 2005). The benefits associated with performing exercise along with music in the wider population have been considered by researchers. Clark et al. (2012) performed a systematic review of quantitative studies. They concluded that while there is good evidence that music improves exercise performance for younger adults there is limited evidence for older people. This is because of the emphasis that many researchers place on quantitative studies, which attempt to measure effect in terms of energy output and endurance. My findings add to evidence from other

qualitative studies that music can in fact exert a powerful influence on how older people with dementia engage in physical activity.

I found that elements of the physical environment influenced participation in physical activity. For example, running well-being cafés in secure buildings and having sole use of these spaces provided a safe spacious distraction-free environment for participants to freely move around. They were free from stigma and the judgement of others. This suggests that the choice of venue is important. Characteristics of the physical environment are rarely considered in studies exploring how people with dementia engage in physical activity. In my study, the cultural characteristics of physical activity, such as the degree of acceptable physical contact and styles of dance, could influence how those present engaged in it. Participants sometimes had difficulties which were likely to be associated with their ethnic identities. Therefore, whilst participants often engaged well in physical activity that supported their ethnic identities, unfamiliar cultural practices, and the use of unfamiliar music could make engagement in physical activity difficult. The tenets of embodiment theory provide a useful means of reflecting on these difficulties. Kontos (2004) suggests that an individual's embodied selfhood includes culturally specific social elements and suggests that it would be hard for someone to engage pre-reflectively in activities within an unfamiliar socio-cultural environment. I concluded that whilst participants with dementia from diverse ethnic backgrounds shared many of the attitudes and beliefs regarding physical activity as the wider older population, they sometimes engaged in physical activity in culturally specific ways.

In chapter two I referred to the work of Barth (1969) who stated that ethnicity was generated through social interaction. I noted that participants constructed their ethnic identity through the manner in which they participated in activities at the well-being cafés and day centres which themselves were clearly ethnicised environments. As well as difficulties in engaging in physical activity because of unfamiliar cultural characteristics, South Asian participants at Chellowfont Day Centre contended with other aspects of their ethnicity. They experienced high levels of excess disability because the difficulties that they faced with verbal communication due to cognitive impairment were exacerbated by the fact that they were expected to talk in their

second language. I concluded that cultural competence is an important component of services and vital in order to facilitate uptake by people from diverse ethnic backgrounds. My findings therefore extend knowledge about how people with dementia from different ethnic backgrounds engage with services.

In my study it became clear that the nature of the physical activity could facilitate engagement. Physical activity which contained an element of play i.e. that was spontaneous, enabled self-expression activity and which was valued in its own sake facilitated engagement. Kitwood (1997a) commented that many people with dementia retain the capacity to celebrate and it is during celebration that the division between caregiver and cared for comes nearest to vanishing. Later in this chapter I will discuss the difficulties that participants had as a result of activities that exerted cognitive demands that they could not meet.

I found that assertive leadership by those running the activity resulted in higher levels of engagement by participants at the well-being cafés and day centres. Those individuals who facilitated engagement most effectively recognised the importance of non-verbal interaction for participants and engaged in it themselves. An implication of these findings is that effective staff who are able to lead activities effectively are crucial. Whilst Hubbard et al. (2002) identified the importance of carers communicating non-verbally in an effective way with people with dementia, there is little in the literature about how the nature of the activity and style of leadership impacts on the degree to which people with dementia engage in physical activity. Two participants spoke about the positive effect that dog walking had on being physically active. This finding concurs with other studies which have found that dog ownership is associated with increased levels of physical activity (Cutt, 2008) and that taking one's dog for a walk acts as a catalyst for social interaction (McNicholas and Collis, 2000).

Sometimes participants engaged in physical activity in a strikingly unselfconscious manner which suggested that having dementia could exert a positive influence on their level of engagement in physical activity. Disinhibition and elation are among an array of behaviours including agitation, aggression anxiety and sleep disturbances

which are categorised as behavioural and psychological symptoms of dementia (Passmore, 2005). These are common among people living with dementia and are considered be potentially distressing to both themselves and to carers (Banerjee, 2009). My findings suggest that the activities at well-being cafés and day centres provided a context where disinhibition could be acceptable and could enhance the benefits of physical activity. Similarly, having dementia could sometimes appear to result in participants appearing to be unaware of their physical frailties. In the literature other studies have found that when people with dementia engaged in social dancing they seemed unaware of their physical frailties (Palo-Bengtsson, 2000). Finally, having dementia was an advantage for some participants in terms of free uncritical engagement in physical activity.

So far I have discussed factors which influenced engagement in physical activity and the experience of well-being on an individual basis. However, it was clear from my study findings that the extent to which participants experienced well-being through physical activity was influenced by a complex interplay of factors. Themes contained within my typology suggest that physical activity was facilitated most effectively when a number of factors coincided. For example, at the Browgate Well-being Café a combination of safe environment, music, familiar activities, effective leadership and celebratory ambience combined to provide high levels of well-being for participants.

Participants experienced a range of benefits as a result of physical activity which could have a positive effect on well-being
My fourth key finding relates to the benefits that participants experienced as a result of being physically active. My finding that participants enjoyed physical activity concurs with studies which included older people in general (Crone et al. 2005) as well as those focusing on people with dementia (Duggan, 2008). Participants' enjoyment of being physically active appeared to be based on a number of factors. Several participants reported that their bodies felt good when engaging in physical activity. Others have noted that the body can be a source of pleasure for older people when they engage in physical activity (Bullington, 2006). Another possible reason why participants expressed enjoyment was that they experienced improved mood as a consequence of being physically active. A positive effect on mood is

widely recognised as a benefit of physical activity (Biddle and Mutrie, 2008). As I mentioned in chapter two, physical activity is thought to promote relaxation through the warmth generated by muscle action (Koltyn, 1997) and as a result of reduced muscle tension following exertion (Webborn, 2002). My finding that walking was a source of pleasure for several of my participants concurs with Duggan's (2008) study in which 22 people with early to moderate dementia were interviewed and who's participants described enjoyment through walking alongside a range of other benefits. My findings also mirror those reported in Eggermont and Scherder's (2006) review of physical activity based interventions for people with dementia in which it was noted that walking was particularly effective in lifting the mood of participants. However, my findings extend those from other studies by identifying group exercise as a source of enhanced mood as well as walking. One participant in my study described the positive effect that burning excess energy had on his mood. He told me that burning energy through dancing resulted in him experiencing a sense of relief. This benefit is not mentioned in the literature.

My participants valued physical activity as a form of meaningful occupation. Meaningful occupation is recognised as being an important influence on the maintenance of quality of life for people with dementia (Phinney et al. 2007; Perrin et al. 2008). Clearly, meaningful occupation is of value to all and not just people with dementia. Studies have found that physical activity gives older people in the wider population a sense of purposeful activity (Crone, et al, 2005). However, meaningful occupation through physical activity is likely to be particularly important for people with dementia because they are at risk of losing other opportunities to engage in it (Steeman, 2008). One of the reasons why participants may have found physical activity so influential in terms of their well-being was because it is possible to engage in it without undue demands on mental processes. Phinney et al. (2007) found that people with dementia enjoyed activities that do not require too much thinking or talking. Duggan (2008) suggested that walking provides an effective way for people with dementia to benefit from occupation because it is simple and doable.

My theme "being in the moment" suggests that several participants experienced the state of energised focus described as flow by Czikszentmihalyi (1990). I introduced the concept of flow in chapter two where I described it as a harmonious state of optimal human experience characterised by an energised focus on a specific task (Czikszentmihalyi, 1990). While others have written about people with dementia achieving a sense of well-being through immersion in the pleasure of the moment (Phinney et al. 2007), the state of energised focus that is identifiable as flow is neglected in the dementia literature. One of my participants told me that walking and swimming provided distracted them from unwelcome thoughts. Diversion from negative thoughts is considered to be a benefit of physical activity in the wider population (Peluso and de Andrade, 2005; Bullington, 2005). Similarly, it has been recognised in the literature that physical activity can help older people cope with the stresses of life (Crone et al, 2005).

In chapter two I introduced the concepts of social identity and the work of Sabat (2003) in which he points out the difficulties that people with dementia have in positioning themselves and construct social identities. I found that the participants in my study were sometimes able to position themselves and construct social identities very effectively whilst engaging in physical activity. Whilst others have recognised that engagement in physical activity is a source of self-esteem and identity for older people (Bullington, 2006), physical activity is particularly well suited to people with dementia because it can be engaged in non-verbally and utilises pre-reflective abilities. I found that dancing together enabled people with dementia and their spouses to position themselves and others and express identities based on their emotional connection rather than care needs. My findings concur with Hasselkuss and Murray (2007) who pointed out that dementia impacts on the identity of the carers and that shared activities such as dance help the carer to reclaim their identity. I also noted how participants occasionally engaged in flirtatious behaviour with members of the opposite sex. Sexuality is present throughout our lives and is an integral part of our identity and self-esteem. Weeks (2003) states that sexuality helps give us our identities, our sense of gendered self. Weeks claimed that our sexuality is the most spontaneously natural thing about us and that it provides us with the basis of some our most passionate feelings and commitments. Dance allowed

participants in my study to express sexuality and gender in an acceptable manner. Physical activity allowed my participants to express other identities as well. For example, participants occasionally took on the role of performer with relish, this may reflect the fact that opportunities for people with dementia to perform and gain affirmation as a result can be rare.

I found that engaging in physical activity could provide participants with an opportunity for positioning themselves as confident individuals which in turn resulted in control and empowerment. Control and independence is something which is lost through the process of dementia (Langdon et al. 2007; Steeman et al. 2008). For example, engaging in physical activity at Chellowfont Day Centre provided participants with the chance to lead staff in activities. Similarly, participants sometimes performed physical activity in a defiant manner, persevering in performing the activity in the way they chose despite instructions to do otherwise by staff. Hockey and James (1993) pointed out that older people can retain power when faced with infantilisation by resisting as children. By disobeying instructions, participants empowered themselves in a childlike manner. Similarly, when given the means to do so, participants at Chellowfont Day Centre were able to briefly sustain an activity without direct intervention from staff. The presence of equipment, placing participants in a circle within a supportive environment and tacit permission from staff enabled this to happen. The suggestion that people with dementia are capable of independently sustaining a ball game is supported by the view of Kontos (2004) who commented that people with dementia can be fully aware of their surroundings and can engage with the world with coherence, purpose and meaning despite their cognitive impairment. My findings relating to the way that participants actively engaged in physical activity contribute to the growing evidence which suggests that when circumstances allow, people with dementia are far from passive in response to the social world around them.

I found that engaging in physical activity could provide participants in my study with a range of other social benefits such as interacting and connecting with others and sharing experiences. This finding is concurrent with the literature relating to older people in general and people with dementia specifically. Studies exploring older

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people's relationship with physical activity have consistently recognised that social benefits are important to those taking part (Crone et al. 2005; Hardcastle and Taylor, 2005; Litzim and Schiovitz-Ezra, 2006; Bowling, 2008). Earlier in the chapter I suggested that the need for social interaction was an important factor in motivating participants to engage in physical activity. My theme "connecting with others" suggests that participants could be successful in meeting this need through physical activity. Social participation and involvement in the world are recognised as having a positive influence on well-being (Bradburn, 1969). My findings that a variety of different forms of physical activity can meet the social needs of people with dementia extend those of Duggan (2008 who found that people valued walking out of doors because it brought them into contact with others.

I found that engaging in various forms of physical activity could provide a chance for participants to experience being together with others. Crone et al. (2005) describe how older people in the wider community attending exercise referral schemes report a sense of belonging and inclusion. My finding that a variety of activities can provide this benefit extends evidence provided by Palo-Bengtsson and Ekman (2002) who commented that walking groups including people with dementia and care staff provided opportunities for mutual tenderness such as linking arms which generated a sense of communion. As I mentioned in chapter three, studies have found that dance promotes a sense of togetherness and inclusion (Palo-Bengtsson and Ekmann, 2000; Ravelin et al. 2006; Whyte, 2010). Dance events with people living with dementia are thought to be valuable for all involved because they can result in the "ontological state of being together" (Palo-Bengtsson and Ekman, 2000, p162). I found that participants in my study sometimes mirrored the movements of others when dancing. The act of dancing is also thought capable of promoting attachment through synchronous movement (Schmais, 1985) and emotional arousal (Palo-Bengtsson and Ekman, 2002). Synchrony in activities such as this is thought to indicate an inter-personal connection (Schmais, 1985). Schmais (1985) describes how the synchronicity of movement during dance allows closeness and togetherness. Studies have considered the issue of emotional arousal. It has been suggested that dancing can change the dynamics of groups when they include people with dementia and carers, breaking down barriers and creating a more

positive relationship between individuals (Duignan et al. 2009). Some participants in my study appeared to gain a sense of inclusion despite the fact that they did not actively participate. This finding concurs with Palo-Bengtsson and Ekman (2002) who noted in their study that participants experienced a significant emotional reaction even if they did not get up and join in the dancing.

Physical activity enabled participants in my study to experience having fun together. Expressions of humour, seeking contact with others and responding to others are all indicators of well-being (Kitwood, 1997a). It occurred to me that interactions were more likely to be successful when they were playful. Kitwood (1997a) describes play as an exercise in spontaneity and self-expression that has great value in itself. Kitwood comments that play is an important aspect of occupation and that a good care environment is one in which play is encouraged. Hubbard et al. (2002) studied non-verbal interaction between people with dementia and staff at a day care centre. Hubbard noted that "larking about" and physical humour provided an effective way for staff and people with dementia to communicate with each other. My findings extend the findings of others by pointing out that physical activity can provide an opportunity for playfulness/larking.

In chapter two I introduced the work of Kitwood (1997a) who stated that the main focus of dementia care should be to maintain personhood for people as they faced the challenges of cognitive loss. Kitwood suggested that personhood is maintained through the meeting of five needs. Kitwood identifies these needs as occupation, identity, comfort, inclusion and attachment. My findings suggest that given the right circumstances, engaging in physical activity could address all of these needs and therefore support the personhood of my participants. I found that many participants displayed a wide variety of well-being indicators whilst engaging in physical activity. These included smiling and laughter, expressions of humour, creativity and affection for others. Therefore, being physically active has the potential to impact on an individual's well-being in a significant manner. Duggan (2008) noted that access to the outdoors could meet the needs of identity, inclusion and occupation for people with dementia. Apart from Duggan I found no other reference to Kitwood's model of personhood being applied in the context of physical activity.

