Because life's there…understanding the experience and identity of people living with dementia in the context of leisure and fitness centres

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Because life's there: understanding the experience and identity of people living with dementia in the context of leisure and fitness centres

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Abstract

Understanding of the meaning and significance of identity, personhood and the social citizenship of people with dementia is growing, and has contributed to progressive approaches in health and social care, which promote the wishes and interests of individuals with dementia. Leisure, physical activity and sport have been part of and shaped lives of individuals and communities throughout history, but only recently have they been considered in relation to people with dementia. This research provides new knowledge concerning how engagement in activity at community leisure and fitness centres (Centres) influences the identity of people with dementia. Four people with dementia, engaging regularly with the offering of their Centre, were recruited as primary research participants, alongside their family carer (applicable to three of the participants), and the Centre Workers supporting engagement. Carers and Centre Workers provided contextual detail to the accounts of primary participants. The methodology endeavoured to co-create knowledge between participants and the researcher, through ongoing consultation with people living with dementia and family carers to inform areas for enquiry and methods. These included participant observation, and go-along interviews. A survey of Centres enhanced understanding of the research context and assisted with participant recruitment. Phenomenological philosophies helped to understand meanings participants drew from their experiences, and thematic analysis of data enabled the distillation of knowledge to address the research question.

Findings show that participation in Centre offerings had benefit for both the person with dementia and their family carer; that Centres can enhance their

offering, and improve the experience of participation; and that the person's choice matters in the design and delivery of sporting and physical activity. More widely, the identities of people with dementia, fostered through engagement at Centres, could be utilised positively within their daily lives in ways that enhanced feelings of agency and supported adjustment to the changing situation that a diagnosis of dementia brings. Thus, identity needs to be included within sport and physical activity policy and practice, and be afforded status alongside traditional features such as enhancing physical fitness. Additionally, enhanced levels of training related to dementia should be provided to Centre Workers because of the important part they play in enabling people living with dementia to engage in activity. The original contribution to knowledge is that people living with dementia can continue to construct their identity through engagement with Centres, so that existing identity can strengthen or new identity form, enabling people with dementia to look forward in aspirational ways and play an active role in their communities.

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Glossary

Alzheimer’s Disease: a physical disease affecting the brain, and the disease that is the most common cause of dementia. Symptoms are progressive and include memory loss and difficulty with orientation in daily activities.

Centre Workers: individuals employed to provide physical and leisure activity within Leisure and Fitness Centres

Co-creation: the making of knowledge and understanding jointly between research participant and researcher.

Corticobasal degeneration: A rare disease where areas of the brain are damaged and shrink. Symptoms include increasing difficulty with speech, movement and dexterity

Dementia: the term to describe different illnesses and conditions affecting and damaging areas of the brain, for example Alzheimer’s disease.

Dementia with Lewy bodies: illness caused as tiny deposits of a protein interfere with the functioning of nerve-cells in the brain. This can cause difficulties with movement, and impaired thinking skills in individuals. Symptoms become more serious over time.

Family carers: individuals who are family members of a person living with dementia, who provide support and possibly care for them on an unpaid basis.

In my study each of the family carers was the female spouse of the person living with dementia.

Leisure and Fitness Centre(s) Abbreviated to ‘Centre(s)’, see Abbreviations, below**:** Places, situated within local neighbourhoods, which are open to the public, and provide a range of opportunity for physical and leisure activity. Typically this will include the chance to take part in sport (for example badminton, table-tennis, five-a-side-football), and physical activity within a gymnasium. Provision will also be likely to include fitness classes. A Centre might also incorporate a swimming pool. In addition such places will typically offer cafe/ restaurant facilities. Centres are not privately run, tending to be provided by charitable trusts. However, in my study one location was added, described as a fitness gym, which was run as a business. The rationale for this is explained within the text.

Participant: person recruited to participate in my research who is not an individual living with dementia. There are seven such participants in my research, either family carers or Centre Workers.

Posterior Cortical Atrophy: Condition or illness where what are known as amyloid plaques and neurofibrillary tangles harm areas of the brain and interfere with its function. Symptoms are progressive and include impaired vision, and memory difficulties in later stages.

Primary participant: participant in my research who is a person living with dementia. There are four primary participants in my research, Ivan, Paul, Leonard and Jacqui.

Syndrome: term used, on occasions, as an alternative to the word dementia, to stand for the same collective of illnesses and conditions causing damage to the brain.

Abbreviations

Centres: Leisure and Fitness Centres (see Glossary, above)

DEEP: Dementia Engagement and Empowerment Project

Chapter 1: Introduction to my study

1.1 Introduction

Identity; who we understand ourselves to be, and how we feel about that, are deeply personal but also public matters, as we take perceptions of our individuality into the world. My PhD investigates the identity held by people living with dementia. Until recently this would not have been a matter prioritised for consideration, in part because it was popularly held that dementia expunged identity (Caddell and Clare, 2010). At the same time dementia was conceptualised as a living death that left the body behind (Moran, 2001), with people with dementia seen and accepted as individuals who had slipped from societal life. This pejorative stance meant there was little inclination to explore facets of existence such as identity, even though who we are is a fundamental part of ourselves and our humanity (Kitwood, 1997).

In more recent times, as this paradigm has been challenged, research has investigated the sense of continuing personal identity in the dementia context (Caddell and Clare, 2010). My study explored how the identity of four people living with dementia was shaped through their engagement with the Leisure and Fitness Centres (hereafter referred to as Centres) close to where they lived, and activities on offer there. My identity was also a part of this study, since who I am informed and moulded the research. It influenced the choice of subject matter, and how I went about investigating my research question. Indeed, undertaking this PhD made me re-evaluate who I am, shaping my identity.

Dementia is the term used to describe a number of diseases affecting brain function, the symptoms of which undermine many of the cognitive skills and abilities required for daily living, including problem solving and sequencing, speech and memory. Its impact extends beyond this, however, with the malignant perception and stigma attached to the syndrome causing distress to people living with dementia and those affected by it, in particular the family members and friends of the person. Symptoms that undermine daily functioning also erode feelings about oneself and one's place in the world (Brooker and Latham, 2016). In combination with the aforementioned perception of dementia, this can prove damaging to personal identity. This is magnified by the fact that dementia is a progressive condition and people are liable to be aware that their situation will deteriorate over time. In addition, no medication exists that can either sustain amelioration of symptoms in the long-term, or offer a cure.

Leisure, physical activity and sport are vast, broad, but related topics. Whilst they have been part of, and shaped lives of individuals and communities throughout history (Hill, 2002), only recently have they been considered in relation to people living with dementia (Genoe and Dupuis, 2011), sport and physical activity especially so (Alzheimer's Society, 2019a). This is part of the rationale for my enquiry, as I will articulate more fully below.

My study intersects with the contexts of sports, physical activity and leisure, and contemporary understandings of dementia. It connects with the alternative narrative, alluded to above, developed not least through advocacy of people living with dementia themselves (Swaffer, LeBlanc, and Mittler, 2020). This is one where an individual’s personhood is highlighted and cherished, and where their future goals and aspirations are the equal priorities of health and care needs. This paradigm promotes rehabilitation rather than the therapeutic nihilism associated with the old culture of care. If people are to be seen as full persons, then the citizenship of people living with dementia, corroded by the syndrome and its societal implications, must be strengthened and inequalities in society redressed. My study embraces this, with a focus upon the identity of people living with dementia, and their experiences of engagement with Centres. It does not seek to prove a hypothesis, since there remains too much uncertainty and lack of knowledge in relation to the topic to support this. However, by hearing from people living with dementia and those closest to them it explores how this might contribute to the new narrative. This is in the context where, because of the progressive nature of dementia illnesses, change to one’s life is liable to be significant.

This first chapter, therefore, introduces the foundations of my research namely dementia, identity, and leisure, sport and physical activity. It will define them and synergise the arguments contained within each that are relevant to my research. These topics are crosscut by concepts such as citizenship, agency, stigma, freedom, and authenticity, which are themselves inherently complex. I also include a section addressing ‘place’, defining this and explaining its relevance to my study. As my thesis progresses I will argue that place is where the theoretical and empirical elements of my research coalesce, here within the ‘bricks and mortar’ of Centres.

In Chapter 2 I set out my review of the literature. This was a critical review, contributing to the grounding of my study, and enabling a focus upon key ideas and concepts. The rationale was also to identify the gap that my research could address. Taken alongside the detail contained within Chapter 1, this process meant I could confirm the aim of my study, its objectives and the research question. I detail these at the conclusion of Chapter 2.

Chapter 3 justifies the research methodology and underpinning philosophy. Here I make clear my ontological, epistemological and axiological standpoints that influenced the design of my research. I also detail the phenomenological ideas that provided the means for me to gain deeper understanding of aspects significant to my enquiry, for example, life as primary research participants experienced it.

In Chapter 4 I describe how I put my methodological orientation into practice. I discuss how participant perspectives informed what I did from the outset. For example, through consultation with people living with dementia, family carers and people providing sports and physical activity. The chapter then addresses the rationale for my choices of research methods, and details of participant recruitment. Latterly, the focus is upon how I understood my data through analysing it thematically, and discussion of ethical considerations.

In Chapter 5 I present my study's findings as they relate to the four primary research participants Ivan, Paul, Leonard and Jacqui, as they engaged at their local Centre.

Chapter 6 explores how my findings extend beyond the context of primary participants. It offers wider understanding into how engagement by people living with dementia at Centres can influence their identity.

Finally, in Chapter 7 I set out my conclusions. These consolidate insights found in the research into the lived experience of dementia in the context of activity within Centre settings, and the influence of this upon identity. Additionally, I make recommendations about how Centres, and sport and physical activity related services and initiatives more widely, can offer people living with dementia opportunity to participate within the daily life of their communities.

At the outset, however, it is necessary to understand what dementia is, and the impact it has upon people and those close to them.

1.2 Dementia

Dementia is the collective name for a number of progressive illnesses and disorders affecting the brain and cognitive function, the most common being Alzheimer’s disease (Alzheimer’s Society, 2019a). These present via a range of symptoms, including impaired memory, difficulty with thinking, changes in behaviour and reduced ability to undertake activities (Alzheimer’s Disease International, 2014). Pharmacological interventions that can modify dementia related diseases remain elusive (Stella *et al.,* 2015). Adjustment to symptoms is complex and dementia is experienced differently by different people (Brooker and Latham 2016). There is also impact at a societal level. Studies estimate that globally there are more than 47 million people living with dementia, and predict this figure will rise to beyond 130 million by 2050 (World Health Organization, 2015). In light of this complexity, and the rising demand for support, international and domestic health and care services are struggling to meet the diverse needs of people living with dementia (Alzheimer’s Disease International, 2015; National Audit Office, 2016). The impact of dementia for individuals and family members can be devastating, for example, placing excessive strain on close relationships as symptoms progress and the behaviour of the person living with dementia changes (Baikie, 2002; Zweig and Galvin, 2014).

People living with dementia experience stigma, for example, frequently being publically perceived as being no more than passive beings, without skills or value to offer society (Alzheimer’s Society, 2017). This stigma is influenced by the way dementia is socially constructed, and this changes over time and plays out differently in different cultures. However, objectification and loss of agency are themes associated with dementia within popular consciousness (Bosco *et al.,* 2019a). Relevant detrimental features include malignant social psychology, and malignant social positioning (Sabat, 2001; Patterson *et al.,* 2018), where people living with dementia are negatively labelled and stereotyped by others.

Other debates that inform the contemporary context of dementia include moving beyond the ‘standard paradigm’ of depersonalised, task centred care that was unchallenged by many in the 20th century (Kitwood, 1997). The new paradigm of enabling personhood to strengthen and flourish, and the application of the principles of care focused upon the person, have since become better established, and begun to be applied in diverse service settings (Brooker and Latham, 2016). More recently, definitions of social health have been utilised to help inform understanding of dementia (Dröes *et al*., 2017). This recognises the impediment caused to individuals by the symptoms of dementia illnesses, but focuses upon the capacities of individuals ahead of deficits.

The perspective and contribution of family carers is also understood as a key component in enabling people with dementia to live healthy and fulfilling lives. This is especially so when the independence of both carer and person living with dementia are recognised, alongside features characterised by interdependency (NICE, 2018; Van't Leven, *et al.,* 2019). Understanding how the relationships people living with dementia have with family, and those others significant to their daily lives, forms an important part of the context of my research. I will return to this as my study continues.

Simultaneously, the rising numbers of people living with dementia globally is another important part of the context, increasing as populations age (World Health Organization, 2015; Alzheimer's Disease International, 2015). This has galvanised initiatives to address the risk of developing dementia, or prevent it (Alzheimer's Disease International, 2014). Alongside these, strategies enabling communities and environments to become 'dementia friendly' have been prioritised (Hare, 2016; de Bruin *et al.,* 2017). Different understandings of these exist, and my study returns to this as its narrative develops. However, essential features are the inclusion of people with dementia and their carers within the life of places or cultures, in ways that offer them opportunity to play the fullest part possible (Phillipson *et al.,* 2019).

By keeping these contextual features in mind it is possible to live well with dementia, but this is not easily achieved (Bartlett *et al.,* 2017). It remains dependent upon multiple factors, key amongst them being the perspective and approach of other people significant to the person living with dementia (Bartlett *et al.,* 2017). It also includes timeliness of diagnosis, and the quality of care or support that might be required. Evidenced-based practice guidelines suggest that support should be centred upon the person, inclusive of a range of interventions appropriate to each individual focusing on physical health, social circumstances, and psychological need. They must also take into account the relationships and wider social systems within which individuals with dementia live (Kitwood, 1997; Brooker and Latham 2016; Adams, 2008; Dröes *et al*., 2017; NICE 2018).

1.2.1 Dementia and Social Citizenship

Social citizenship, within the context of dementia, is the active participation by people living with dementia in their lives and society (Bartlett and O'Connor, 2007; Bartlett and O'Connor, 2010; Bartlett, 2016). It is a status, underpinned by rights, to have opportunities for growth, to be recognized beyond being a person with dementia, to preserve purpose and to be able to participate in life, to have a sense of camaraderie with others, and to be free of discrimination (Bartlett and O'Connor, 2007 & 2010).

Social citizenship played an important part in my study because it allowed me to attend to matters relating to the primary participants and their identity, but within the societal context. I judged this important because my research was located in public spaces, often at the heart of communities. I also anticipated that social citizenship could contribute to my analysis as a framework through which I could consider the public perception of people living with dementia as citizens. For example, matters such as agency, stigma, freedom, and authenticity, arose as my research progressed. Each held relevance in relation to social citizenship, but in themselves were extensive and detailed topics. Therefore social citizenship, acting as an overarching concept, helped me to consider and understand each, and weave their significance into my core arguments.

At the point I embarked upon the research my understanding of social citizenship had been informed by my academic study, and personal experiences. I relate examples of formative experiences in the section below, explaining how my identity influenced my research. However, I expected my understanding of social citizenship to grow and develop as my study progressed. This felt positive, because it is essential to reflect upon social citizenship, and reconceptualise it, so that it sustains meaning and applicability (Bartlett and Brannelly, 2019a). Indeed, it is also important not simply to accept understandings of citizenship as exclusively virtuous and positive. I will return to this as my study continues, for example in Chapter 3 where I relate how a critical focus was part of my axiological approach.

Inherent in my discussion thus far about people living with dementia, their personhood and citizenship, is identity. It is to an explanation of this and to its contextualisation within my study that I now turn.

1.3 Identity

1.3.1 The nature of Identity

Identity, the sense an individual has of who they are, is a contested concept, and it has both personal and social components (Yuval-Davis, 2010). Thus, there will be private elements of our identity, but also public facing aspects. Some propose the primacy of genetic heritage, but it is argued by Markovitch *et al.,* (2017) that social experience will always be significant. My study focuses upon understanding of identity in a social sense because I believe that people employ the context of the external world to provide themselves with meaning about who they are, in the manner outlined by Spracklen (2013). This aligns with the argument, advanced by Snyder and Spreitzer (1979), understanding identity as something fluid, that will change for individuals over time, influenced by their experiences and interpretation of them.