Achieving well-being through physical activity was often a precarious and fragile undertaking for participants. Opportunities to take part in physical activity could be limited and engagement could be easily disrupted.

My final key finding is related to the fact that the experience of well-being through physical activity was often fleeting, difficult to attain and easily disrupted. I noted that whilst participants in my study were well motivated to be physically active, they faced a variety of barriers which they had to overcome in order to engage in physical activity. Some of the barriers were associated with being older and were shared with others who are not experiencing dementia. After all, it is recognised in the literature that participation in physical activity in the wider population declines with age (Chaudhury and Skelton, 2010). Ill-health represented one barrier for some participants. This finding is unremarkable as physical health problems are a common challenge when older people attempt physical activity (Iliffe, 1994). Other barriers faced by my participants such as cultural expectations relating to being older have been identified elsewhere as being significant for older people in general (Stead et al. 1997). Likewise, aspects of the physical and social environment such as lack of space, layout of furniture and constant distractions from other activities represented other barriers that participants had to overcome in order to engage in physical activity. These factors are likely to present barriers to anyone irrespective of their dementia status (Thurston and Green, 2004). Some barriers to physical activity in my study were social. Participants were generally reliant on others in order to be active and sometimes failed to get the support that they needed. Evidence from the literature suggests that lack of social support is a barrier for older people in the wider population too (Orsega-Smith, 2007; Gellert et al. 2011). Gellert et al. (2011) found that having social support and more specifically, being accompanied by a spouse was positively related to engagement in physical activity among older people in the wider community. Nevertheless, a lack of social support is particularly significant for people with dementia because of the potentially disempowering effects of the condition (Kitwood, 1997a) which increases their reliance on others.

As well as barriers shared with other older people, participants experienced difficulties that were clearly related to dementia. The cognitive difficulties experienced by several of my participants resulted in them not being able to go out

alone due to fear of getting lost. This finding is similar to that by Duggan (2008) who described a "shrinking world" in which the degree to which people with dementia can access the outdoors becomes restricted. It was clear that difficulties relating to cognition presented a barrier for participants attempting to engage in physical activity. For example, I noted that participants in my study could struggle when faced with over-demanding activities. It appeared that participants' ability to engage in activities in a pre-reflexive manner was easily disrupted by overcomplicated instructions. When this took place evidence of well-being was lacking. After all, an activity is unlikely to be a positive experience for an individual if the demands made by it outweigh the skills that they possess (Csikszentmihalyi, 1990). This finding implies that when promoting physical activity for people with dementia it is essential that activities are "doable".

I previously discussed how engaging in dance resulted in a number of social benefits associated with well-being and that the inhibition relating to dementia enabled some participants to dance freely. I also noted that engaging in this type of activity was not always easy and that both participants with dementia and carers appeared to struggle to dance due to inhibition. Van Manen (1990) discusses how when the body is the object of other's gaze it may lose its naturalness; "Under the critical gaze the body may turn awkward, the motions appear clumsy" (p104). Palo-Bengtsson and Ekman (2000) completed a study during which people with dementia engaged in social dancing with staff at a nursing home. They commented that the activity led to emotional arousal for all concerned which could be problematic for them. The carers found dancing difficult because the activity was associated with aspects of their identity that they did not usually consider when at work, such as their gender and the way their professional role dictated how they interacted with others. I noted that from my perspective of a health care professional, the non-clinical nature of the setting and the activities felt uncomfortable. I felt exposed without the protection of a professional identity. To me the well-being cafés felt a little forced at times. We were being invited to participate in a party but it was lunchtime, there was no alcohol. We were surrounded by people we might not know very well and it was the reason for the celebration was unclear. These musings reflect the negative side of activities at the well-being cafés.

Contribution to empirical knowledge

In the last section I have outlined my key findings and discussed them. I have identified a number of ways in which my findings have contributed to current knowledge of the relationship between physical activity and well-being for people with dementia. I found that people with dementia from a variety of ethnic backgrounds can be highly motivated to participate in physical activity. I pointed out that physical activity can be an effective way for people with dementia to meet their social needs because it taps into the innate resources of the human body. I have contributed to knowledge relating to the factors which influence participation in physical activity and how it can promote the well-being for people with dementia. I have added to the understanding of what factors relating to physical activity contribute to the well-being of people with dementia. I have found that the relationship between physical activity and well-being can be a complex one. I have pointed out that providing physical activity for people with dementia in a manner which results in positive effects in terms of well-being can be difficult to get right.

Aspects of my study findings contribute to existing knowledge on the basis of its scope. Firstly, I included participants living in the community who attended community based services and my findings therefore complement quantitative research featuring community dwelling people with dementia performing physical activity. These studies have found that people with dementia are able to perform unstructured physical activity (Netz et al. 2007) and that being physical active can be beneficial in terms of maintaining the ability to perform activities of daily life (Teri et al. 2003) and managing the effects of BPSD (Woodhead et al. 2005). More importantly, my findings help fill a gap as most studies exploring dementia and physical activity have included participants that reside and engage in activities in care homes (Mathews et al. 2001; Palo-Bengtsson and Ekman, 2002; Nyström and Lauritzen, 2005; Eggermont and Scherder, 2006; Rolland et al. 2007; Hokkanen et al. 2008). Focusing on people who live outside care institutions is important because most people with dementia live in the community (Luengo-Fernandez et al. 2010).

Secondly, in contrast to much previous research, participants in this study were ethnically diverse and participated in physical activity in settings that provided services for both highly diverse and ethnically specific social groups. This is significant because currently there is little available evidence relating to the influence of ethnicity on how people with dementia experience services. Thirdly, my study included physical activity that was unstructured and performed in participants' homes and local communities. This is relevant and timely because the Prime Minister's Challenge on Dementia (DOH, 2012) emphases the need for effective community based services that support people with dementia. My focus on activities which included carers is in contrast to most dementia and dance studies in the literature which have focused on the interaction between people with dementia and paid carers (Ravelin et al. 2006), this allowed me to explore the value of physical activity and dance in normalising relationships between people with dementia and their spouses.

Theoretical contribution

In this study both social interactionist (Goffman, 1959; Blumer, 1962) and embodiment (Merleau-Ponty, 1962; Bourdieu, 1977) theories were recognised as useful theoretical lenses through which to understand the experience of physical activity for people with dementia. Kitwood (1997a and 1997b) and others (Sabat and Harré, 1992) applied the principles of interactionism to the experience of dementia fifteen years ago. More recently the concept of embodiment has been applied to dementia (Phinney and Chesla, 2003; Kontos, 2004; Martin et al. 2013). My study is unusual because it has combined both theoretical positions whilst focusing on physical activity and well-being. This is the only study I am aware of apart from Duggan (2008) which has applied Kitwood's model of personhood to explore the relationship between physical activity and well-being. I found that Kitwood's model provides a useful framework with which to explore how engaging in physical activity exerted a positive influence on many participants in my study.

Methodological contribution

A secondary aim of my research was to contribute to the debate regarding the most effective methodologies to employ when conducting research involving dementia, physical activity and ethnically diverse populations. My study adds further evidence in support of the view put forward by others that people with significant cognitive difficulties are able to engage well in a research study (Dewing, 2007) and describe their experiences in a meaningful way (Page and Keady, 2010). Furthermore, as noted elsewhere (MacRae, 2008) I found that several participants in my study were keen to talk about their experience of the condition. However, I found the application of Dewing's (2007) process consent model difficult due to the busy and dynamic nature of the social environments in which my study was based.

I used participant observation and semi-structured interviews in exploring the lives of people with dementia. These methods enabled me to consider both behaviour and the self-reported views of participants. Participant observation and interviews proved to be an effective combination and provided me with a number of crucial insights. On a fundamental level, it reminded me that what participants said and what they did could be very different. It also provided important insights into the dementia experience. For example, the embodied nature of dementia became visible when participants struggled to talk to me during their interviews and communicated non-verbally instead. Furthermore, by observing people with dementia perform physical activity after they had struggled to talk with me, it was clear that much of what constituted their selfhood remained and that they could sometimes flourish in a non-verbal environment. The findings would have been much poorer had only one or the other method been used. This combination of methods has been used in a small number of dementia studies (Phinney and Chesla, 2003; Phinney et al. 2007; Hulko, 2009; O'Connor et al. 2010).

In chapter three I noted that most research evaluating physical activity for people with dementia has been positivist in nature and has employed quantitative methods. Systematic reviews of RCTs have stated that conclusions regarding the usefulness of physical activity are difficult to reach due to methodological inconsistencies between studies (Forbes et al. 2008; Potter et al. 2011). My study employed an

interpretative approach using qualitative methods and found clear evidence that physical activity has the potential to positively impact the well-being of some people with dementia. My findings demonstrate the value of qualitative approaches in exploring how physical activity can be important for people with dementia. Studies such as this complement quantitative research and can assist it by identifying what forms of physical activity should be evaluated by larger studies and reminding researchers that factors such as ethnicity and environmental characteristics are important to consider.

Summary of chapter seven

In this chapter I began by listing my key findings and then discussed them in relation to the literature. I identified the contribution that my study has made to dementia studies in three areas. Firstly, by adding to existing empirical knowledge relating to the experience of physical activity for people with dementia and the impact that being physically active can have on their well-being. Secondly, by applying both psychosocial and embodiment models in the context of physical activity and well-being I have contributed to the debate regarding the value of a number of theoretical models. Thirdly, I have contributed to debate regarding the most effective methods of undertaking research with people who have dementia. In my final chapter I will place my findings in the context of dementia policy and practice and reach my conclusions.

CHAPTER EIGHT

Conclusions and recommendations

Introduction

In the previous chapter I identified the five key findings that emerged from my study and discussed them in relation to the literature. By doing this I was able to highlight the contribution that my study has made to dementia studies in the fields of empirical knowledge, theory and methodology. In this final chapter I will begin by re-visiting my research questions, I will then present a synthesis of my study findings. I will follow this by relating my findings to current dementia policy and practice. In the second half of the chapter I will make recommendations regarding research and discuss the strengths and weaknesses of my study. I will then finish the thesis with some concluding remarks.

Revisiting my research questions

The aim of my study was to explore how physical activity influenced the well-being of a group of older people from diverse ethnic backgrounds. In chapter one I identified five research questions which would enable me to do this. In this section I will return to these questions and answer them by referring to my findings.

Question One: How do older people with dementia from diverse ethnic backgrounds engage in physical activity?

The participants in my study performed structured physical activity in a variety of settings which included well-being cafés and community centres. They also engaged in unstructured physical activity in their own neighbourhoods and homes. Whilst some settings provided care solely for people with dementia, others also served the wider older population. Some of the day centres and well-being cafés attended by participants provided a service for specific ethnic communities. My findings concur with Phinney et al. (2007) who found that people with early and middle stages of dementia continued to engage in social activities and valued contact with others who had dementia. I found that whilst most participants were capable of engaging in physical activity on their own terms in spite the presence of substantial barriers, they were often reliant on the support of others in order to be physically active. Social

support for engagement in physical activity has been found to be important for older people in the wider population (Oresa-Smith et al. 2007). My study participants usually performed physical activity in a non-verbal manner and often engaged pre-reflective skills when being physically active. Furthermore, participants could be physically active in an expressive way and sometimes performed physical activity in a strikingly unselfconscious manner. Others have noted how activities such as dance enable people with dementia to express themselves (Nyström and Lauritzen, 2005). Participants in my study generally engaged well in dance-based activities and this finding concurs with other studies which have included people with dementia (Palo-Bengtsson 1998; Kontos, 2004; Duignan et al. 2009; Whyte, 2010; Hammill et al. 2011; Ravellin et al. 2011). When participants in my study engaged in physical activity at the day centres and cafés they did so collaboratively with others, both with and without dementia. I found that this interaction could often be playful and humorous. This mirrors findings by Hubbard et al. (2002) who explored how people with dementia communicated with others in a day centre. It was notable in my study that participants sometimes engaged in physical activity in ways they had shown no interest in before. This was particularly the case with dancing. A new found enthusiasm for dance amongst people experiencing dementia has been noted elsewhere by Pickles and Jones (2006). Finally, I found that participants did not always engage in physical activity when invited to do so because they were not interested or chose not to conform.

Question Two: What benefits do older people with dementia from diverse backgrounds experience?

Engaging in physical activity provided participants with a variety of benefits. Some of these have been reported in studies including people with dementia engaging in a variety of activities. My finding that physical activity could be the source of enjoyment and improve the mood of participants concurs with other studies (Eggermont and Scherder, 2006; Duggan et al. 2008). Other benefits that have been reported elsewhere include occupation (Perrin et al. 2008), social interaction (Cahill et al. 2004; Katsuno, 2005; Beard and Fox, 2008) and diversion (Phinney et al. 2007). I found that participants were able to express themselves and form social identities in the context of physical activity. Whilst this benefit has been noted for older people engaging in physical activity in the wider community (Bullington, 2006) and for

people with dementia engaged in activities of daily living (Phinney et al. 2007) it has not been recognised as being significant for those with dementia outside the context of dance. My contribution therefore has been to identify physical activity as a context within which these benefits can clearly be found. Participation in physical activity resulted in evidence of a wide range of well-being indicators (Bruce, 2000) which suggested that being physically active could have a significant effect on participants' well-being. It was apparent that physical activity could impact the well-being of many participants by helping them to experience comfort, occupation, attachment and supporting their identities. Whilst Duggan et al. (2008) found that walking outdoors met Kitwood's needs of identity, inclusion and occupation I found that all five needs were met through a range of physical activity.

Question Three: What barriers influence how older people with dementia engage in physical activity?

Participants faced barriers relating to their individual characteristics, social factors, type of physical activity and aspects of the environment. Barriers associated with individual characteristics included attitudes held by others and those with dementia relating to getting older which included the assumption that reduced activity and ill-health were inevitable. These finding concur with other studies (Iliffe et al. 1994; Stead et al. 1997; Chaudhury and Skelton, 2010). In my study, participants were sometimes prevented from being as physically active as they wanted to be. They often faced barriers associated with social factors which included lack of practical support. For example, several individuals were unable to go on long and energetic walks because there was no-one to accompany them. Lack of social support has been found to be a barrier to physical activity for older people in general (Orsega-Smith, 2007; Bird et al. 2009). Lack of encouragement and fact that staff and volunteers sometimes failed to engage non-verbally with them during physical activity was also a barrier for some participants. For example, at some well-being cafés, tentative attempts by people with dementia to participate in dance failed because members of staff and volunteers did not engage in the activities themselves. Others have found that effective communication between staff and people with dementia within the day centre environment has a powerful influence on those receiving services. For example, Hubbard et al. (2002) commented that the failure of carers to interact non-verbally can impede the efforts of people with

dementia to communicate. I found that the type of physical activity that the participants in my study were encouraged to perform could also constitute a barrier. For example, activities they were encouraged to engage in were sometimes too cognitively demanding. Phinney et al. (2007) found that participants valued activities that they could do without having to think about them. Similarly, although effective for some participants, the use of dance at the well-being cafés was not always successful. Some participants, carers and staff found it hard to engage in dance. This finding concurs with Palo-Bengtsson (1998). Finally, I found that aspects of the physical environment such as lack of space, layout of furniture and constant distractions from other activities could make engagement in physical activity difficult. None of the studies which included people with dementia in physical activity that emerged from my review of the literature addressed these factors.