When conceptualising social understandings of identity there are nuances significant to my study to consider. For example, the psychosocial growth model where identity is developed by experiences that foster opportunities to express one's individuality, and receive feedback and validation from others (Erikson, 1995). Social identity theory explores this further, suggesting self-contextualization occurs within intergroup contexts (Wearing, 2011). Here individuals define themselves, and behave as group members as well as individuals, understanding themselves as ‘we’ and ‘us’, as well as ‘me and ‘I’ (Stevens, *et al.,* 2017). The social identity approach also suggests that when people perceive themselves as group members, this affords meaning to their behaviour. Thus, the behaviour of the group is linked to evolving structure in the sense of one’s self. The person becomes interested in the norms, values, and ideals of what it means to be a member of the group, and so align themselves with it (Stevens, *et al.,* 2017).

Two other factors are important to introduce to my early discussion of identity, because they are inherent throughout the context of my research. These are how relationships people have with others, and how places, including physical spaces, influence the shaping of identity.

In relation to the first, an individual’s experience of relationships forms a key part of identity formation from earliest years and then throughout life (Pittman *et al.,* 2011). Indeed, human beings have an innate need of interpersonal relations and social support (Bowlby, 1988). This context is of increasing interest to scholars and researchers of dementia, because of the significance relationships hold for people (White, Cotter and Leventhal, 2019), and because relationships matter especially as the changes wrought by symptoms increasingly have impact upon the person (Walsh, *et al.,* 2019). Relationships that participants held with others in the context of my study would thus be likely to influence experiences of engagement in activity.

Place was of relevance to identity also. My research was located in the United Kingdom, specifically in the West Midlands and South-West of England. Identity is comprehended differently in alternative parts of the world, for example dependent upon cultural understandings prevalent within locales (Holliday, 2010). Thus the geographic setting of the research meant interpretations held about identity by research participants would likely to be influenced by prevailing understandings held within this ‘western’ part of the world. Recognition of this is important also because my research involves exploration of the identity of people living with dementia, and identity traits valued within western cultures, for example autonomy, are ones upon which the symptoms of dementia are liable to have adverse impact (Birt *et al.,* 2017).

How we experience places, how we feel within them, and what our opinions are about what we do there, have been shown to relate to the formation and shaping of identity (Lengen and Kisteman, 2012). Further, Maersk, Cutchin, and la Cour (2018) use social identity theory to argue that people develop identities through the relationships they have with places. Thus, individuals contextualise their identity through the differences and similarities they feel with others in those spaces, through feelings about the consistency of a place over time, and how places make individuals feel about the abilities and value they have within society (Maersk, Cutchin, and la Cour, 2018). Since place and spaces were inherently a part of my study, through location within Centres, these arguments about identity were formative to my thinking. This had additional significance because there are thought to be linkages between identity and physical activity spaces (Wise, 2015). How this relates to the context of living with dementia is explained later in this chapter. However, it is to consideration of matters related to identity and dementia to which I now turn.

1.3.2 Identity and Dementia

The new paradigm of dementia has fostered interest in investigating what identity means in the context of living with the syndrome. This is particularly because of its focus upon seeing people with dementia as people, rather than simply medical cases with a collection of symptoms to be addressed (Kitwood, 1997). Identity is relevant to the research because whilst a person's sense of identity plays a significant role in their understanding of who they are; dementia can erode this with consequent negative impact upon well-being (Kitwood, 1997; Brooker and Latham 2016). Identity is subject to particular threat at specific points within the course of the illness, in particular at diagnosis, as individuals attempt to adjust to their changed circumstances and future (Bunn *et al.,* 2012). Adjustment to change has significance for potential identity maintenance and development because the period following diagnosis can be especially traumatic for and threatening to the well-being and identity of the person (Lishman, Cheston and Smithson, 2016; Vince, Clarke, and Wolverson, 2017). Successful readjustment can enhance the well-being of individuals and those who care about them (Bunn *et al*., 2012; Cheston 2013; Brooker *et al.*, 2017).

Evidence suggests that, in contrast to earlier assumptions, identity endures for people living with dementia, certainly throughout mild and moderate phases of the illnesses, and possibly beyond (Caddell and Clare, 2010). Precisely what identity means, and its nature, remain open to debate, however. For example, influential scholarship by Sabat and Harre (1992) argued that particular elements of self-exist to make up identity. These relate to an individual's personal identity (i.e. 'I' or 'me'), their beliefs and attributes (determined through their conversation), and how they manifest different social personae whilst interacting with others (i.e. presenting on the basis of one's employment role, and / or as a member of a domestic or familial household, for example). However, others have suggested it is more appropriate to see identity as a holistic entity, rather than something that requires separating into such component parts (Li and Orleans, 2002).

Whatever conceptualisation might be agreed upon, however, it is essential to ensure that the heterogeneity of people living with dementia is recognised (Thomas and Milligan, 2018). This must be inclusive of difference related to gender, social class, ethnicity, sexual orientation and other matters that will influence the identity of people with dementia, as part of membership of the societies within which they live (Bartlett *et al.,* 2018; La Fontaine et al., 2007; Villar *et al*., 2019). There is also diversity inherent within dementia itself, predicated upon the impact the symptoms of the different illnesses have, and the progression of these (Caddell and Clare, 2010). This is important because the context of living with dementia means that the sense individuals have of who they are will alter over time (Caddell and Clare, 2011).

Memory contributes to the sense of identity held by people living with dementia (Bryden, 2012). It is significant because of its relationship with identity, with one shaping and reshaping the other (Cabillas, 2014; Bryden, 2012; Conway et al., 2004). However, several causes of dementia hinder the ability to form accessible memory in the present, and so have a negative impact upon identity (Alzheimer's Society, 2014; Yokoi and Okamura, 2012). For example, identity has been conceptualised as narrative identity where a person living with dementia is able to share the story of themselves (Surr, 2006). Difficulty with memory is likely to disturb the presentation of such a coherent self-narrative. For example, people experiencing trouble recalling events from recent times might explain their identity in relation to circumstances before becoming unwell (Caddell and Clare, 2010).

However, the presumption that all people living with dementia have difficulties with memory is incorrect. Diverse types of dementia illnesses have different patterns of cognitive changes over time and not all impact on memory, for example some present difficulties with practical problem solving and sequencing (NICE, 2018). Diversity of symptoms can have an important interplay with identity too. For example, narrative identity is also difficult for people for whom speech is compromised (Caddell and Clare, 2010). This is because it is likely to make interactions with others difficult, and will therefore impact upon individuals' ability to realise identity within social contexts (Sabat, 2018).

Understanding identity in the manner I have described, in a social sense, of belonging, and understanding where we fit into social structures around us, has been regularly applied within the sporting and leisure context (Spracklen, 2013).

I progress my discussion with that in mind, therefore, in the section that follows, defining leisure, sport and physical activity and exploring how they relate to my research.

1.4 Leisure, Sport and Physical Activity

These are broad terms, used to describe a wide range of activities and pastimes. My study is located within this, because it investigates a range of congruent activity people living with dementia participate in, and because the location of the research, Centres, include elements of such activity within their provision. However, particular features of leisure were relevant to my research – because of the types of activity primary participants engaged with, and the circumstances in which this occurred. Thus it is necessary to identify, define and explain these.

1.4.1 Definitions and Concepts

1.4.1.1 Leisure

Leisure encompasses a range of activities, the things we do, and things that are of interest to us, when we have the opportunity and choice to partake in them (Torkildsen, 1999; Spracklen, 2013). Leisure is difficult to define because it ranges across diverse and often interlocking practices, characterised by different values (Rowe, 2016). It can include both sport and physical activity. Precise definitions of leisure therefore, or indeed sport or physical activity, are problematical because of their scale, and the fact each interrelates with the other.

Broader debates about the value of leisure to individuals and society have endured throughout modern times (Hill, 2002). These extend to moral dimensions, where leisure that is good is understood often to include self-improvement, and healthy living (Rojek, 2005). The opposite is bad, or even dark leisure, which involve activities considered strange or deviant within the context of societal opinion (Spracklen, 2017). Understanding this context is important because my research involves people with dementia engaging in leisure activity, as citizens, in public spaces. These matters will influence what research participants have thought, and continue to think about, engagement in leisure activity. It is likely this will continue to influence their identity. It will, of course, also influence other participants in the research, and those people engaging alongside participants in activity. I will return to this, therefore, as my discussion continues.

Leisure has been widely studied and conceptualised by scholars (Rowe, 2016), and this is helpful because it enables a clearer understanding of concepts inherent to it. One interpretation is ‘serious leisure’, which is the regular progression of amateur activities that are substantial, of interest and fulfilling, and where skills, knowledge, and experience are acquired and enacted (Stebbins, 1992, p.3). This appealed to me as I considered the context of the research, because I anticipated primary participants would be engaging in activity as amateurs, and I was curious whether those fundamental aspects of their involvement would be manifested by what I found. It seemed too that they accorded with core components of social citizenship, for example opportunities for personal growth, recognition beyond being a person living with dementia, and sustaining purpose and participation in life (Bartlett and O’Connor, 2007 & 2010). I will return to serious leisure, therefore, as I continue to contextualise my study, and later as I analyse what the research found.

1.4.1.2 Sport and Physical Activity

Turning to sport and physical activity, they encapsulate all forms of human movement, active living, and activity, which aim to express or improve physical fitness and mental well-being, form social relationships, or obtain results in competition (Council of Europe, 2001; International Society for Physical Activity and Health, 2016). This is where arguments surrounding attitudes society has regarding leisure have relevance therefore, because people will engage in sport and physical activity for many reasons, including those linked to their emotions. In turn these are connected to the complexity of daily life, where value judgements are constantly made by individuals and those around them.

The link between identity negotiation and sport/ physical activity is of long-standing interest to scholars, policy makers and practitioners, seeking a better understanding of the potential relationship between the two and consequent outcomes (Bennett *et al*., 2017; Evans *et al.*, 2016). For example, interest in how identity negotiation plays a role in enabling people to maintain involvement in physical activity during the life course (Allender, Cowburn, and Foster, 2006). It is believed that identity intersects with physical activity as new identities form or existing identity strengthen, through participation within such activity or related settings (Perras, Strachan, and Fortier, 2015; Fairley and Gammon, 2005).

The context of physical activity interplays with identity. For example, a symbolic interactionist approach, whereby people build comprehension of their identity through engaging alongside others and attaching meaning to those interactions (Stryker and Vryan, 2006), helps understanding of this. Thus, in their 2007 study Allen-Collinson and Hockey report on their experience as serious amateur runners, having their progress and perception as such interrupted by injury. The study offers insights into changed identity, caused by injury, with neither able to run, and thus understand themselves as ‘runners’. New biographical circumstances challenged the understanding of the continuation of their ‘athletic identity’. There was a lack of harmony between their self-concept, including how they perceived their former selves, and their existing ‘imputed social identities’ as attributed to them by others (Allen-Collinson and Hockey 2007). This illustrates how the symbols we attach to our identity are important, and how discontinuity in personal life story can influence such contexts.

Another way in which the context of physical activity interplays with identity is set out by Mayoh and Jones (2015). Their study conjectures that individuals construct meaning about their identity through engagement with sport and physical activity, and that this is experienced as personal well-being. Mayoh and Jones argue well-being for individuals is characterised by a sense of agency and situated freedom. This is an understanding of freedom rooted in phenomenological philosophy (Heidegger, 1962), which also forms part of my discussion in Chapter 3 in the context of my research methodology. Situated freedom is where individuals continue to engage with the world and the structures that constitute social contexts, for example such as obligations towards others, whilst at the same time retaining the opportunity and ability to exercise freewill and choice (Mayoh and Jones, 2015). I have already alluded to the individual well-being of people living with dementia being important, and well-being also forms part of my definition of sport and physical activity (above). Thus, it is relevant to my study, and later I will show how well-being informed elements of my research and contributed to how I understood my findings.

I will primarily use the term leisure to describe the participation of those involved in my research because it is valuable as an overarching term. I will make distinction where necessary, however. For example, using physical activity, or sport, where one or other of those better describes the activity participants are engaged in.

1.4.2 Linking leisure concepts to the context of the research

The involvement in leisure by people living with dementia has become the subject of public and scholarly interest only relatively recently. I utilise my literature review to explore this in detail. For example, including a focus upon matters relating to engagement by people living with dementia in activities of Centres. However, elements inherent to leisure, described above, were useful as I considered the context of my research, components of the definition of leisure I set out being especially so. For example, individuals being able to make choices about engagement in activity, and its nature. Additionally, leisure activities offering more than the fulfilment of tasks, potentially offering individuals interest and meaning (Torkildsen, 1999; Spracklen, 2013).

These components were enlightening as they suggest that to make personal meaning from leisure is a fundamental part of humanity, and helps shape who we are (Spracklen, 2013). This felt significant with regard to people living with dementia, because of the tendency to erode individuals' social standing and influence, as detailed earlier. People are likely to struggle, therefore, to realise the sort of freedom implied here. Further, within the context of the westernised world individuality has increasingly been recognised and felt to matter (Spracklen, 2013), for example, via growing individualism and declining community, which begets corresponding lifestyles and leisure activities (Lee, 2005; Harris, Nichols, and Taylor, 2017). This increases the challenge of being free, and within this context freedom is portrayed as a combination of being an individual without constraint, but within the 'safety net' of community, with its accompanying duties and commitments (Cohen-Gewerc and Stebbins, 2013, pp. 6-7). This has resonance with my earlier discussion about situated freedom (above).

It is suggested that within such freedom lie elements of identity. For example, individuality, as it relates to people living with dementia, and their sense of personhood (Kitwood, 1997). If individual identity is linked to understanding ourselves as human, in the manner Spracklen (2013) suggested, then it is likely to incorporate feelings of personal authenticity. The work of Cohen-Gewerc and Stebbins (2013) is helpful in making linkages here to the leisure context. As proponents of serious leisure these scholars argue that through leisure individuals set preferences which meet their values, tastes, and ability to participate in activities. Authenticity arises from this and self-assessment of achievements, and via comparison with others engaged in the same activities. Thus, through engagement in serious leisure people can find personal and social identities.

Fundamental to this, according to Cohen-Gewerc and Stebbins, is the ability to put into effect what one intends to do, to produce the intended outcome. This is how they define agency, and illustrate how agency is linked to both freedom and authenticity. However there exist in the leisure context contemporary challenges to individuals wishing to put agency into effect. For example, the prohibitions imposed by financial austerity (Findlay-King *et al.,* 2018), contributing to the consequent commodification of leisure (Spracklen, 2013). In addition, the disempowerment of people living with dementia might be liable to further erode agency for individuals in the context of their engagement with leisure. In consequence the feelings individuals have about their identity, and its authenticity may be adversely impacted.

One response might be via the concept of performativity, presented as performing a role through participation within physical activity (Spracklen, 2013). This links to earlier where I discussed symbolism, because it considers how people take on and perform roles, often subconsciously, within social settings. However this is bound by societal expectation (Spracklen, 2013). Thus, for people living with dementia there may be inherent challenges here too. For example, in relation to preconceived stereotypes held by others about the capabilities and aspirations of individuals. This could have consequences for how people living with dementia perceive themselves within public spaces. Potentially the peer group with whom individuals living with dementia engage within leisure will be of significance. This is because of arguments suggesting that engagement alongside peers can help address stigma, albeit made within a context of people with mental health difficulties (Corrigan, Sokol, and Rusch, 2013; Ditchman *et al.,* 2013; Jones *et al.,* 2013).

In addition, how family carers and Centre Workers might be able to support matters relevant to the identity of people with dementia engaging in leisure activity, such as freedom, authenticity and agency, will be of interest. Personal agency can operate in collaboration with other people, and thus enable intended outcomes through their help (Cohen-Gewerc and Stebbins, 2013). This might pertain to practical constraints to engagement, for example, relating to transport.

1.5 Place

As stated above the notion of place is fundamental to my research. It is another comprehensive topic, with diverse meaning. To help shape my understanding of it and to guide my enquiry, therefore, I used the three conceptualisations of place articulated in Lengen and Kisteman (2012). These were place as:

- physical location.
- concentrations of social relations and social practices.
- zones of experience and meaning.

In the sections below I explain each as they relate to the context of my research.