Question Four: What facilitators influence engagement in physical activity?

My study found that most participants were motivated to be physically active despite the presence of dementia and I identified a number of facilitators which influenced engagement in physical activity. For example, positive beliefs and attitudes regarding physical activity were often reported during interviews. Others have found that older people in the wider population hold positive attitudes towards physical activity (Katz, 2000; Bond and Corner, 2004; Bowling, 2008). My participants reported that the advice of health care professionals had a positive influence on their engagement in physical activity. This finding concurs with other studies which have included older people from the wider community (Horne et al. 2010). Personal characteristics such as the need for movement, occupation and social interaction, were also an important influence for some of my participants. I found that particular elements of physical activity facilitated engagement in it. These elements included social ritual, music and rhythm, and familiar activity. My finding that music is both remembered and an important component of well-being is mirrored elsewhere (Kontos, 2004; Pickle and Jones, 2006; Sixsmith and Gibson, 2006). I found that physical activity which contained an element of play i.e. that was spontaneous, enabled self-expression activity and which was valued in its own sake facilitated engagement. This finding is similar to Hubbard et al. (2002) who discussed the importance of light-hearted non-verbal interaction in promoting well-being in a day centre setting. However, my study

differs by pointing out that physical activity can provide a particularly effective context for this type of interaction.

Social factors such as the active encouragement by staff at well-being cafés and day centres resulted in high levels of engagement by participants. I found that the staff and carers who facilitated engagement most effectively recognised the importance of non-verbal interaction for participants and engaged in it themselves. Whilst Hubbard et al. (2002) stress the importance of non-verbal interaction; there is nothing in the reviewed literature about how adopting a pre-reflective non-verbal approach of leadership impacts engagement in physical activity for people with dementia. Finally, I found that environmental factors influenced participation. For instance, running well-being cafés in secure buildings and having sole use of these spaces provided a safe spacious distraction–free environment for participants to freely move around**.** Young and Dinan (2005) recommend safe, well-lit environments for undertaking physical activity with older people in the wider community. However, research including people with dementia neglects the importance of these factors.

Question five. What role does ethnicity have in the experience of physical activity?

People with dementia in my study generally reported positive beliefs and attitudes regarding physical activity regardless of their ethnic background. Participants from all ethnic backgrounds sought to engage in physical activity, followed the advice of their GP to partake in physical activity and reported similar benefits from performing it. My findings are similar to Horne et al. (2010) who reported little difference in the uptake of physical activity recommended by health care professionals between whites and south Asians. In contrast, an Australian study reported by Bird et al. (2009) found that certain barriers to physical activity were specific to ethnic groups. Participants in my study engaged well in physical activity when their cultural identities were supported through familiar cultural practices. For example, dances such as the Conga, which were well-known to the majority of those attending Browgate Well-being Café, were particularly well received. A similar finding was noted by Kontos (2004) who found that care home residents in her study remembered and sang along with traditional Jewish songs. However, participants in my study sometimes had difficulties which were likely to be associated with their cultural identities. For

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example, the use of western music and dance styles could make engagement in physical activity difficult for south Asian participants. I concluded that participants with dementia from diverse ethnic backgrounds shared many of the attitudes and beliefs regarding physical activity as the wider older population but they may engage in physical activity in culturally specific ways.

Synthesis of study findings

Based on my study findings, I concluded that physical activity was useful for many participants because it gave them an opportunity to respond to the challenges of dementia. Physical activity provided the context within which they could engage the innate skills that their bodies possessed which had survived the process of cognitive impairment. When engaging in physical activity, most participants could position themselves and others effectively and therefore construct a variety of social identities. Aspects of their selfhood were supported through physical activity and a number of psychological needs were met. Meeting these needs had a positive effect on their well-being. The degree to which participants could achieve well-being through physical activity was dependent on the interplay of the following factors. Firstly, the attitudes and behaviours of the participants and those around them were important. For example, a positive relationship with physical activity on the part of the individual with dementia and staff who are supportive, assertive and who are able engage in activities non-verbally. Secondly, aspects of the social and physical environment where the physical activity took place were influential. Locating activities in a secure and comfortable space helped make them effective. Thirdly, components of the physical activity itself were significant such as familiar activity, the use of equipment to physically connect those involved and the effective use of music and rhythm. Effective engagement was more likely to take place when there was a match between participants' ethnic identities and the cultural components of available activities such as music and choice of activity. Achieving well-being through the performance of physical activity was often a fleeting and fragile undertaking for participants. This was because their engagement in physical activity could be easily disrupted by a lack of social support, over complex activities and inhibition relating to dance.

Relating my study findings to dementia policy and practice

In chapter one I identified two secondary study aims. The first of these was to contribute to the debate about the most effective methodologies to adopt in undertaking studies with people who have dementia. My second aim was to inform dementia policy and provide practical recommendations for physical activity based activities for people with this condition. I have already discussed the extent to which I met the first of these aims in my discussion chapter. I will now turn to my second aim and relate my findings to dementia policy before discussing the implications of my findings in terms of practice.

Implications for dementia policy

I will start by identifying recent influential dementia policy. In the last few years dementia has been the focus of increasing amounts of attention from policy makers in both the national and international context. Several national key policy documents have recently emerged. These include the NICE clinical guidelines for dementia originally released in 2006 and updated in 2011 (NICE, 2011) and Living Well with Dementia: A National Dementia Strategy (Department of Health, 2009). Another recent key policy document is The Prime Minister's Challenge on Dementia (Department of Health, 2012). Recent international policy documents include the World Alzheimer Report, 2011 (Prince et al. 2011) published by Alzheimer's Disease International and Dementia: A Public Health Priority produced by the World Health Organisation in 2012. Findings from my study are relevant to several strands in current policy which will now be discussed in turn.

Recent NICE guidelines (2011) offer advice on best practice on the care of people with dementia. They state that person-centred care underpins good practice in the field of dementia care. These guidelines share the view taken in my study that the experience of dementia is partly influenced by individual factors such as personality and life experiences. The NICE (2011) guidelines also recognise that social relationships are important for people with dementia and can strongly influence their well-being. My study contributes to the understanding of how the well-being of people with dementia can be supported by engaging in physical activity within a social environment. NICE recommends that interventions should be tailored to the individual needs of the person with dementia. One of the contributions that this study

makes is to point out that when interventions are offered, individual factors such as ethnicity should be taken into account.

Both UK and international policy documents call for the development of community-based services because they are thought capable of providing valuable support for people with dementia (Department of Health, 2009; World Health Organisation, 2012). This theme is echoed in the Prime Minister's Challenge on Dementia (Department of Health, 2012) which recently called for the creation of dementia friendly communities. My findings are particularly relevant to this agenda. Firstly, participants spoke about the stigma that persists around dementia and how their interaction with others in the community is coloured by this stigma. This suggests that work in educating the public and reducing stigma remains to be done. Secondly, my study found that most participants valued the social support that they received through community based services. Furthermore, my findings have the potential to assist in developing effective services that enable people with dementia living in the community to live active lives and experience well-being.

Policy documents are tentatively supportive of physical activity for people with dementia. For example, NICE (2011) recommends "physical exercise" as a means of promoting and maintaining independence. NICE guidelines recommend that exercise should be available for people with dementia who have depression and/or anxiety and that music and dancing can be useful for "non-cognitive symptoms and behaviour that challenges". Similarly, the recent World Alzheimer Report (Prince et al. 2011) found that the available evidence from RCTs which includes physical activity based interventions for people with dementia in order to maximise physical function was equivocal and of insufficient quantity. The report states that whilst consideration should be given to developing physical activity programs, the benefits for people with mild dementia are uncertain. The general consensus expressed by those involved in dementia policy is that more research on interventions for people with dementia is needed (DOH, 2009, DOH, 2012). This is particularly important in relation to physical activity because the evidence base is limited (Forbes et al. 2008; Potter et al. 2011).

My study contributes to this evidence base by supporting the proposition that physical activity can be helpful for some people with dementia. Furthermore, my study extends current knowledge by identifying a wider range of the potential benefits than is usually associated with physical activity for people with this condition. These benefits include enjoyment, meaningful occupation, the construction of social identities and connecting with others, all of which contribute to enhanced well-being. The evidence considered by reviewers contributing to reports focus primarily on quantitative research and RCTs in particular (Prince et al. 2011). In chapter three I discussed how RCTs provide a specific type of evidence; they fix physical activity type, fix "measurable" outcomes and make assumptions about the significance of these outcomes. Observational tools are available (Perrin, 1997; Bradford Dementia Group, 2005) which suggests that measuring the degree to which people with dementia experience well-being through physical activity within a trial methodology is feasible. However, these methods have been difficult to operationalise due to the fleeting and highly subjective nature of well-being (Whyte, 2010). Bearing in mind these limitations, there is a need on the part of policy makers to recognise the contribution that other research studies which use other methodologies can make.

Recommendations for dementia practice

In this section I will identify aspects of my study findings that relate to the provision of effective physical activity for people with dementia. Firstly, I found that many participants in my study had a strong relationship with physical activity and had much to gain by continuing to engage in it. I would therefore suggest that physical activity is encouraged and facilitated for people with dementia by community based organisations, NHS Trusts and local authority bodies wherever possible. Secondly, I found that most participants were in need of practical help to perform physical activity. I would therefore recommend that the manner in which physical activity is promoted for people with dementia is carefully considered and the appropriate levels of assistance given where possible. An example of this is the provision of support for older people with dementia to go walking. Thirdly, I found that participants from ethnic minority groups could experience cultural barriers and were sometimes at risk from racism. I recommend that cultural and ethnic factors should be taken into account when facilitating physical activity with people from diverse ethnic

backgrounds who have dementia. Such factors include social norms relating to touch, styles of dance, type of activities and the selection of suitable music. Dance based activities may be welcomed by some but it is important to be aware that this does not suit everybody. Fourthly, in my study I found the approach of individuals leading the session was of key importance; a willingness to allow people with dementia to take the lead during activities and to adopt a non-verbal embodied approach to the activity themselves was crucial. However, there were many instances when physical activities could have been led much more effectively. I would therefore recommend that those involved receive adequate training which includes raising awareness of the significance of non-verbal communication and the facilitation of pre-reflective engagement in activities. The importance of a secure, uncluttered environment which is free from distractions should be also stressed. Furthermore, training should include guidance on the effective use of equipment, the avoidance of over complicated and cognitively demanding activities and the use of music and rhythm. Finally, promoting activities that are culturally appropriate for those taking part is vital.

Recommendations for future research

The emerging literature in the field of dementia is still biased towards a positivist, biomedical view of the condition. Further research is needed which addresses the subjective view of the individual living with the condition in order to redress this imbalance and help increase understanding of how elements of the dementia experience are constructed in the social world. I would suggest that further research is needed in a number of areas. Firstly, how using an ethnically appropriate environment can influence the participation in physical activity for people with dementia from ethnically minority communities. Secondly, which types of music, activities and environmental factors most effectively meet the needs of ethnically mixed groups of people with dementia when performing physical activity. Thirdly, what attitudes staff harbour relating to using physical activity with people who have dementia and what barriers staff experience when leading interventions for people with dementia from ethnic diverse backgrounds. Finally, research that explores the feasibility of interventions that support energetic physical activity for people with dementia such as hiking /mountain walking would be useful.

Limitations and strengths of the study

In this section I will start by discussing the limitations of my study. The first issue to consider is generalisability. This involves questioning whether a study's results are valid not only for its participants but also for the wider population (Mayring, 2007). There are several types of generalisability. Empirical generalisation is based on the argument that findings can be applied to a wider population on the premise that the study population is statistically representative of that wider population (Mason, 2002). My study is idiographic and involves a small number of people with dementia attending eight different locations providing care and social support based within a single city in the north of England. Clearly it would be inappropriate to claim that the participants and their experiences are representative of people with dementia elsewhere. I can nevertheless claim that the findings from this study possess theoretical generalisability. This term refers to the potential for the theoretical framework used in a particular study to be applied usefully within similar populations elsewhere (Mason, 2002). Given the large numbers of older people living with dementia throughout the UK it is likely that the theoretical framework used in this study to explore physical activity and well-being could be applied elsewhere. Similarly, Lincoln and Guba (1985) wrote about the concept of "transferability" which implies that whilst direct comparisons between different study settings may not be possible some similarities will exist and it is possible to develop working hypotheses that transfer between settings.

I recognise that because my participants were experiencing dementia, there was a limit to their engagement in the research process. There were inevitably times when participants found it difficult to understand and reflect on my questions and express their views. This is the nature of research involving people living with dementia and another reason why it was important to employ participant observation as well as interviews. I had difficulty in recruiting participants as planned in my protocol. This was because I underestimated the difficulties of using the process consent method for a large and constantly changing group of individuals, many of whom only attended the fieldwork location on a monthly or fortnightly basis. I concluded that this method was more suited to studies including small numbers of participants and when more time is available to establish a relationship with them.

I was less successful than hoped in exploring issues of ethnicity. For example, fieldwork at an African/Caribbean Well-being Café was abandoned. This was due to difficulties in identifying which attendees had dementia and reluctance on the part of those attending the café to discuss health issues. Lack of detail regarding participants' dementia diagnosis status could be considered a limitation. This is because although access to records enabled participants' dementia diagnoses to be verified, I was unable to describe participants in terms of the type or severity of their dementia. This study included participants who had recently been diagnosed and had mild cognitive impairment as well as people with severe cognitive impairment who were well known to mental health services. This variance in terms of severity of cognitive deficit makes it difficult to compare findings directly with other studies. However, I am viewing dementia as a social and embodied phenomenon rather than a medical illness that can be "staged" in a meaningful way. Two of the South Asian participants (Najma and Fameeda) were interviewed on the basis that they self-reported dementia. They spoke about their memory loss but I had doubts whether they had cognitive difficulties at all but were experiencing anxiety and low mood instead. It proved impossible to validate diagnoses through the day centre records due to the lack of medical histories. The data from their interviews were used during analysis as they met the criteria for inclusion. This suggested that "dementia" may be constructed differently across ethnic and cultural diversity and that the concept is constantly undergoing reconstruction.