1.5.1 Place as physical location

The physical places where dementia, leisure and identity would coalesce were the locations for the research, the places where my investigations would take place. My definition of Centres was based upon my own knowledge and experiences, and the work of Taylor, Panagouleas, and Ping Kung (2011). Centres are defined as:

Places, situated within local neighbourhoods, which are open to the public, and provide a range of opportunity for physical activity. Typically this will include the chance to take part in sport (for example badminton, table-tennis, five-a-side-football), and in physical activity within a gymnasium. Provision will also be likely to include fitness classes. A Centre might also incorporate a swimming pool. In addition such places will typically offer cafe/ restaurant facilities. Centres are not privately run, tending to be provided by charitable trusts.

In Chapter 4, where I detail how I shaped my project and what guided it, I set out fully the reasons for selecting Centres as the locations for my research. However, my choice was determined in part because Centres are often located geographically within neighbourhoods (Ping Kung and Taylor, 2010), neighbourhoods being spaces, close to where individuals live (Odzakovic *et al.,* 2019). The venues were also informed through consultation with people living with dementia and family carers (see Chapter 4). Consultees were supportive of locating the research within the Centres in large part due to matters related to physical place, for example aspects of their environments.

I believe Centres are public spaces which are similar to parks and libraries, in that they offer the potential for people to come together in social situations, to build identity linked to community and/ or shared interest, in the manner outlined by Young, (1990). It is possible, therefore, that through collaborative practice within the Centre location meanings will emerge that inform the identity of research participants (Jenkins, 1996).

In addition, physical spaces are ‘geographic spaces’, places where leisure activities are pursued (Cohen-Gewerc and Stebbins, 2013). Activities of leisure going on within these spaces are fundamental, in combination, to shaping the meaning of leisure for an individual (Cohen-Gewerc and Stebbins, 2013). Such spaces can be environments where one’s real identity and freedom be manifested, because they offer original opportunity for individuals to be who we genuinely want to (Cohen-Gewerc and Stebbins, 2013). This is of particular pertinence because a diagnosis of dementia often leads to the shrinking of an individual’s world, as fewer places are visited by them, or feel accessible (Ward *et al*, 2018).

1.5.2 Place through social relations and social practices

Social interaction is an important component of identity formation. Thus, places where people living with dementia engage in leisure will be significant as they enable individuals to make sense of their own identity through social relations and social practices (Odzakovic, *et al.,* 2019). ‘Dementia friendliness’ is of relevance to places where social relations and practices pertain. That term is utilised by initiatives that aim to make geographic areas or communities amenable to people living with dementia, such as that coordinated by the Alzheimer's Society in England (Alzheimer's Society, 2019b). However, the concept, and its application, has been criticised for ignoring diversity and intersectionality, which can render them patronising and disempowering (Thomas and Milligan, 2018). According to Glicksman, Ring and Kleban (2016), to make environments genuinely 'friendly' they must enable effective social connectivity. What 'friendliness' should involve, therefore, must be to find ways that environments can support people to participate in the life of their communities (Menec *et al.,* 2011). People with dementia who live alone are especially being failed in this regard (Odzakovic *et al.,* 2019).

Understanding the relevance of leisure spaces, and how the individual may develop their identity alongside others there is important. After all, a sense of belonging is inter-related with a sense of self (Spracklen, 2013). Notions of community are related to this. For example, membership of a community, characterised by identification with sporting activity, can become a part of an individuals' self and collective identity (Jones, 2017). The choice of whom one participates alongside is also agentic (Spracklen, 2013). The ideal, perhaps, is a combination of a strong sense of one's individuality and its recognition, alongside feeling within a community that affords purpose and meaning (Cohen-Gewerc and Stebbins, 2013).

1.5.3 Place as zones of experience and meaning

One explanation of leisure is as a ‘function’ (Spracklen, 2013). For example, leisure is used within societies as a tool to implement policy relating to physical health (Green, 2006). It follows, therefore, that the meanings functions of Centres will also inform their conceptualisation as places. This has implications for what this might mean for people living with dementia and their sense of identity. For example, if remaining an active social citizen is valued, a means to achieve this would be staying involved in leisure activities providing services within a public setting, at the heart of one’s neighbourhood.

Alongside this, the growing preference for expressing individualism through leisure, as described by Lee (2005), and Harris, Nichols, and Taylor (2017), above, makes this understanding timely and relevant. Potentially people living with dementia may employ the functional aspects of their Centre to express that they remain present as an individual. This has resonance with the moral meaning attached to leisure (Rojek, 2005). For example, people living with dementia connecting with norms of their local societies as they engage in leisure at their Centres.

Meaning made in these places might also be considered as personally rehabilitative, through the social connections it enables. Rehabilitation is a concept now applied to the context of people living with dementia, pioneered in particular by people living with dementia themselves (Swaffer, 2016). Within the context of living with physical disability, it meant the reframing of identity from a negative sense of self, through physical activity, to one characterised by personal empowerment (Huang and Brittain, 2006). Such rehabilitation helped to address ‘ableist stigma**’,** with resistance to stereotypes promoting feelings of freedom (Guthrie and Castelnuovo, 2001). Indeed, leisure as, “a privileged space of self-re-education, might in turn lead to feelings of freedom, and authenticity” (Cohen-Gewerc and Stebbins, 2013, p.9).

Thus, by using leisure to resist stereotypical assumptions, and shape their identity, people living with dementia might allay stigma. Spracklen has aligned such notions to the necessity of leisure enabling people to demonstrate freedom of expression, involvement and discourse (Spracklen, 2013). If leisure includes activities that enable people with dementia to feel they have shared identities with others, simultaneously these identities and the means of realising them might support the resistance of dementia, by providing opportunities to counter stigmatising attitudes. Caddell and Clare (2010) suggest that by understanding identity, better informed support and interventions can be developed which focus upon what people living with dementia need and want. This resonates with social citizenship, as measures to enhance the status of people living with dementia and opportunities for participation in societal life, afford antidotes to oppression (Bartlett, 2016; Birt *et al.,* 2017).

1.6 My Identity

Who I am is relevant to my study because it has identity as its cornerstone. In Chapter 3 I discuss how my identity informed my worldview or research paradigm. However, my life experiences (professional and personal), my socialisation, education and training have influenced how I have gone about my study in its entirety (Sparkes and Smith, 2014, p.9; Gill, 2011, p.309). My identity has been influenced, in particular, by social work with its inherent values and practices, the profession within which I have spent the majority of my employment. My involvement with physical activity has also contributed to who I am and how I perceive myself. Earlier in my life I was a player, teammate and competitor in sports, and latterly I have been the coach for a football team of young players for over ten years. This affinity with physical activity was thus fundamental to my PhD. Without it, it is unlikely I would have gone down this track at all.

Reflecting upon my experience of social work I drew upon a professional ethos based upon human rights and social justice (British Association of Social Workers, 2014). My experience extended from working with adults in primary care settings in the late 1990's, into an adult safeguarding context in the earliest years of the new millennium, before spending time working with people with dementia, learning and physical disabilities, and older people in the community until 2013. Issues that were formative included disability rights, community care, equality and diversity, inclusion, safeguarding, human rights, and mental capacity (NHS & Community Care Act, 1990; Department of Health, 2000; Department of Health, 2001; Department for Constitutional Affairs, 2007). The inherent humanitarian and democratic ideals of social work resonated with my own approach to life. As my career developed, I became interested in how my professional practice could move beyond approaches led by services and their requirements, striving instead to work together with people so that they could realise the outcomes they wished (Think Local Act Personal, 2018). I carried each of these conceptualisations and motivations into my experience working alongside people with dementia and their family carers. Allied to this was the necessity to understand the experience of living with dementia through consideration of every individual’s physical and cognitive health, psychological and social needs, in order to recognise the person living with dementia in a holistic sense (Brooker and Latham, 2016). I also incorporated the notion of citizenship into the context of understanding the experience of living with dementia, because it added to this inclusive milieu. This was through its association with rights that afford people living with dementia entitlement to inclusion, access, equity, participation and empowerment, and because groups of people who are marginalised have learning to share, based upon their own struggles and experiences, which can contribute to society (Voluntary Organisations Disability Group, 2016). Thus, my understanding of citizenship also included the relevance of entitlement and contribution.

A personal experience which influenced my thinking in this respect was the period between 2013 and 2016, when I was a facilitator with the LINK Group at the University of Worcester. Its membership comprised people living with dementia and family carers, and the group’s role was to inform and contribute to dementia related teaching and research at the University. I witnessed and recognised both the contribution members of the LINK Group made to the offering of the University, and the challenges inherent in enabling this contribution within a physical and cultural environment not specifically tailored to meet the needs of people living with dementia.

My value base informs every aspect of my life, however, including my interest in sport. This is demonstrated in my role as the coach for a local under eighteen boys’ football team, where my coaching philosophy draws upon aspects of my worldview (Carless and Douglas 2011). This philosophy encourages me to work with the players to support and enable them to improve as a footballer, and to enjoy their time on the sports field. This places personal emphasis upon knowing the players well, and taking pride and care in their development as sports players.

1.7 Conclusion

In this chapter I have considered each of the underpinning concepts for the research. The discussion has demonstrated that identity is a feature for individuals that can be understood in a social context, is fluid, and can change over time. This is interesting in light of the fact that the lived experience of dementia can be influenced by social features, and is a progressive syndrome, which will inevitably mean change for individuals with dementia. Significant also is that notions of individual personhood and social citizenship are viewed as essential to maximising the ability of people with dementia to live well. Thus, the personal and communal are coalescing in terms of their importance to the study. Leisure is an important part of citizenship, not least because of how it links with freedom, authenticity and agency, and in turn what these mean.

Finally, place has been shown to have multiple meanings and potential relevance to my study. As this discussion progressed I suggested that Centres could be the physical place for the location for my study. It is time now to hone my enquiry further, through a critical review of relevant published literature that can help understand what role such Centres play in identity formation for people with dementia, and whether there are gaps in knowledge that my study should seek to address.

Chapter 2: Literature Review

2.1 Introduction

The first chapter provided the contextual background to my study through its exploration of essential debates and arguments related to its fundamental components, dementia, identity and sport/physical activity, and place. As well as setting the scene for the study, that chapter enabled me to begin to crystallise my thoughts about what the study should investigate, and how I might go about my research. Subsequent chapters offer more on this, setting out the philosophical basis for the study, how I consulted with people living with dementia and others, and the research methods employed to pursue my study's outcomes. However, an authoritative understanding of relevant literature was also essential to enable me to shape the study and analyse its findings, and this is what this chapter addresses.

Whilst an understanding of the literature was essential, it became clear that a comprehensive review would be problematic, for reasons this extract from my supervisory meeting notes illustrate, "…the pillars of the study, dementia, sport, and identity, are enormous, with potentially inexhaustible literatures to seek and review" (Supervision Meeting, 8th February 2018). This alongside, reflection upon the other components I have discussed, led to the formulation of a review with this question as its focus:

"What is already known from the research literature about people who live with dementia and their participation in leisure centres, and what role does this have in their identity?"

The rationale was to identify the gap that my research could address. This review would also determine the stage of development for the topic. Taken alongside the detail contained within Chapter 1, this process meant I could confirm the aim of the study, its objectives and the research question. These are set out at the conclusion of this chapter.

2.1.1 Format of my literature review

I used Grant and Booth's, 2009, 'Typology of Reviews' to enable me to determine the review format best suited to the needs of my study. Their definition of a critical review of the literature most closely matched my requirements. This was particularly because its, "…emphasis is upon the conceptual contribution of each item of included literature…" (Grant and Booth, 2009, p. 97). This format, however, has been criticised for lacking the systemacity of more structured reviews of the literature (Grant and Booth, 2009, p. 93). Thus, I included a systematic approach to ensure rigour and transparency, and to afford my review integrity (Jones, 2015).

After weighing the merits of different approaches I concluded a critical review was the right style because, as well as affording opportunity to search and critique relevant literature, it would also provide a solid grounding to my study, and allow a focus upon its key ideas and concepts. The critical stance also leant itself to an approach that would discourage me from making presuppositions about what I might find in the primary research (Jones *et al.,* 2013). In this way I could explore what had been published in relation to relevant conceptual ideas. It would not be a critical review in absolute terms, however, because no hypothesis or model would be advanced as an outcome (Grant and Booth, 2009, p. 94). Indeed, this was not what I was seeking, anticipating that the amount of existing literature related to my review question would be insufficient to support such. However, the critical approach aligned with the central thread of the study, and helped to make sense of its component parts.

In the following sections I explore how I went about searching the literature to answer my review question. Articles retained for more scrutiny are discussed, and are critically analysed individually and in relation to each other to allow me to build an argument relevant to my topic. This enabled me not only to identify what is known about the participation of people living with dementia in activities of Centres, and how this has a role in their identity, but also to contribute to matters relating to the shape and focus of my study, for example the methods my enquiry might use.

2.2 Search Strategy and Process

This section outlines the search process I employed to review the literature. Throughout this, unless otherwise stated, I used Medline to access the following databases CINAHL; Academic Search Complete; PsycINFO; MEDLINE; SPORTDiscus. I took this decision based upon conversations with more experienced researchers, including my supervisors, and my own experience of conducting literature searches. Due to its scope and focus I believed the Medline database would enable me to locate literature relevant to my review.

Details of the route to retained articles, search terms, and progress towards retained articles, are summarised in Appendix 1, and explained further as this chapter continues. My search strategy and process are set out in the flowchart, Figure 1, below. Results at each stage (number of articles) are set out there also. In summary, my initial approach was to identify articles through an exploratory search phase, adjusting this search using keywords. Subsequently, I moved into a screening phase, applying a screening tool (detailed in Figure 2, below). This tool enabled me to assess full-text articles in terms of eligibility for retention for critical review.

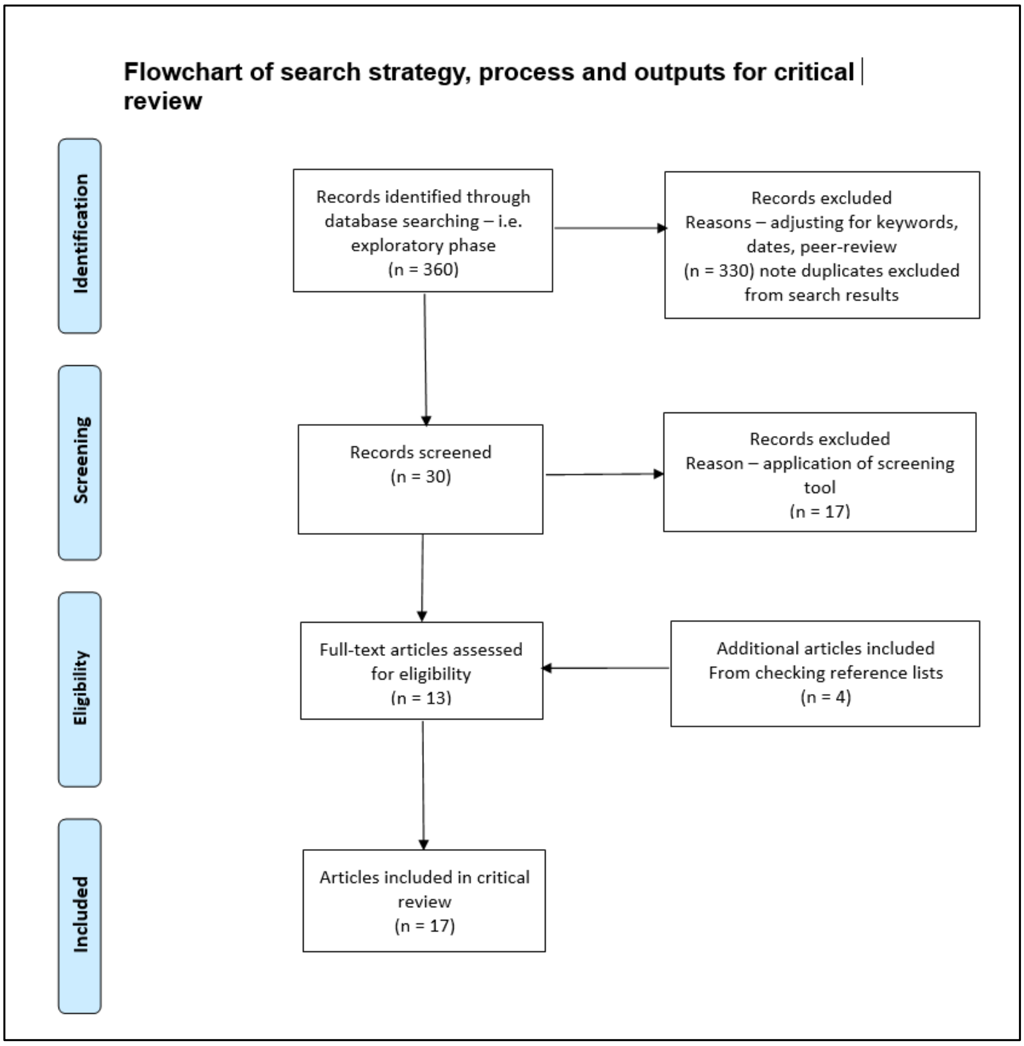

Figure 1: Flowchart of search strategy, process and outputs for critical review (Moher *et al.,* 2009)