As well as limitations, my study also has a number of strengths. The qualitative approach employed in my study provided data that had depth and richness. My study has produced evidence that physical activity is useful for people with dementia in complex ways that have not been identified by quantitative research. Generating data at eight different fieldwork locations including both NHS/health and voluntary/non-health settings with an ethnically diverse group allowed a wide range of experience to be captured. This study used interviews and participant observation to generate data. These two methods have specific strengths. Interviewing participants provided insight into their relationship with physical activity and experience of dementia. Talking to participants with dementia also provided a sense of how they struggled with verbal communication.

Participant observation over sustained periods of time provided an opportunity to become familiar with participants and join in with their activities in an inconspicuous manner. The strength of participant observation lies in the fact that it provides access to behaviour that may be taken for granted by participants or difficult for them to describe (Phinney et al. 2007). Data from participant observation in this study was useful in showing how participants struggled in social settings, how people engaged in physical activity, how physical activity brought some participants to life. A particular strength of this study is the use of two methods of data generation within the same setting. Adopting two complementary methods enabled the incongruence between what people said and what people did to be identified. For example, during her interview Barbara spoke about her enjoyment of talking to others at the well-being café but participant observation data recorded that her interactions were almost entirely non-verbal. A further strength is that data relating to specific participants were generated in a variety of settings. For instance, watching Simon engage in the activities at the well-being café, walking with him together with family members and talking to him during an interview allowed a multifaceted picture of his experience to be constructed.

Concluding comments

In the UK, dementia is usually viewed in a medicalised way as a condition of the brain that results in a number of problematic symptoms, without considering it as a complex experience that involves an individual's social and embodied self which is influenced by the physical and social environment. Consequently, when physical activity has been considered in relation to people with dementia it has been perceived as a potential treatment option for the problems associated with a degenerative brain condition. The type of research undertaken which involves physical activity and includes people with dementia has been influenced by this medicalised view, with the RCT given most credence. In this study I have taken a different perspective by attempting to give a group of people with dementia a voice. I have explored the lived experience of people with dementia and found that physical activity can positively influence the well-being of an ethnically diverse group of people with this condition by supporting their personhood. Adopting a social science approach has been challenging for me as a practising clinician embedded within the NHS because I have spent the last twenty four years working predominantly within

the medical model of health. At times during field work, I missed the protection that my professional identity as a physiotherapist can provide. However, overcoming these challenges has been a hugely rewarding experience for me. Undertaking this PhD has made me a better practitioner with a broader appreciation of what the people I meet as a physiotherapist who have dementia are going through. I have learned that it is important that social science research engages with medicalised concepts such as dementia. Doing so brings aspects of complex human experiences into view and reminds us that conditions such as dementia do not exist in isolation; they are woven into the social fabric of people's everyday lives. It is vital that researchers from different disciplines and using a range of methodologies engage in dialogue with each other as this is the key to improving care for those living with dementia.

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Appendix One

Study protocol

(Version 1 19/01/10 Draft)

Study protocol

Title: "The experience of physical activity and wellbeing amongst older people with dementia from ethnically diverse backgrounds".

Short version: "Physical activity, ethnicity and dementia".

Name and address of chief investigator
Alan Wright,
Daisy Hill House
Lynfield Mount Hospital
Heights Lane
Bradford
BD9 6DP
01274 363842
Alan.wright@bdct.nhs.uk

Chief investigators supervision team
Professor Mike Lucock (Director of studies).
HW3/02
The University of Huddersfield
Queensgate
Huddersfield
West Yorkshire
HD1 3DH
01484 473876
m.lucock@hud.ac.uk

Dr Jane Morrell
HHR3/02
The University of Huddersfield
Queensgate
Huddersfield
West Yorkshire
HD1 3DH
01484 472989
j.morrell@hud.ac.uk

Dr Sharon Wray
HHR 3/14
The University of Huddersfield
Queensgate
Huddersfield
West Yorkshire
HD1 3DH
01484 472796
s.wray@hud.ac.uk

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1. Summary

This study plans to investigate how engagement in physical activity affects the wellbeing of older people with dementia from several different ethnic backgrounds. The intention is to explore the views and experiences of these individuals in the context of mental health promoting interventions. The purpose of this study is to increase knowledge in order to assist in the development of services that employ physical activity in the promotion of wellbeing amongst older people with dementia. Research in this area is needed for several reasons. Firstly, there has been a neglect of the individual experience of the condition because of the dominant biomedical model which views dementia primarily as a disease of the brain. Recognition of this has resulted in calls for research which humanises dementia. Secondly, there is a need for research which views physical activity as a means of increasing wellbeing for people with dementia rather than simply a treatment modality for relieving symptoms of the condition. Thirdly, the degree to which ethnicity influences the experience of dementia is currently subject to debate. Part of this debate focuses on whether dementia services situated in ethnically diverse populations should target specific ethnic populations or if tailored mainstream services are more effective. A qualitative methodology is planned using participant observation, focus groups and one to one interviews. This approach has been chosen because it enables older people's views and perspectives to be captured. Data will be gathered from three Wellbeing Cafés which are community based interventions designed to promote positive mental health for Bradford's ethnically diverse older population.

2. Study Aims and Research Questions

The primary aim of the research is to explore how physical activity influences the wellbeing of older people from diverse ethnic backgrounds who are experiencing dementia.

Research questions:

i) How do older people with dementia engage in physical activity and what benefits do they identify?

ii) What barriers and facilitators influence how older people with dementia engage in physical activity?

iii) How do older people with dementia experience Well-Being Cafés?

There are two secondary aims. Firstly, to contribute to the debate regarding the most effective methodologies to employ when conducting research involving dementia and ethnically diverse populations. Secondly, to advise organisations in the statutory and voluntary/community sectors on the development of strategies to promote the wellbeing of older people with dementia.

3. Background

3.1 The conceptualisation of dementia

Dementia directly affects 700,000 people in the UK and represents a considerable threat to the physical health and wellbeing of older people (Alzheimer's Society 2006). The condition is most often viewed from a biomedical perspective as a disease state characterised by a decline in memory, reasoning and communication skills together with a gradual loss of the skills needed to carry out daily activities (Knapp and Prince 2007). However, dementia can also be seen in terms of a social construct. This is because the psychosocial effects of the condition such as lowered self esteem, reduced feelings of autonomy and the loss of a sense of personhood are thought to be products of dysfunctional social interaction (Kitwood 1997). If dementia is defined in terms of a social construction it is clear that the discourses surrounding older people experiencing the condition exert a critical and often negative influence on their wellbeing (Sabat and Harre 1992). Nevertheless, it has been acknowledged that there has to be an organic as well as social foundation to human activity. Clearly the actions of human beings cannot be explained in terms of social construction alone (Turner 1992). Our bodies have their own inherent ability to apprehend and convey meaning (Kontos 2004) and express their nature in a manner over which we have little control (Toombs 2006). In this conceptualisation, people interact meaningfully with the environment through their embodied way of "being in the world" (Kontos 2004). There is a growing literature addressing how dementia impacts on our embodied being which owes a debt to the work of Heidegger and Merleau-Ponty (Davis 2004). In the embodiment literature, dementia is viewed not just as a "disease" of the brain which leads to cognitive loss and functional decline, or a process of social loss caused by altered relationships with others. Rather, it is a condition involving a breakdown of our embodied sense of self (Phinney and Chesla 2003). Currently there is a need to define dementia which takes all three conceptualisations of the condition into account.

3.2 Dementia and ethnicity

If one accepts the view that the experience of dementia is partly constructed socially there is an implication that the cultural or ethnic basis of the prevailing discourse will exert an influence. However, due to small size of communities, the stigma often attached to dementia in ethnic groups and low levels of diagnosis, ethnic minority populations remain underrepresented in research into dementia (Hulko 2009). Although, evidence does exist relating to some communities which suggests some variation in the experience of dementia on grounds of ethnicity. For example, studies have found less knowledge about dementia and a greater emphasis on the role of the family in South Asian communities compared to the wider population (Turner, Christie & Haworth 2005). Others however, have suggested that a focus on ethnicity may be over simplistic and encourage an assumption of homogeneity which does not exist (Iliffe & Manthorpe 2004). Another aspect of the debate is concerned with how to offer effective interventions for ethnically diverse populations. Services are provided which target specific ethnic communities even though it is accepted that the best option are high quality mainstream services which are sensitive to individual need (Iliffe & Manthorpe 2004). Nevertheless, there is a need to be more sensitive to differences between ethnic minority groups and a need to look at which services are effective for which ethnic groups and why (MHF 2003).

3.3 Dementia and Wellbeing.

Wellbeing is a relative, subjective and transient state (Hasselkus & Murray 2007) which incorporates one's sense of satisfaction with life, optimism, and the degree to which one experiences a sense of control and belonging (Health Scotland 2006). An influential figure in the field of wellbeing is Bradburn (1969) who considered the term to be synonymous with happiness. Bradburn defined wellbeing within the general population as a dynamic state which is influenced by the interplay of two opposing dimensions operating independently of each other. One dimension is associated with positive affect and the other dimension with negative affect. Bradburn's model places an individual's degree of wellbeing on a scale with the position shifting towards greater or lesser degrees of wellbeing according to the relative strengths of the two dimensions. Variables associated with negative affect include interpersonal tensions and feelings of anxiety and worry. In contrast, variables associated with positive

4

affect include the degree to which a person is involved in their environment, social contact, active interest in the world around them and the experience of novel life events. A similar approach to wellbeing was taken by Kitwood and Bredin (1992) but with a specific focus on dementia. Kitwood and Bredin identified five needs which greatly influence an individual's wellbeing: attachment, identity, inclusion, comfort and occupation. Twelve indicators of wellbeing were also identified which allow researchers to measure levels of wellbeing. For example, the ability to experience and display pleasure, the initiation of social contact, and the expression of creativity. Both Bradburn's model and the work of Kitwood and Bredin have influenced recent models of dementia care (Perrin, May & Anderson 2008) which emphasise the benefit of meaningful activity for people with dementia. In this study, the intention is to generate themes relating to wellbeing, physical activity and ethnicity that can then be viewed in relation to the above models.

3.4 Physical activity and dementia

One way in which the wellbeing of people experiencing dementia can be enhanced is through the use of physical activity. This is because activities such as dance, walking with friends and participating in exercise groups are inherently social and inclusive activities which fit well with the models of wellbeing mentioned above. Kitwood and Bredin's indicators provide a potential theoretical framework when gathering evidence relating to levels of wellbeing during engagement in physical activity. Research using this conceptual framework is needed because most studies including physical activity and dementia have adopted a biomedical perspective using outcomes such as cognition, sleep, functional abilities (Eggermont and Scherder 2006) and the impact of the condition on caregiver's health (Forbes et al 2008). Meanwhile, the subjective experiences of people with dementia performing physical activity and the value that they attach to it in terms of their wellbeing have been neglected. This study aims to capture aspects of the personal experience of physical activity and its impact on individuals' sense of wellbeing from the point of view of the older person with dementia.

4. Methods

4.1 Research design

Because the research outlined here intends to investigate the subjective experiences of older people with dementia, a phenomenological approach using qualitative methods

to generate data is proposed. The study will involve three Well-Being Cafés. These are community based interventions created to promote the mental health of older people which take place monthly. Physical activity in various forms takes place as part of the programme. Two out of the three cafés are designed specifically for people with dementia and the third has a number of people with dementia attending. Data collection will take place in three phases (see Figure One). The first phase will consist of six months participant observation. The aim of the first phase is to identify themes relating to the experiences of physical activity, wellbeing and ethnicity. The second phase will involve exploring these themes with regular participants from the first phase. A focus group from each setting will take place during which these themes will be discussed and developed. In phase three, individual interviews will be performed in order to further explore the themes arising from the first two phases within the context of the individual.

4.2 Study settings

The research will involve pre-existing interventions which have not been developed for the purposes of research. The study will investigate how older people with dementia experience three different Wellbeing Cafés in Bradford. The Wellbeing Café network comprises approximately 16 separate groups that meet monthly in a variety of settings such as church halls and community centres. Well-being Cafés are run by several different organisations and are co-ordinated by the Bradford Community Involvement Project (a partnership between Bradford District NHS Care Trust and Bradford Metropolitan Council which was created to promote the mental health of older people). Wellbeing Cafés provide social support, information and offer activities for older people. Physical activity at these cafés consists of social dance and exercise in various forms. Cafés generally attract between 20 and 30 older people to each meeting and individuals attend with varying degrees of regularity. Several of the Wellbeing cafés target particular ethnic minority groups for example members of South Asian and African Caribbean populations. Data will be collected from Cafés which provide services for predominantly White, African Caribbean and South Asian older people.

Figure one. Study settings and phases.

Alzheimer's Society Café	▩▩▩▩▩Café	▩▩▩▩▩Café
Phase One Ethnicity=Mostly White/British Participants=Older people with dementia and their carers. Physical activity=Social dance Six months participant observation. Aim: Identify themes	**Phase One** Ethnicity=South Asian Participants=Older people with dementia and their carers. Physical activity=Exercise. Six months participant observation Aim: identify themes	**Phase One** Ethnicity=African/Caribbean Participants=Older people (some with dementia) and carers. Physical activity=Exercise/Social dance. Six months participant observation Aim: identify themes
↓	↓	↓
Phase Two Focus group 5-8 people with dementia. Aim: Explore + develop themes within group context.	**Phase Two** Focus Group 5-8 people with dementia. Aim: Explore + develop themes within group context.	**Phase Two** Focus Group (group discussion if insufficient numbers) 5-8 people with dementia. Aim: Explore + develop themes
↓	↓	↓
Phase Three 1:1 interviews (+/-5) (People with dementia who attended at least 4 cafés). Aim: explore themes within individual	**Phase Three** 1:1 interviews (+/-5) (People with dementia who attended at least 4 cafés). Aim: explore themes within individual	**Phase Three** 1:1 interviews (+/-5) (People with dementia who attended at least 4 cafés). Aim: explore themes within individual

The research will involve collaborative work with the agencies responsible for running these three interventions. These consist of the Bradford branch of the Alzheimer's Society (predominantly White), ▓▓▓▓▓▓ (African Caribbean) and ▓▓▓ ▓▓▓▓ (South Asian). ▓▓▓▓▓ ▓▓▓▓ is a community development charity working with people from ethnic minority communities. Meri Yaadain is a Social Service led multi-agency partnership created to raise the awareness of dementia related issues within the South Asian community in Bradford.

4.3 Defining study participants in terms of dementia

The majority of people with dementia never receive a formal diagnosis (NAO 2007) and both the Alzheimer's Society and ▓▓▓ ▓▓▓▓▓ accept referrals regardless of diagnosis. Therefore, for the purposes of the participant observation stage, all individuals attending The Alzheimer's Society and ▓▓▓▓ ▓▓▓▓▓ wellbeing Cafés will be assumed to be experiencing some degree of dementia irrespective of their status regarding formal diagnosis. Following receipt of participants' consent, their status regarding diagnosis will be checked by referring to records kept by The Alzheimer's Society and ▓▓▓▓ ▓▓▓▓▓▓ In the case of the ▓▓▓▓▓ ▓▓▓▓▓ Café, participants may or may not be experiencing dementia. Their status regarding the condition will be ascertained on an individual basis through discussion with them and by referring to ▓▓▓▓▓▓ ▓▓▓▓▓ records following receipt of consent. Participants will be included the focus group and individual interview stages if they have attended a Wellbeing Cafe on at least four occasions and have received a diagnosis of dementia and/or consider themselves to have dementia.

4.4 Consent issues

Careful consideration is needed regarding consent in this study due to the inclusion of individuals experiencing cognitive impairment. It is possible that for some individuals the presence of cognitive impairment may present little difficulty. After all, the Mental Capacity Act (2005) states that the capacity to give informed consent varies between individuals and that consent should not be assumed to be lacking because a person has dementia. Therefore, the capacity to give informed consent may be clearly evident. On the other hand, if informed consent is considered problematic this does not necessarily exclude individuals from participation. According to the Mental capacity Act (2005), an individual who has been identified as lacking capacity can

still participate in a research project if an ethics committee agrees that the research is safe and cannot be performed using people who have mental capacity. A further consideration is the effect that identifying a lack of consent has on an individual's sense of wellbeing (Sabat 2005). When the capacity to give informed consent is unclear, a more flexible approach to gaining consent may therefore be needed. In order to seek consent in a transparent and sensitive manner in this study a systematic approach to gaining consent will be undertaken. Firstly, on receipt of permission to access the Wellbeing Cafés, the principle investigator will attend the café in order to explain the reason for his presence and distribute information leaflets. During this initial visit to the café he will talk to individuals in the presence of a carer in order to ascertain their capacity to give informed consent. If the capacity to give informed consent is clearly identified, potential participants will be invited to give written consent for the researcher to engage in participant observation. Participants will be told that they can withdraw their consent at any time at which point data collection involving them will cease unless consent is re-established. Participants will be informed that their decision to participate or otherwise will not affect the services that they receive. In the unlikely event that some individuals decide not to give consent, the researcher will not collect data relating to them. Consent for phases two and three will involve the same process of information provision, ample opportunity to ask questions, 24 hours to consider decision and reassurance that they can withdraw from the study at any time.

However, if capacity to give informed consent is in doubt during initial contact with potential participants, Dewing's (2007) process consent approach will be adopted. Process consent is intended for use with persons who have limited capacity for informed consent or are incapable of granting legally informed consent but nevertheless can communicate their wishes. Process consent recognises that capacity is situational and comprises five elements. The first stage involves obtaining permission to approach individuals with dementia from the principle carer with dementia and also gaining an understanding of how the individual presents when in a state of wellbeing. Stage two involves getting to know the individual and establishing the basis for their capacity. In the case of the wellbeing cafés this process may take several visits to complete. Stage three involves gaining initial consent with carer as validator. Stage four involves ongoing consent monitoring as individuals' views on

consent may change over time. This means seeking consent (which may be verbal or non-verbal) at the start of each data collection period. Any sign of distress or resistance on the part of the participant will be interpreted as a withdrawal of consent and data collection will cease until evidence of renewed consent is gained. Stage five involves regular feedback to carers in order to monitor consent issues. Irrespective of capacity, data generated from both the interviews and observation will be offered to all participants before both analysis and dissemination stages of the project to enable them to withdraw consent if they wish. This process will be repeated for each of the three phases of the project. Verbal consent to audio record data will also be sought prior to each focus group and individual interview.

4.5 Outline of study phases.

Phase One: Participant observation involving people with dementia from diverse ethnic backgrounds engaging in physical activity at three Wellbeing Cafés.

Aim: To explore how participation in physical activity influences the wellbeing of older people with dementia in three different settings.

Outcome: The development of themes relating to dementia, physical activity and wellbeing.

Design: Participant observation during which the chief investigator will join the activities on a monthly basis for a six month period.

Sample size: Sample size will be approximately 20 individuals per Wellbeing Café.

Participants: People attending Alzheimer's Society, ▓▓▓▓▓ ▓▓▓▓▓ and ▓▓▓ ▓▓▓▓▓ Wellbeing cafés. Participants' status regarding dementia will be identified through records kept by the Café organisers. As participant observation will be used participants will also include carers, staff and volunteers. The Sharing Voices Wellbeing Café has not been developed for people with cognitive impairment alone so some people attending may not have received a diagnosis of dementia or be experiencing associated signs and symptoms.

Recruitment: Initial contact has been made with the service providers and permission has been given for the research project to be undertaken. Following receipt of ethical approval, the principle investigator will re-contact the cafés and talk to the group as a whole in order to explain details of the project. Information sheets and letters of invitation will be distributed to all present. There will be an opportunity to ask the principle investigator questions. The chief investigator will meet all potential

participants and their carers and an initial assessment of their capacity to give informed consent will be made. Potential participants who are judged to have capacity will be asked to complete the consent form if they decide to do join the study. Whenever possible, participants will be given 24 hours to make their decision. However, given the sporadic nature of some individuals' attendance this may not always be possible. For those who's ability to give informed consent is in doubt, stage three of the process consent method will be employed. Ongoing consent will be monitored in line with the principles of process consent.

Data collection and management: Data collection will commence following the receipt of signed consent relating to all participants. Data will be collected in the form of field notes. Individuals will be allocated pseudonyms in order to protect their identity. Data collection and storage will be undertaken in line with data protection legislation and both NHS and University of Huddersfield guidance on secure storage. Data will be stored in a locked drawer within a secure office at Daisy Hill House, Lynfield Mount Hospital. Completed consent forms will be kept apart from transcribed data. Thematic analysis will be used to generate themes.

Phase Two: The subjective experience of physical activity and wellbeing amongst people with dementia from diverse ethnic backgrounds.

Aim: To gain an understanding of how engagement in physical activity influences the subjective wellbeing of older people with dementia from different ethnic populations.

Outcome: Exploration of initial themes identified in phase one.

Design: Exploratory study using focus groups in three settings. One focus group will be run in each setting. The focus groups will be run by the principal investigator.

Sample size. 18-24 (6-8 participants will be recruited for each focus group).

Participants: People who have attended a wellbeing café on at least four occasions.

Recruitment: People who have attended Wellbeing Cafes on at least four occasions and who has received a diagnosis of dementia and/or who considers that they have dementia will be approached by the chief investigator. In the case of the Sharing Voices café where fulfilling the inclusion criteria is less certain consultation with senior Wellbeing café staff will take place in order to identify potential participants as well as a review of phase one participants' records. An information sheet will be given and an opportunity made available to ask questions. If individuals are identified as having capacity they will be asked to complete a consent form if they decide to

participate. When capacity is in doubt process consent will be employed as stated above. People will be given at least 24 hours during which to make their decision. If less than five participants are recruited from any café, a discussion group will be undertaken instead of a focus group.

Data collection and management: Focus groups will take place in a private room separate from the main activities of the café. Data from the focus groups will be recorded using a digital recording device. The transcription of recorded data will be undertaken by the chief investigator. The data will be managed using NVivo software programme. Data will be stored on a password secured computer at Lynfield Mount Hospital, Bradford.

Phase three: An in-depth exploration of the individual experience of physical activity among older people with dementia from diverse ethnic backgrounds.

Aim: To further explore the themes relating to physical activity and wellbeing developed in the previous studies within the individual context.

Outcome: Description of the individual experience of physical activity for people with dementia

Design: Exploratory study in three settings using one to one interviews. Interviews will be conducted by the principle investigator.

Sample size 15 individuals

Participants: People who have attended a Wellbeing Café on at least four occasions and who have received a diagnosis of dementia and/or consider themselves to have dementia.

Recruitment: Potential participants will be given a letter inviting them to participate in a research project that involves one to one interviews and an information sheet by the researcher. They will then be asked to carefully consider whether they wish to participate and asked to complete the consent form if they decide to do so. There will be an opportunity for the individuals who have been approached to ask the researcher questions. Potential participants will be given 24 hours to make their decision.

Data collection and management: Interviews will take place in a private room away from the main activities of the café. Data will be audio recorded. The location of interviews will depend on the wishes of the participant. Carers may be present if the participants prefer. Participants will be allocated pseudonyms in order to protect their identity. Written data will be stored in a locked filing cabinet in a locked office within

a secure building at Lynfield Mount Hospital. Electronic data will be kept in a password secured computer in the principle investigator's office at Lynfield Mount Hospital.

5. Ethical considerations and research governance

5.1 Research governance

It is recognised that this is a sensitive area of research involving a potentially vulnerable group and that issues of a personal nature are likely to arise. Ethical approval will be needed from NREC as well as SREP. The research will adhere to the principles set out by the Declaration of Helsinki (2008). This document stipulates that the dignity and well-being of the participant takes precedence over all other aspects of the research project. Transparency will be achieved by having the supervision team analyse decision making trails throughout the duration of the project.

5.2 Confidentiality

Participant's confidentiality and their right to privacy will be respected at all times unless disclosures are made which suggest that the participant is at risk of abuse or other danger. In this case actions will be taken according to the protocol identified by Bradford Metropolitan Council's Adult Protection Unit. In order to maintain confidentiality and privacy all names will be changed and data will be stored in a locked drawer in a secure office at Lynfield Mount Hospital, Bradford. Participants will be made aware that quotations will be used in the dissemination of results but there will be no personally identifiable information contained in quotes. The participants' information sheet and consent form will directly refer to issues relating to confidentiality. All participants will be reassured that their personal details will be kept secure and that no identifying data will be shared with third parties. Ground rules for focus groups which refer to respecting the confidentiality of other participants will be suggested by the researcher and agreed by the participants before the groups commence.

5.3 Anonymity

Although it is recognised that complete anonymity cannot be guaranteed in groups, every precaution will be taken to protect the identity of every participant and preserve their privacy. Pseudonyms will be allocated to each participant, their friends and

carers during the writing of reports. Identifiable information will be excluded from any documents arising from the study.

6. Resource requirements

Equipment in the form of a digital audio recorder will be required. This will be loaned from the University of Huddersfield. Travel monies and incidental expenses such as stationary will be provided by the Bradford District Care Trust. The chief investigator has the use of a computer and secure storage facilities in a lockable office at Lynfield Mount Hospital Bradford.

7. Schedule of work

October 2009 January 2010	Submission to University and NHS ethical and R+D review. Await approval from NREC and SREP.
March 2010	Seek consent for Study 1.
March 2010 - December 2010	Participant observation undertaken for Study 1. Initial analysis of data and identification of themes. Completion of qualitative methods modules at Huddersfield University.
July 2010-August 2010	Seek consent for Study 2 (focus groups). Complete focus groups.
September 2010-November 2010	Analysis of data from Study 2.
December 2010- January 2011	Recruitment for Study 3
February 2011-May 2011	Study 3 interviews undertaken.
June 2011- September 2011	Analysis of data from Study 3
September 2011- October 2012	Writing up

8. Dissemination

Study participants will be offered a copy of the study findings. Verbal feedback will be offered for those who prefer it or who may have difficulties with literacy. Study findings will be disseminated through peer reviewed publications, conference presentations and a PhD Thesis.

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Appendix Two

THE UNIVERSITY OF HUDDERSFIELD: RISK ANALYSIS & MANAGEMENT

ACTIVITY: Dementia, physical activity and wellbeing study		Name: Alan Wright	
LOCATION: Well-being Cafés		Date: 26/07/2010	Review Date: 26/07/2011

Hazard(s) Identified	Details of Risk(s)	People at Risk	Risk management measures	Other comments
Risk of participant becoming upset.	There is a possibility that participants may become upset when discussing issues relating to their sense of wellbeing.	Research participants	Members of staff who work at the well-being café will be available to offer support to participants if needed. If upset the participant will be asked if they want to continue to be involved in the study.	The principal investigator is an experienced health professional who has worked closely with people who have dementia for the last ten years
Risk of the principal investigator becoming upset.	There is a slight possibility that the principal investigator may become upset during interviews/observation.	Principal investigator	The researcher will be supported by his director of studies who is also a Consultant Clinical Psychologist.	The principal investigator has worked clinically as a physiotherapist for 19 years and is used to dealing with potentially upsetting situations.
Risk of injury.	There is a possibility of injury associated with physical activity.	Principal investigator and research participants	Well-being cafés are run according to established xxxxxxxxxxxx risk management strategies.	The proposed research is focused on well-established activities which present very little risk to those involved. The presence of the principal investigator will not increase risk.

Appendix Three

University of Huddersfield
School of Human and Health Sciences
School Research Ethics Panel (SREP)

Approval letter

Alan Wright - Your SREP Application (Alan Wright) - APPROVED - "The experience of physical activity and well-being amongst older people with dementia from ethnically diverse background"

From: Kirsty Thomson <K.Thomson@hud.ac.uk>
To: "'Alan Wright'" <Alan.Wright@bdct.nhs.uk>
Date: 26 January 2010 15:54
Subject: Your SREP Application (Alan Wright) - APPROVED - "The experience of physical activity and well-being amongst older people with dementia from ethnically diverse background"
CC: Nigel King <n.king@hud.ac.uk>, Mike Lucock <m.lucock@hud.ac.uk>

Dear Alan,

Prof Nigel King (Co-Chair of SREP) has asked me to confirm to you that your SREP application, "The experience of physical activity and well-being amongst older people with dementia from ethnically diverse background", has now received full ethical approval from the School of Human and Health Sciences Research Ethics Panel, University of Huddersfield.

With best wishes for the success of your research.