2.2.1 Exploratory Phase

I used Boolean logic, and inclusion and exclusion criteria to maximise the opportunity of returning successful searches. Full details of the searches, including search terms, were recorded using a Microsoft Excel spreadsheet. As Jones *et al.* (2013) suggest is often the case, I was already familiar with some of the literature. I could not remove myself and my prior experience and knowledge from the research. Indeed, as I will argue throughout, my knowledge and experience brought benefit to my enquiry. For example, here enabling me to reflect upon published articles new to me in light of those I already had an awareness of. Therefore, I utilised this as part of my search strategy, and to help determine what publications I might retain.

My very first searches were experimental in nature and employed terms that were broad in scope as related to my research. For example, dementia, AND leisure AND identity, in different combinations of titles, abstract and texts. Numbers of results were too unwieldly and insufficiently focussed to be useful. These are reflected in Appendix 1 as topics 1 and 2, and were not incorporated further into the search process.

Next, I undertook searches that were more specific and focused upon the words contained within my review question. By searching for peer reviewed articles in the English language using the terms, ‘dementia’ AND ‘leisure centre*’ / center*, for example (Topic 4) I was able to identify articles that were potentially useful, such as Atherton, *et al*., (2016).

What my early searches had shown was that my challenge was how to reconcile a context that offered either a very high number of results, or next to none. I amended my search strategy afterwards, for example excluding the word ‘risk’ from searches, as there is considerable literature on the prevention of dementia, and that was not a priority for enquiry within my research. The results of these more focussed searches started to provide numbers of articles that were more manageable, and I began to be able to select sources for closer investigation. A decision was taken to review the first thirty articles provided by Medline in every exploratory search where there were more returns than that number. My experience of using Medline was that any useful relevant articles were returned within the top thirty listed. I ran checks on every topic search to ascertain whether there were relevant articles outside these lists. On these occasions I used my prior experience and knowledge.

2.2.2 Screening Phase

Whilst I went into the enquiry process with an open mind about what I might find I needed parameters to contribute to the necessary rigour of the review (Jones *et al.,* 2013). Thus, I developed a filter tool to assist me to complete searches in a systematic manner and select literature (see Figure 2, below). I used the following to assist in its design:

- The Critical Appraisal Skills Programme (2017) Qualitative Research Checklist available at: http://www.casp-uk.net/casp-tools-checklists
- Discussions with academic colleagues in the School of Allied Health and Community, and School of Sport and Exercise Science.

Selection criteria	Weighting and comments (see text below)
1. Relevance to PhD	Yes/ No
2. Clearly focused issue	2
3. Explicit theoretical framework or literature review	2
4. Evidence of critical reflection	2
5. Clear statement of findings and discussion of validity and reliability	2
6. Discussion of strengths and limitations	2
7. Robust methodology and method	2
8. Relevance to research	3
Total score	
Key findings of relevance	Summary
Full investigation?	Yes / No

Figure 2: To show criteria I used to complete searches and select literature

The screening tool enabled me to record the key points of detail for each article. The first question sought a basic 'yes/ no' answer based upon my research question, and my own experience and judgement. Numbers 2-7 were scored out of two, number 8 out of three. I afforded that number this higher weighting because my earliest searches had identified a dearth of literature relating to the review question. In light of this I wanted to ensure I gave due attention articles that seemed to offer direct relevance to my research. As well as using the tool to enable me to identity articles I also included texts that recommended themselves as of particular interest and relevance. I retained four articles in this manner. Table 1, below, lists the retained articles. See also Appendix 2 which summarises the rationale for my selections, which are also discussed more fully in the sections that follow.

Table 1: Showing retained articles, in alphabetical order, by lead author.

Anderson, S. and Whitfield, K. (2013) ‘Social identity and stroke: ‘they don’t make me feel like there’s something wrong with me’’, *Scandinavian Journal of Caring Sciences*, 27(4), pp.820-830. doi: 10.1111/j.1471-6712.2012.01086.x.

Atherton, N., Bridle, C., Brown, D., Collins, H., Dosanjh, S., Griffiths, F., Hennings, S., Khan, K., Lall, R., Lyle, S., McShane, R., Mistry, D., Nichols, V., Petrou, S., Sheehan. B., Slowther, A., Thorogood, M., Withers, E., Zeh, P. and Lamb, S. (2016) ‘Dementia and Physical Activity (DAPA) – an exercise intervention to improve cognition in people with mild to moderate dementia: study protocol for a randomized controlled trial’, *Trials,* 17(165), pp.1-12. doi: 10.1186/s13063-016-1288-2.

Brown, J. (2017) ‘Self and identity over time: dementia’, *Journal of Evaluation in Clinical Practice,* 23(5), pp.1006-1012. doi: 10.1111/jep.12643.

Dupuis, S.L., Whyte, C., Carson, J., Genoe, R., Meshino, L. and Sadler, L. (2012) ‘Just dance with me: an authentic partnership approach to understanding leisure in the dementia context’, *World Leisure Journal*, 54(3), pp. 240-254. doi: 10.1080/04419057.2012.702454.

Genoe, M.R. (2010) ‘Leisure as resistance within the context of Dementia’, *Leisure Studies,* 29(3), pp. 303-320. doi: 10.1080/02614361003720570.

Genoe, M.R. and Dupuis, S.L. (2011) ‘“I'm just like I always was”: a phenomenological exploration of leisure, identity and dementia’, *Leisure/Loisir*, 35(4), pp. 423-452. doi: 10.1080/14927713.2011.649111.

Kissow, A. (2015) ‘Participation in physical activity and the everyday life of people with physical disabilities: a review of the literature’, *Scandinavian Journal of Disability Research*, 17(2), pp. 144-166, doi: 0.1080/15017419.2013.787369.

Lindelof, N., Lundin-Olsson, L., Skelton, D., Lundman, B. and Rosendahl, E. (2017) ‘Experiences of older people with dementia participating in a high-intensity functional exercise program in nursing homes: "While it's tough, it's useful"’, *PLoS ONE,* 12 (11), pp. 1-14. doi: 10.1371/journal.pone.0188225.

Lundberg, N., Tanaguchi, S., McCormick, B., and Tibbs, C. (2011) ‘Identity Negotiating: Redefining Stigmatized Identities through Adaptive Sports and Recreation Participation among Individuals with a Disability’, *Journal of Leisure Research,* 43(2), pp.205-225. doi: 10.1080/00222216.2011.11950233.

Oliver, E.J., Hudson, J. and Thomas, L. (2016) ‘Processes of identity development and behaviour change in later life: exploring self-talk during physical activity uptake’, *Ageing and Society*, 36(7), pp.1388-1406. doi: 10.1017/S0144686X15000410.

Phinney, A., Kelson, E., Baumbusch, J., O’Connor, D. and Purves, B. (2016) ‘Walking in the neighbourhood: Performing social citizenship in dementia’, *Dementia*, 15(3), pp. 381-394. doi: 10.1177/1471301216638180.

Snyder, E.E. and Spreitzer, E. (1979) ‘Lifelong Involvement in Sport as a Leisure Pursuit: Aspects of Role Construction’, *QUEST*, 31(1), pp. 57-70. doi: 10.1080/00336297.1979.10519923.

Son, J., Kerstetter, D. and Mowen, A. (2009) ‘Illuminating Identity and Health in the Constraint Negotiation of Leisure-time Physical Activity in Mid to Late Life’, *Journal of Park and Recreation Administration,* 27(3), pp.96-115.