Regards,

Kirsty
(on behalf of Prof Nigel King, Co-Chair of SREP)

Kirsty Thomson
School Research Office (HHRG/01)
School of Human and Health Sciences
The University of Huddersfield
Queensgate
Huddersfield HD1 3DH
Tel: +44 (0) 1484 471156
Email: k.thomson@hud.ac.uk

Appendix Four

National Research Ethics Service (NRES)
Approval letter

Bradford Research Ethics Committee
Top Floor
Extension Block
St Lukes Hospital
Little Horton Lane
Bradford
BD5 0NA

Chairman: **Professor Alan C Roberts**
                 OBE TD DL MPhil PhD DSc DTech LLD FLS FSB
Administrator: Susan Jude

Tel: 01274 365508   **Email:** susan.jude@bradfordhospitals.nhs.uk
Fax: 01274 365509   **Email:** alan.roberts@bradfordhositals.nhs.uk

Mr Alan Wright
Lynfield Mount Hospital
Heights Lane
Bradford
BD9 6DP

Dear Mr Wright

Study title: **The experience of physical activity and well-being amongst older people with dementia from ethnically diverse backgrounds.**
REC reference: **10/H1302/14**

The Research Ethics Committee reviewed the above application at the meeting held on 16 February 2010. Thank you for attending to discuss the study.

Ethical opinion

   This research is to be carried out in three phases, the first is a six month period of participant observation the next phase will be a focus group and then there will be 15 one to one interviews.

The safeguards in place are in line with the MCA.

The Committee noted that on the consent forms the word pseudonym is used and this should be replaced with my real name will not be used.

The Committee were satisfied that there were no ethical issues with this study.

<u>Decision</u>

Favourable opinion with conditions

1   **Consent Forms - Replace with word pseudonym with my real name will not be used, send the revised forms with new version numbers and dates to the Committee.**

This Research Ethics Committee is an advisory committee to Yorkshire and The Humber Strategic Health Authority
The National Research Ethics Service (NRES) represents the NRES Directorate within
the National Patient Safety Agency and Research Ethics Committees in England.

F206€

The Committee delegated authority to confirm its final opinion on the application to the Chair. Contact person for clarification susan.jude@bradfordhospitals.nhs.uk or 01274 365508.

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Ethical review of research sites

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

Mental Capacity Act 2005

The members of the committee present approved the application on the basis described in the documentation submitted. 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 favourable opinion is subject to the following conditions being met prior to the start of the study.

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

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk. Where the only involvement of the NHS organisation is as a Participant Identification Centre, management permission for research is not required but the R&D office should be notified of the study. Guidance should be sought from the R&D office where necessary.

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

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

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Covering Letter		01 February 2010
REC application	1	01 February 2010
Protocol	1	19 January 2010
Investigator CV		01 February 2010
Participant Information Sheet: Observation	1	15 January 2010
Participant Information Sheet: Focus Group	1	15 January 2010
Participant Information Sheet: Interview	1	15 January 2010
Participant Consent Form: Observation	1	15 January 2010
Participant Consent Form: Focus Group	1	15 January 2010

Participant Consent Form: Interview	1	23 October 2007
Letter of invitation to participant	1	15 January 2010
Summary/Synopsis	1	29 October 2009
Interview Schedules/Topic Guides	1	15 January 2010
Focus Group Invitation	1	23 October 2009
Letter of Invitation Interview	1	23 October 2009

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

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

After ethical review

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

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

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

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

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.
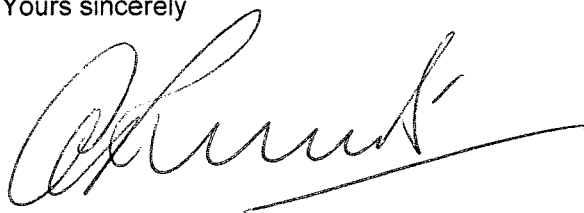
We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

10/H1302/14	**Please quote this number on all correspondence**

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

Yours sincerely

Professor A Roberts
Chairman – Bradford Research Ethics Committee

Appendix Five

NHS Research & Development

Approval letter

Bradford Teaching Hospitals **NHS**

NHS Foundation Trust

1st June 2010

Mr Alan Wright
Physiotherapist
Bradford District Care Trust
Daisy Hill House
Lynfield Mount Hospital
Heights Lane
Bradford
BD9 6DP

Dear Alan

R&D Management Approval - Bradford District Care Trust

Re: The experience of physical activity and well-being amongst older people with dementia from ethnically diverse backgrounds.
Sponsor: University of Huddersfield
REC Ref No: 10/H1302/14
R&D Ref No: 2/BDCT

Following submission of your Site-Specific Information (SSI) form 15/03/2010 and supporting documentation for the above project, on behalf of Bradford District Care Trust ("the Trust"), I am pleased to inform you that the above project has successfully undergone an internal review process appropriate for this type of project and has satisfied our research governance checks. A record has been created on the Trust's research database. You may commence research activities at the Trust in the locations indicated in your SSI form subject to the terms of this letter. The effective start date is 01/06/2010 and this is the earliest commencement date for research activities at this site(s).

Documents Reviewed
- **SSI form** 25750/106135/6/640/51531/170421
- **NHS R&D form Parts A-D** 25750/106138/14/588
- **the study protocol** V1 19/01/2010
- **the patient information sheet** (Focus Group V1 15/01/2010, Interview V1 15/01/2010 and MY INFO V1 15/01/2010)
- **the consent form** (Focus Group V2 01/03/2010, Interview V2 01/03/2010 and Participant Observation V2 01/03/2010)

Version 1: 27 05 2010
INVESTOR IN PEOPLE

The terms referred to are:

- Ongoing R&D Approval is subject to you adhering to the Trust's standard conditions of R&D Management Approval (attached).

- You do not commence recruitment at the Trust unless there continues to be Research Ethics Committee approval in place.

- You complete and return to the Research Support & Governance Office the PI Annual Progress Report available to download from the Downloads section of our website at www.bradfordresearch.nhs.uk due every year for the life of the study on the anniversary of the date of this letter.

- You notify the Director and the Research Support & Governance Office immediately should concerns arise about the safety and welfare of participants in this study at the Trust.

- You inform the Research Support & Governance Office immediately when the study has reached its end date (as defined in the protocol) together with final accrual figures for this site.

- You forward a copy of your final report/peer reviewed papers or any other publications relating to this research to the Research Support & Governance Office as soon as possible.

If you have any queries during your research please contact the Research Support & Governance Office using the contact details provided at the top of this letter. May I take this opportunity to wish you well with the project.

Please help us to improve our service by completing the feedback form emailed previously to you and returning it to the Research Support & Governance Office as soon as possible.

Yours sincerely

JANE DENNISON
Research Governance Manager

Encs

Appendix Six

Permission to access the well-being café network

Department of Adults & Community Services

Health & Wellbeing Team
Suite 28, Carlisle Business Centre
60 Carlisle Road
Bradford, BD8 8BD.

Tel: (01274) 436469
Fax: (01274) 436688

Email: chris.ireson@bradfor.gov.uk

Date: 28th March 2011

To Whom it may concern

re. Physical activity, dementia and well-being study

I acknowledge that permission has been given to Alan Wright in order for him to undertake research at the well-being cafes as stated in the study protocol.

Your signature

Chris Ireson
Well-being Café Development Officer
Health & Wellbeing Team

Appendix Seven

Permission to access Alzheimer's Society well-being cafés

Alan Wright - ethics

To whom it may concern,
re. Physical Activity, Dementia and Wellbeing Study.
We acknowledge that permission has been given to Alan Wright in order for him to
undertake research at the ████████████████████████ as stated in the study
protocol.

Yours sincerely

Ruth Gallagher
Branch Manager

Alzheimer's Society, Bradford branch, 16-18 North Parade, BRADFORD, BD1 3HT

T: 01274 733880   F: 01274 733881
E: ruth.gallagher@alzheimers.org.uk

www.alzheimers.org.uk

Alzheimer's Society's new report 'Counting the cost' reveals scandalous variations in the quality of ca
Make your voice count - join our campaign for better care for people with dementia
alzheimers.org.uk/countingthecost

Alzheimer's Society is a charity (registration no. 296645) and a company registered in England and '
Registered office is Devon House, 58 St Katharineb□s Way, London E1W 1JX

Appendix Eight

Permission to access the South Asian Well-being Café

Alan Wright - Acknowledgement

From: "Akhlak Rauf" <akhlak.rauf@bradford.gov.uk>
To: "Alan Wright" <Alan.Wright@bdct.nhs.uk>
Date: 22 March 2010 11:17
Subject: Acknowledgement

Happy to hear that things are moving on. Please pass on the email to whomever requires it. Look forward to hearing from you soon

Akhlak:

To Whom it may concern,

re Physical Activity, Dementia and Wellbeing Study.

We acknowledge that persmission has been given to Alan Wright in order for him to undertake research at the ▓▓▓▓▓▓▓well-being cafe as stated in the study protocol.

Yours sincerely

Akhlak Rauf
Health & Social Care Projects Manager
Communications Team
5th Floor, Olicana House
Chapel Street
Bradford   BD1 5RE

Tel: (01274) 431308
Email: akhlak.rauf@bradford.gov.uk
        akhlak.rauf@bradford.nhs.uk

Appendix Nine

University of
HUDDERSFIELD

Alzheimer's
Society

Leading the
fight against
dementia

Daisy Hill House
Lynfield Mount Hospital
Bradford
BD9 6DP

I am doing some research with Huddersfield University and I wonder if you would like to help.

I am interested in how taking part in physical activity affects the lives of people attending the Wellbeing café.

I am hoping that this research will help people who have memory difficulties to lead active and fulfilling lives.

I have included an information sheet which I hope will answer your questions. Please take some time to consider whether you would like to be involved. If you would like to discuss anything further, feel free to contact me.

If you are willing to help me please complete the consent form. Put the completed form in the confidential envelope and give it back to a member of staff.

With many thanks and best wishes

Alan Wright
01274 363842

University of
HUDDERSFIELD

Alzheimer's
Society

Leading the
fight against
dementia

Physical activity and wellbeing study.
Information about the research

I would like to invite you to take part in a research study. Before you decide if you want to help it is important for you to understand why the research is being done and what it would involve for you. This information sheet gives details of the project and is intended to help you to decide if you want to be involved. It should take no longer than five minutes to read. Please feel free to ask me if you have any questions or contact me on the number provided if you would like more information. Take plenty of time to decide whether you want to take part and discuss your thoughts with others.

What is the purpose of the study?

Evidence suggests that being physically active with friends and loved ones can have an important effect on a person's sense of wellbeing. However, more research is needed which includes people with memory difficulties. In this study I plan to join in the activities of people who are experiencing memory loss and make a note of what goes on.

Why have I been invited?

Because the research study is designed to involve the activities of the whole group, everybody who attends the wellbeing café are being asked if they would like to participate. This includes carers and people helping to run the sessions.

Do I have to take part?

No, you don't have to if you don't want to. Participation in the research project is entirely voluntary. You can choose not to become involved and the services you receive will be completely unaffected.

What will happen to me if I take part?
If you agree to help, I will join in with the some of the activities that you already do at the Wellbeing café for about six months. The idea is for you to carry on with your activities as normal. As well as participating in the activities I will make notes describing what goes on.

Are there any disadvantages and risks of taking part?
I will be joining you in activities that you would be doing anyway. The only difference that you may notice is the presence of an extra person at the Well-being café.

What are the possible benefits of taking part?
I cannot promise that the study will directly help you but it is hoped that the research will help to raise awareness of the issues faced by people living with memory difficulties.

What happens when the research study stops?
After about six months I will stop coming to the Well-being Café and the activities will continue in the usual way.

What if there is a problem?
If you have any concerns about this study please contact me and I will do my best to address the issue. If you remain unhappy and wish to complain formally you can do this by contacting Ruth Gallagher (Alzheimer's Society) 01274 733880 or Mike Lucock (Huddersfield University) 01484 473876.

Will my taking part in the study be kept confidential?
Your confidentiality will be safeguarded during and after the study. No-one other than my self and my university supervisor will have access to information which may identify you. Your name will be changed in any documents and reports resulting from this study. Any information that I collect will be locked in a safe place at Lynfield Mount Hospital.

What will happen if I don't want to carry on with the study?
You can withdraw from the study at any time. If you do decide
not to continue you have the right to decide if the information
collected prior to your withdrawal to be used in the study or not.

What will happen to the results of the research study?
The information that I gather will be used to write a scientific
report. A shortened less detailed version of this report will also
be written. The scientific report will be given to
  • The Alzheimer's Society.
  • Bradford District Care Trust.
  • Huddersfield University.
Individuals who have participated in the research will be
offered a choice of the full report or shortened version. It is also
likely that the research will be published in some format and
presented at a conference.

Who is organising and funding the research?
I am organising the research along with Huddersfield University
and the Alzheimer's Society. It is being done as part of a PhD
degree.

Has the study been approved?
In order to protect everyone involved, all research in the NHS is
looked at by an independent group of people, called a Research
Ethics Committee. This project has been reviewed and approved
by both Huddersfield University and the NHS Research Ethics
Committees.

Further information
For further information please contact Alan Wright by telephone
on 01274 363842 or by email on alan.wright@bdct.nhs.uk

Thank you for reading this information sheet.

Appendix Eleven

UNIVERSITY OF HUDDERSFIELD

Physical activity and wellbeing study

Alan Wright

Participant observation consent form

Please initial

I have been fully informed of the nature and aims of this research and consent to taking part in it.	
I understand that I have the right to withdraw from the project at any time without giving any reason, and that I have a right to withdraw my data if I wish.	
I give my permission for my activities to be recorded in the form of written notes.	
I give my permission to be quoted (my real name will not be used).	
I understand that the written notes will be kept in secure conditions at Lynfield Mount Hospital.	
I understand that no persons other than Alan Wright and his university supervisors will have access to the written notes.	
I understand that my identity will be protected. My real name will not be used and no information that could lead to my being identified will be included in any report or publication resulting from this research.	
I give my permission for Alan Wright to access written records kept by the Well-Being Café containing information about myself.	

Name of participant...

Signature...

Date...

Name of researcher...

Signature...

Date...

Two copies of this consent from should be completed: One copy to be retained by the participant and one copy to be retained by the researcher

Appendix Twelve

Permission to access local authority day centres

Alan Wright - ████ ████

From: Dean Roberts <dean.roberts@bradford.gov.uk>
To: Alan Wright <Alan.Wright@bdct.nhs.uk>
Date: 01 March 2011 10:04
Subject: ████ ████

Alan

To Whom it may concern
Re Physical Activity, Dementia and Wellbeing Study

I acknowledge that permission has been given to Alan Wright in order for him to undertake research at ████ ████ centre as stated in the study protocol.

Dean Roberts

Please acknowledge that you have received this email

Dean Roberts
Service Manager, Residential and Day Care
Department of Adult and Community Services

Access, Assessment & Support Services ● Community Care Services ● Integration & Transition
City of Bradford Metropolitan District Council - **Olicana House, Chapel Street, Bradford BD1 5RE**

T   01274 432942
E   dean.roberts@ bradford.gov.uk
W   www.bradford.gov.uk

Appendix Thirteen

Permission to access "Chellowfont Day Centre"

Bradford District Care Trust

Tel: 01274
Fax: 01274
www.bdct.nhs.uk
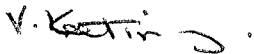
26th October 2011

To whom it may concern,

Re Physical Activity, Dementia and Well-Being Study

I acknowledge that permission has been given to Alan Wright in order for him to undertake part of his research at ████████████ centre.

V. Keeting

Vivien Keeting
Day Centre Manager

You and Your Care

Appendix Fourteen

Permission to access "Women's Action Partnership" day

centre

7th November 2011

To Whom it may concern

Re. Physical activity, dementia , ethnicity and well-being study.

This letter is to acknowledge that permission has been given to Alan Wright in order for him to undertake part of his PhD research study at ████████████ community centre.

Poonam Joshi
Project Co-ordinator

Appendix Fifteen

Approval from Local Research Ethics Committee to conduct

the study in day centres as well as well-being cafés

Bradford Research Ethics Committee

Yorkshire & Humber REC Office
Millside
Mill Pond Lane
Meanwood
Leeds
LS6 4RA

Tel: 0113 305 0116

21 March 2011

Mr Alan Wright
Lead Physiotherapist
Bradford District Care NHS Trust
Lynfield Mount Hospital
Heights Lane
Bradford
BD9 6DP

Dear Mr Wright

Study title:	**The experience of physical activity and well-being amongst older people with dementia from ethnically diverse backgrounds.**
REC reference:	**10/H1302/14**
Amendment number:	**1**
Amendment date:	**24 February 2011**

Thank you for your letter of 24 February 2011, notifying the Committee of the above amendment.

The Committee does not consider this to be a "substantial amendment" as defined in the Standard Operating Procedures for Research Ethics Committees. The amendment does not therefore require an ethical opinion from the Committee and may be implemented immediately, provided that it does not affect the approval for the research given by the R&D office for the relevant NHS care organisation.

Documents received

The documents received were as follows:

Document	Version	Date
Notification of a Minor Amendment		24 February 2011
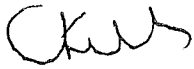
Statement of compliance

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

This Research Ethics Committee is an advisory committee to the Yorkshire and The Humber Strategic Health Authority
*The National Research Ethics Service (NRES) represents the NRES Directorate within
the National Patient Safety Agency and Research Ethics Committees in England*

Yours sincerely

Miss Claire Kelly
Committee Assistant Co-ordinator

E-mail: Claire.kelly@leedspft.nhs.uk

Copy to: *Professor Mike Lucock*

Appendix Sixteen

Approval from University of Huddersfield to include day

centre clients

From: Nigel King <n.king@hud.ac.uk>
To: Alan Wright <Alan.Wright@bdct.nhs.uk>
Date: 08 March 2011 10:56:36
Subject: Re: Sponsors representative signature on IRAS form

Dear Alan
Regarding your recent letter: I am happy to approve the small amendment to the recruitment process
for your PhD research to now include clients at ████████ day centre.
Best wishes
Nigel

___

This transmission is confidential and may be legally privileged. If you receive it in error, please notify
us immediately by e-mail and remove it from your system. If the content of this e-mail does not relate
to the business of the University of Huddersfield, then we do not endorse it and will accept no liability.

CC: Kirsty Thomson <K.Thomson@hud.ac.uk>

Appendix Seventeen

Local Research Ethics Committee (LREC) approval for

access to participants' medical records

NHS

National Research Ethics Service
NRES Committee Yorkshire & The Humber - Bradford

Yorkshire & Humber REC Office
Millside
Mill Pond Lane
Meanwood
Leeds
LS6 4RA

Tel: 0113 305 0116

23 September 2011

Mr Alan Wright
Lead Physiotherapist
Bradford District Care NHS Trust
Lynfield Mount Hospital
Heights Lane
Bradford
BD9 6DP

Dear Mr Wright

Study title:	The experience of physical activity and well-being amongst older people with dementia from ethnically diverse backgrounds.
REC reference:	10/H1302/14
Amendment number:	2
Amendment date:	15 September 2011

The above amendment was reviewed on 22 September 2011 by the Sub-Committee by correspondence.

Ethical opinion

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

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Extracts from original protocol and proposed changes	1	15 September 2011
Participant Consent Form: Access to medical notes consent form	1	25 August 2011
Participant Information Sheet: Request for access to medical notes	1	20 August 2011
Notice of Substantial Amendment (non-CTIMPs)	2	15 September 2011

Membership of the Committee

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

R&D approval

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

Statement of compliance

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

10/H1302/14:	**Please quote this number on all correspondence**

Yours sincerely

PP   *C . G . Appleby*

Professor Alan Roberts
Chair

E-mail: craig.appleby@nhs.net

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

Copy to: *Professor Mike Lucock, The University of Huddersfield*
Mr Simon Gelsthorpe, Bradford District Care Trust

NRES Committee Yorkshire & The Humber - Bradford

Attendance at Sub-Committee of the REC meeting on 22 September 2011

Name	Profession	Capacity
Dr Mark Busby	Consultant Neurologist	Expert
Professor Alan Roberts	Chair	Expert

University of
HUDDERSFIELD   **Interview Information form**

Physical activity and wellbeing study

Information about the research

I would like to invite you to take part in a research study which is part of a PhD. Before you decide if you want to help it is important for you to understand why the research is being done and what it would involve for you. This information sheet gives details of the project and is intended to help you to decide if you want to be involved. It should take no longer than five minutes to read. Please feel free to ask me if you have any questions or contact me on the number provided if you would like more information. Take plenty of time to decide whether you want to take part and discuss your thoughts with others.

What is the purpose of the study?

Evidence suggests that being physically active with friends and loved ones can have an important effect on a person's sense of wellbeing. However, more research is needed which includes people with memory difficulties. In this study I plan to ask individuals who have been attending the Wellbeing café about their experiences of being physically active.

Why have I been invited?

Because you have already participated in the earlier stages of the research project.

Do I have to take part?

No, you don't have to if you don't want to. Participation in the research project is entirely voluntary. You can choose not to become involved and the services you receive will be completely unaffected.

What will happen to me if I take part?
If you agree to help, I will invite you to talk to me on an individual basis. We will discuss your experiences of attending the Well-being café and your views on physical activity. I will record the interview and write down what has been said shortly afterwards.

Are there any disadvantages and risks of taking part?
The interview will last an hour at most and you may miss some of your regular activities on the day that it takes place.

What are the possible benefits of taking part?
I cannot promise that the study will directly help you but it is hoped that the research will help to raise awareness of the issues faced by people living with memory difficulties.

What if there is a problem?
If you have any concerns about this study please contact me and I will do my best to address the issue. If you remain unhappy and wish to complain formally you can do this by contacting Professor Mike Lucock at The University of Huddersfield on 924327560.

Will my taking part in the study be kept confidential?
Every effort to maintain your confidentiality will be made during and after the study. No-one other than my self and my university supervisors will have access to information which may identify you. Your name will be changed in any documents and reports resulting from this study. Any information that I collect will be locked in a safe place at Lynfield Mount Hospital.

Are there any possible circumstances in which the confidential information I give is shared with others?
If anything you say makes the researcher believe you are at risk of harm he may alert the appropriate services.

What will happen if I don't want to carry on with the interview?

You can withdraw from the interview at any time. If you choose not to continue you have the right to decide whether the information collected prior to your withdrawal is used in the research or not.

What will happen to the results of the research study?

The information that I gather will be used to write a scientific report. A shortened less detailed version of this report will also be written. The scientific report will be given to

- The Alzheimer's Society.
- Bradford District Care Trust.
- ██ █████.
- █████ █████.
- The University of Huddersfield.

Individuals who have participated in the research will be offered a choice of the full report or shortened version. It is also likely that the research will be published in some format and presented at a conference.

Who is organising and funding the research?

I am organising the research along with The University of Huddersfield, ██████ ██████, ████ ███████ and the Alzheimer's Society. It is being done as part of a PhD degree.

Has the study been approved?

In order to protect everyone involved, all research in the NHS is looked at by an independent group of people, called a Research Ethics Committee. This project has been reviewed and approved by both The University of Huddersfield and the NHS Research Ethics Committees.

Further information

For further information please contact Alan Wright by telephone on 01274 363842 or by email on alan.wright@bdct.nhs.uk

Thank you for reading this information sheet.

Appendix Nineteen

UNIVERSITY OF HUDDERSFIELD

Physical activity and wellbeing study

Alan Wright

Interview consent form

Please initial

I have been fully informed of the nature and aims of this research and consent to taking part in it.	
I understand that I have the right to withdraw from the project at any time without giving any reason, and that I have a right to withdraw my data if I wish.	
I give my permission for my views to be recorded.	
I give my permission to be quoted (my real name will not be used).	
I understand that the recording of the interview will be kept in secure conditions at Lynfield Mount Hospital	
I understand that no persons other than Alan Wright and his university supervisors will have access to the recording.	
I understand that my identity will be protected by the use of a pseudonym throughout the research and that no information that could lead to my being identified will be included in any report or publication resulting from this research	
I give my permission for Alan Wright to access written records kept by the Well-Being Café containing information about myself.	

Name of participant……………………………………………………

Signature………………………………………………………………

Date……………………………………………………………………

Name of researcher…………………………………………………….

Signature……………………………………………………………….

Date…………………………………………………………………….

Two copies of this consent from should be completed: One copy to be retained by the participant and one copy to be retained by the researcher

Appendix Twenty

Ethnic categories as used by the Office of Populations, Censuses and Surveys.

White British.
White Irish.
White other.
Mixed: white and black Caribbean.
Mixed: white and black African.
Mixed: white and Asian.
Mixed: other mixed.
Asian or Asian British: Indian.
Asian or Asian British: Pakistani.
Asian or Asian British: Bangladeshi.
Asian or Asian British: other Asian.
Black or Black British: Black Caribbean.
Black or Black British: Black African.
Black or Black British: other Black.
Chinese or other ethnic group: Chinese.
Chinese or other ethnic group: Other

Office of National Statistics (ONS) 2009

"Population estimates by ethnic group for primary care organisations and strategic health authority in England for 2007" (2009)

http://www.ons.gov.uk/ons/taxonomy/index.html?nscl=identity

Accessed on 14th September 2011

Appendix Twenty One

Interview questions

Can you tell me about how you have been physically active through your life?

What does physical activity mean to you?

Can you tell me why you attend this group?

How do you feel about coming here?

What do you think you gain from being physically active?

How do you feel when you're dancing/exercising?

How do you feel at the end of the group?

How long does this feeling last?

Appendix Twenty Two
Initial Template

Particpant observation themes in italics.

1) <u>How</u> do people with dementia engage in physical activity (a priori theme).
    i) **Characteristics of physical activity at intervention**
    -Environmental
      * *In a group with others who don't have dementia*
      * *Led by a leader adopting biomedical approach*
      * *In a chaotic and unplanned environment*
      * *Women only*
      * *Ethnically separate*
      * *Multi-ethnic environment*
      * *Institutional environment*
    -The personal experience of physical activity
      * *Without difficulty*
      * *Despite barriers*
      * *Spontaneously*
      * *Unmet need for physical activity*
      * *Doing something new*
      * *Struggling to participate*
      * *Engaging with others*
      * *Expressing enjoyment*
      * *Communicating through physical activity*
      * *Self expression through PA*
      * *Performance*
      * *Touching others*
      * *Adhering to rules/rituals*
      * *Intoxication*
      * *Like a party*
      * *Using retained abilities (eg sense of rhythm)*
      * *Without inhibition*
      * *With humour*
    ii) **Characteristics of physical activity outside the café/day centre**
    -Environmental
      * Being outdoors
    -Personal experience of physical activity
      * *Their need for PA is not fully met*
    iii) **Not engaging in physical activity**
      * At café/intervention
      * Elsewhere
    iv) **The contrast between what is said and what is done**

2) **Attitude to physical activity (inductive theme)**
    i) **Expressed opinions of physical activity in general.**
      * Positive
      * Negative e.g. Dislike of gardening
    ii) **Expressed opinion of physical activity at café/day centre.**
      * Positive- eg Exercise is enjoyable
      * Negative- eg Dancing is foolish
    iii) **Identifying self in terms of physical activity**
      * Busyness
      * Nostalgia

3) What benefits to performing physical activity do *they* identify? (a priori theme)

i) Benefits from physical activity at day centre or cafe
- Feel great
- Enjoyment of activities at day centre/café
- "Treatment" for joint problem
- Social benefit
- To burn energy

ii) Benefits from physical activity in general
- Body benefits from physical activity & busyness
- Its good for you
- It feels good/great
- Relaxation
- It keeps the brain working

4) What barriers to physical activity do people with dementia face? (a priori theme)

i) In general
- Internal factors
- Lack of motivation
- Not knowing where to go
- Fear of strange places
- Health/Depression
- Tiredness (Najma)
- Age
- Weight loss (Fameeda)

- External factors
- Lack of social support
- Lack of transport
- Weather
- Finances

ii) In the café or day centre
-Internal factors
- *Self consciousness*

-External factors
- *Use of inappropriate materials (DVD, tape)*
- *Cognitive overload*
- *Imposed rules*
- *Unhelpful interaction with staff/volunteers*
- *Chaotic environment*
- *Culturally inappropriate environment/activity*

5) What are the facilitators of physical activity?(a priori theme)

i) In the café/day centre
-Internal factors
- Personal characteristics?
- Personal history?
- *Knowing the" rules"*

-External factors
- Transport provided
- Medical advice

- Characteristics of activity that facilitate engagement
- *Playful*
- *Familiar rituals (incl. applause)*
- *Spontaneity encouraged*
- *Pre-reflective activity*
- *Use of effective equipment*

- *Rhythm*
- *Use of music*
- *Humour*
- *Competition*
- *Co-operation*
- *Breaking rules together*
- *Encouragement*
- *Celebratory ambience*
- *Safe social environment*
- *Effective interaction with volunteers and carers*
- *Acceptance by others*
- *Routine*

ii) Factors that help to facilitate physical activity generally
- Social support
- Dog
- Medical advice
- Routine
- TV advice (Fameeda)

6) What role does the background and ethnicity of participants have on their experiences of physical activity?(a priori)

i) Previous history of physical activity & previous social history
ii) School
iii) Family
iv) Employment
v) Church
vi) Ethnicity and Identity
- Sticking together?
- Ethnicised environment
- Ethnicised physical activity
- Similarities of engagement along ethnic lines
- Attitude to health- what is discussed and what is hidden

vii) Irrelevancy of ethnicity
viii) Expressions of racism
ix) The concept of ethnicity

7) Having dementia

i) Defining Dementia
- Awareness of society's view of dementia
- Normality of memory loss
- Self defining dementia purely as memory loss (Najma)

ii) Attitude to having dementia
- Part of identity
- Pride in retained abilities
- Worrying about the future
- Putting up with it
- Its not so bad
- Denial of dementia
- Frustration
- Avoiding thinking about dementia
- It comes and goes

iii) Interpersonal relations
- Reliance on others
- Caring for others
- Dealing with the negative response of others to dementia
- Not going out much
- Concern with the opinions of others

- Deference to carer
- Difficulty keeping up with others
- Experiencing conflict with carer
- Carer taking over
- Being undermining by carer
- The importance of support from familiar people

iv) Participants' self-view & self-presentation
- Negative self-appraisal.
- Fear of losing dignity
- Insight into their deficits
- Presenting self as a capable functioning person

v) Attitude to participating in study and talking about dementia
- Its fine to talk about dementia
- Its important to talk about dementia
- Dread of talking about it
- I won't be of any use

vi) The effects of cognitive deficit as revealed to researcher
- Words failing them
- Memory difficulties

vii) Humour
- Retained sense of humour

viii) Carers perspectives
- Dismissive of partners abilities
- Surprise at partner talking so openly about their dementia
- Advising the researcher to keep things simple
- Concern at what might be revealed or how person with dementia will present
- Openness about the difficulties of caring for someone with dementia

ix) Developing dementia
- The story of how dementia became apparent
- Being told that you have dementia

8) The body
i) Attitude to body
- The ageing body (Including pride in age)
- Pre-occupation with physical health
- Pride in what the body can do
- My body is in good shape even if my brain is affected by dementia

ii) Living through the body
- *Engaging/disengagement through body*
- *The restless body*
- *Enjoyment of body*
- *Innate body skills*
- The expressive body
- Keeping busy
- Awareness of the body
- The out of control body
- Touch (?)

9) Reflexive themes
i) My identity- discomfort with difference and resolution
- Gender
- Ethnicity
- Age
- Unable to understand language (spoken and otherwise)
- Privileged position

ii) My assumptions/prejudice challenged
- Cultural stereotyping

iii) My sense of Time
- Dragging
- Sense of flow

iv) My sense of environment
- Gendered/ethnicised
- Hostile/chaotic
- Institutionalised
- Buzz in room
- Gloom in room

v) My interaction with others
- Pleasure in shared activity
- Pleasure at communicating in a non-verbal manner
- Pleasure in breaking rules together
- Difficulty in joining in
- Difficulty with "breaking in" to social group.
- A sense of tacit rules being created and followed

vi) My mood/feelings
- Feeling bored
- Shame at grabbing advantage

vii) My engagement in activities
- Pleasure in movement
- Music helping things along
- Disengaging the brain and following the rules
- Excitement of competition
- Struggling to follow the instructions
- Difficulty in losing inhibitions
- Doing things to justify my role (scoring games)

viii My views on the participants
- Its hard to see who has dementia and who doesn't
- Its easy to tell who has dementia and who doesn't

10) How do people with dementia experience interventions intended to promote positive mental health (a priori)?

i) Attitude to day centre/café
- Positive attitude to attending
- Looking forward to attending
- Worth dressing up for
- Its an opportunity to mess about
- Its somewhere to talk

ii) Interpersonal relationships
- Mixing with others who have dementia
- *Acceptance of others*
- *Engagement and disengagement with others*
- *Retained social awareness-intact social rituals*
- *waiting for things to happen*
- *Gaining affirmation of self from others*
- *Expressions of racism*
- *Control and resistance (friction).*
- *Passivity*
- *Being assertive*

iii) Communication
- *Communication breakdown*
- Confabulation (present in both interview and PO data)
- Spoken language is problematic
- *Not talking*
- *Non-verbal communication (eye contact, hand shaking, expressive body)*

- Awareness of the value of non-verbal communication.
- *Not initiating conversation*
- Expressed humour

iv) Cognitive impairment
- *Music and retained memory*
- *Remembered rules*
- *Areas of intact memory*
- Struggling to remember
- *Disorientation*
- *Lost*
- *Coarsened social behaviour*

v) Environment
- A sense of occasion (reflexive theme)
- Gendered/ethnicised
- Safe
- Hostile/chaotic (reflexive theme)
- Institutionalised (reflexive theme)
- Buzz in room (reflexive theme)
- Gloom in room (reflexive theme)
- *Non-verbal environment*

vi) Unmet needs

vii) Activities
- Doing things you would not normally do

viii) Reason for attending intervention/benefit

ix) Carer attending alone
- Supporting one another

Appendix Twenty Three
Categories, themes and subthemes
(Part.Observation sub-themes in italics).

Section one: Categories relating to the lived experience of dementia, how it impacts on well-being and the significance of the body

Coping with a new dementia identity
"AWARENESS OF SPOILED IDENTITY"
- Awareness of society's view of dementia (Sub-themes)
- Normality of memory loss
- Making sense of having dementia
- Self defining dementia purely as memory loss (Najma)
- Attempting to present oneself to the world in the best way possible.
- Negative self-appraisal.
- Fear of losing dignity
- Insight into their deficits
- Presenting self as a capable functioning person
- I won't be of any use
- Worrying about the future

"TALKING ABOUT DEMENTIA"
- It's fine to talk about dementia
- It's important to talk about dementia
- Dread of talking about it

"COMING TO TERMS WITH DEMENTIA"
- Denial of dementia
- Frustration
- Avoiding thinking about dementia
- It comes and goes
- It's part of my identity

"PROBLEMATIC RELATIONSHIPS"
- Reliance on others
- Caring for others
- Dealing with the negative response of others to dementia
- Not going out much
- Concern with the opinions of others
- Deference to carer
- Difficulty keeping up with others
- Experiencing conflict with carer
- Carer taking over
- Being undermining by carer

"IT'S NOT ALL BAD…LOOKING ON THE BRIGHT SIDE"
- Pride in retained abilities
- Putting up with it
- Expressed humour

"BEING SOCIAL IS IMPORTANT TO ME"
- The importance of support from familiar people

Well-being under threat from cognitive loss
"STRUGGLING TO FIND THE WORDS"
- Words failing them
  - *Communication breakdown*
  - Confabulation (present in both interview and PO data)
  - Spoken language is problematic
  - *Not talking*
  - *Non-verbal communication (eye contact, hand shaking, expressive body)*
  - *Not initiating conversation*

"FEELING LOST AND OUT OF THE SOCIAL LOOP"
- *Disorientation*
- *Lost*

"UNRELIABLE MEMORIES"
- Memory difficulties
- Struggling to remember

"I'M STILL HERE; RETAINED MEMORIES"
- *Music and retained memory*
- *Remembered rules*
- *Areas of intact memory*

"BREAKING THE SOCIAL RULES"
- *Coarsened social behaviour*
- The out of control body

The social consequences of dementia
"LOSS OF SOCIAL ROLES"

"DISENGAGING AND WITHDRAWING"

"A CONTRACTING SOCIAL WORLD"

The significance of the body in maintaining selfhood and constructing identity (Inductive category)
"PRIDE IN THE BODY"
- The ageing body (Including pride in age)
- Pre-occupation with physical health
- Pride in what the body can do
- My body is in good shape even if my brain is affected by dementia

"SHE HASN'T FORGOTTEN HOW TO DANCE"
- *Innate body skills*

"THE RESTLESS BODY"
- *The restless body*
- Keeping busy

"CONNECTING WITH THE WORLD THROUGH THE BODY"
- *Engaging/disengagement through body*
- *Enjoyment of body*
- The expressive body
- Awareness of the body
- Awareness of the value of non-verbal communication.

Section two: Categories relating to factors influencing participation in physical activity.

Participants' relationship with physical activity: Attitudes and beliefs
"A PASSION FOR PHYSICAL ACTIVITY"
- Positive

"INDIFFERENCE OR DISLIKE OF PHYSICAL ACTIVITY"
- Negative e.g. Dislike of gardening
- Negative e.g. Dancing is foolish

"PHYSICAL ACTIVITY IS GOOD"
- Body benefits from PA & busyness
- It's good for you
- It feels good/great
- Relaxation
- It keeps the brain working
- Positive e.g. Exercise is enjoyable

"I'M A BUSY PERSON"
- Busyness

"IT'S SOMETHING I'VE ALWAYS DONE"
- Nostalgia

Factors influencing participation in physical activity: relationships with others
"THE DOG NEEDS A WALK"
- Dog ownership

"LACK OF SOCIAL RESOURCES"
- Lack of social support
- Lack of transport
- Not knowing where to go
- Fear of strange places

"WE'RE IN THIS TOGETHER"
- Social support
- *Playful*
- *Spontaneity encouraged*
- *Pre-reflective activity*
- *Humour*
- *Competition*
- *Co-operation*
- *Breaking rules together*

- *Encouragement*

"PRACTICAL HELP AND ENCOURAGEMENT TO PARTICIPATE"
- Transport provided
- *Effective interaction with volunteers and carers*
- Medical advice
- Routine
- TV advice (Fameeda)
- *Led by a leader adopting biomedical approach*

"THE IMPORTANCE OF SOCIAL RITUAL"
- *Knowing the" rules"*
- *Routine*
- Disengaging the brain and following the rules

"US AND THEM"
- *Unhelpful interaction with staff/volunteers*

Factors influencing participation in physical activity: the lived body
"FACILITATING MOVEMENT THROUGH THE BODY"
- *Use of effective equipment*

"FACILITATING ENGAGEMENT THROUGH MUSIC AND RHYTHM"
- *Rhythm*
- *Use of music*
- Music helping things along

"THE FRAIL BODY"
- Getting older
- Lack of motivation
- Health/Depression
- Tiredness (Najma)
- Weight loss (Fameeda)

"COGNITIVE OVERLOAD; ENGAGEMENT THROUGH THE BODY DISRUPTED"
- *Use of inappropriate materials (DVD, tape)*
- *Cognitive overload*
- *Imposed rules*
- I'm struggling to follow the instructions

"BREAKING THE ICE: THE INHIBITED BODY"
- *Self consciousness*
- *Culturally inappropriate environment/activity*
- My difficulty in losing my inhibitions

"ETHNIC INCONGRUITIES"
- *Unhelpful interaction with staff/volunteers*
- *Knowing the" rules"*

"LIBERATED BODIES"
- *Bodies taking the lead*

- *Loss of inhibition*

Factors influencing participation in physical activity: the lived environment
"FAMILIAR TERRITORY, ETHNIC IDENTITIES SUPPORTED"
- *Women only*
- *Ethnically separate*
- gendered/ethnicised
- Safe
- *"Knowing the" rules*

"SAFE ENVIRONMENTS"
- *Celebratory ambience*
- Weather
- *Safe social environment*
- *Acceptance by others*
- *Multi-ethnic environment*
- Safe
- Buzz in room (reflexive theme)

"DIFFICULT ENVIRONMENTS"
- *In a chaotic and unplanned environment*
- Hostile/chaotic (reflexive theme)
- Institutionalised (reflexive theme)
- Gloom in room (reflexive theme)
- *Chaotic environment*
- *Institutional environment*

The influence of lived time on physical activity
"GETTING OLDER, I'M NOT AS PHYSICALLY ACTIVE AS I USED TO BE"

Section three: Categories relating to the experience of physical activity and well-being
The benefits of physical activity for people with dementia
"ENJOYMENT OF PHYSICAL ACTIVITY"
- Enjoyment of activities at day centre/café
- "Treatment" for joint problem
- Social benefit
- My own Pleasure in movement

"HAVING FUN TOGETHER"
- The pleasure of competition

"A MEANS TO EXPERIENCE FLOW"

"BODIES FEELING GOOD"
- Feeling great

"ENHANCING MY MOOD BY BEING PHYSICALLY ACTIVE"

"A CHANCE TO BURN ENERGY"
- Taking the opportunity to burn energy

"MAKING CONNECTIONS THROUGH PHYSICAL ACTIVITY"
- Mixing with others who have dementia
- *Acceptance of others*
- *Engagement and disengagement with others*
- *Retained social awareness-intact social rituals*
- *Gaining affirmation of self from others*

"BEING TOGETHER THROUGH PHYSICAL ACTIVITY"

"PROVIDING DIVEERSION AND STRUCTURE TO SOCIAL LIFE"
- Positive attitude to attending
- Looking forward to attending
- Worth dressing up for
- It's an opportunity to mess about
- It's somewhere to talk
- A sense of occasion (reflexive theme)

"CONSTRUCTING IDENTITIESS THROUGH PHYSICAL ACTIVITY"

"EMPOWERMENT THROUGH PHYSICAL ACTIVITY"

"SELF-EXPRESSION THROUGH THE BODY"

The experience of well-being through physical activity: a typology
"IT'S ALL COMING TOGETHER"
"PARTY TIME AT BROWGATE"
- *Intoxication*
- *Like a party*
- *Using retained abilities (eg sense of rhythm)*
- *Without inhibition*
- *Touching others*

"BERCIK TAKES TO THE STAGE"
- *Without difficulty*
- *Spontaneously*
- *Self-expression through PA*
- *Performance*
- Doing things you would not normally do

"A GLIMPSE OF SUNLIGHT ON A CLOUDY DAY"
- *Engaging with others*
- *Expressing enjoyment*
- *Communicating through physical activity*

"DOING IT ANYWAY"
"BEING PHYSICALLY ACTIVE THEIR WAY"
- *Despite barriers*
- *Being assertive*

"MRS BEGUM TAKES CONTROL" (theme)

"WANTING TO BUT NOT QUITE GETTING THERE"
"THERE'S SOMETHING STOPPPING ME"
- *Struggling to participate*
- *Unmet need for physical activity*

"UNBROKEN SOCIAL ICE"
- *Passivity*

"IT'S JUST NOT HAPPENING"
"REFUSING TO PLAY THE GAME"
"IT'S NOT FOR ME"
"BEING IGNORED"
- *Their need for physical activity is not fully met*