Tregaskis, C. (2003) ‘Towards inclusive practice: an insider perspective on leisure provision for disabled people’, *Managing Leisure*, 8(1), pp. 28-40. doi: 10.1080/1360671032000075225.

Weiss, O. (2001) ‘Identity Reinforcement in sport. Revisiting the symbolic interactionist legacy’, *International Review for the Sociology of Sport*, 36(4), pp. 393-405. doi: 10.1177/101269001036004002.

Williams, T. (1994) ‘Disability Sport Socialization and Identity Construction’, *Adapted Physical Activity Quarterly*, 11(1), pp.14-31. doi: 10.1123/apaq.11.1.14.

Wright, A. (2018) ‘Exploring the relationship between community-based physical activity and wellbeing in people with dementia: a qualitative study’, *Ageing and Society*, 38, pp.522-542. doi: 10.1017/ So144686X16001124.

Having detailed how I structured and progressed my searches, and how I retained articles, the chapter now turns to a discussion of the key debates contained within the seventeen retained articles. This offers a critique of that literature as it relates to my project focus, and an introduction to the core concepts contained there that influenced my thinking.

2.3 Main findings

2.3.1 Participation of people living with dementia in Centres

The research literature is largely silent about the specific participation by people living with dementia engaging with leisure centres. Related scholarship comes primarily from North America and Western Europe. This made me reflect again upon cultural comprehension of identity, and highlighted how my enquiry was predicated on the ‘western’ understandings of the phenomenon, through the narratives in the published literature in the English language. Additionally, as the first chapter highlighted this was also a reminder that notions of spaces dedicated to physical activity, in the manner of leisure centres, are entities which are more familiar in some parts of the world than others. Having said this there remains limited literature on the engagement of people living with dementia with activities of leisure centres.

Indeed, based on these parameters, only one article was judged noteworthy. This was Atherton *et al.* (2016), and I noted this article because it located a significant part of its research within similar situations to my own. However, there was little else of relevance to my study that recommended it to me. For example, it set out to investigate a physical activity intervention aimed at enhancing cognition, rather than exploring matters related to identity. Even so, the article showed that dementia and physical activity were matters for contemporary interest in the United Kingdom. It also indicated that this interest encompassed the sort of community settings I was concerned about. In addition, and importantly, the article demonstrated that people living with dementia were engaging within the type of activity my research had a focus upon, within locations similar to leisure centres.

2.3.2 Participation in leisure and its role in identity for people living with dementia.

At an early stage, therefore, it was clear there was a gap in the literature. In that very little had been published relating to the engagement of people with dementia within leisure centres. I would need to explore more widely to understand about how participation in different, but relevant, contexts might influence identity. One focus was upon the concept of leisure, having discussed the complex and diverse nature of this in Chapter 1.

Genoe (2010) addresses the type of oppression and stigmatisation people living with dementia face, and the malignant social psychology, both described in Chapter 1. The author comments that leisure is used by people living with dementia to resist loss of identity. This notion of utilising personal power in the face of adversity led me to conclude that agency would be a concept requiring scrutiny and analysis within my study. In particular, how different sorts of agency held by people living with dementia might influence their sense of identity as they engaged with the activities I was researching. Genoe's article discussed how the informal nature of leisure may enable decisions with very little threat from others who may override personal choice. However, she also highlighted how engagement in leisure activities fosters occasions where reminders of losses might be of undue prominence. This study was helpful to me because it drew upon a range of scholarly authority to provide me with underpinning knowledge relating to leisure and identity for people living with dementia. Its narrative encouraged a focus upon the future of people living with dementia, as well as recognising people experience feelings of loss.

Understanding of a potential sense of loss was developed by Genoe in the article she co-authored with Dupuis in 2011. The article explored the role of leisure in maintaining identity in early-stage dementia. The authors highlighted the complexity people face about notions of themselves following diagnosis.

They suggest that identity is not only retained but can be nurtured by people living with dementia as they engage in leisure. How to enable this in a positive, person-centred way is a challenge. However, Genoe and Dupuis point out that people living with dementia strive to cope. The article relates that leisure risks threatening a person’s identity by demonstrating reduced ability to perform roles and loss of independence. Intriguingly though it also suggests that through leisure people can consider hopes for the future. This notion of ‘aspiration’ interested me, particularly because this is a key component of social citizenship, in that it advocates for, “…opportunities to grow and participate in life to the fullest extent possible” (Bartlett and O’Connor, 2010, p. 37).

Genoe and Dupuis considered their topic alongside exploring leisure, identity, and chronic illness. This reinforced my awareness that potential research participants living with dementia would have an identity influenced by additional factors, such as features relating to age. This article highlighted how structural aspects of daily life, such as the impact of societal attitudes towards gender, ethnicity and class, would also play a role in how people living with dementia could experience engagement within Centres.

Exploration of the nature of identity for people living with dementia by Brown (2017) highlighted how this is fluid, and how this has congruence with the lived experience of dementia, because of the progressive nature of illnesses included within definitions of the syndrome. Brown highlights loss and continuity as being important as part of this, identifying features such as reduced memory and practical abilities as part of loss. However, she extends the discussion to talk about how dementia is associated with loss in popular consciousness, in particular loss of equity and reciprocal meaning within close relationships. She goes on to explore how the fear of future loss is powerful, arguing this renders a feeling of helplessness in many people living with dementia (Brown, 2017). Later, I will explore the work of Lundberg *et al.,* (2011) and their understanding of ‘negative disability identity’, and ‘identity crisis’, to show how this has resonance with Brown’s arguments. The phrase ‘the plasticity of identity’ is used by Brown to suggest the dynamic nature of identity means growth and progression might be possible for people living with dementia.

Brown also draws attention to the significance the ‘experiential self’ gaining pre-eminence over the socially constructed self (Brown, 2017, p.1007). She explains that, because of increasing difficulties with memory, individuals living with dementia are gradually obliged to pilot themselves through daily life based upon interpretation of their experiences (often immediate ones), rather than by reference to accumulated shared experiences and history. This had consequences for how I devised and structured my methodology, the details of which are discussed in the following two chapters. A similar theme is addressed in Wright (2018), his article primarily investigating well-being. However, it suggests that physical activity can provide a context within which people with dementia are able to use embodied skills to support their identity. Additionally, Brown’s (2017) work highlighted the significance of attachment when exploring identity and people with dementia, arguing that relatedness is important in this regard, particularly, how interaction between individuals fosters identity (Brown, 2017, p.1010).

Dupuis *et al.,* (2012) was helpful by providing a congruent understanding relevant to my study. This explored leisure in broader terms than my study, for example without a specific setting, such as Centres, in mind. I noted outcomes which might help me inform my analysis, however. For example, the article offered a discourse where leisure is treasured as an expression of humanity, a space for being one-self, a chance to be with and alongside others, to look for freedom, find balance, but also grow and develop, and enjoy oneself (Dupuis *et al.,* 2012). This supported the arguments I had noted in the work of Brown in particular, in relation to the ‘plasticity of identity’. There might be something dynamic about the notion of continuity therefore. The focus Dupuis *et al.,* gave to understanding leisure as a past-time, and something that might be motivated by a sense of enjoyment for participants was also valuable. This was because, as the article suggests, leisure tends to be seen as being a mode of therapy, or a medical intervention post diagnosis for people living with dementia. My study’s emphasis on the citizenship perspective meant I was keen to understand leisure beyond the therapy context.

Phinney, *et al.* (2016) addressed the issue of how physical fitness is used by people living with dementia. That was helpful because so much of the activity inherent to my study would be of a physical nature. The article counsels for an awareness of the ‘privilege’ participants held being physically well enough to engage in exercise, and thus in that research. Social citizenship was also utilised, the authors arguing that this is constructed and made apparent through the practice of a walking-club, the location of the research, as people with dementia walk in their neighbourhood. Three themes were identified, ‘to keep the focus off dementia’ throughout activity, ‘creating a place of belonging’, and ‘claiming a place in the community’. My discussion returns to these matters as it considers the nature of opportunities to engage in physical activity, and the significance of place.

My review progressed my understanding of perceptions of self, and how individuals meld this with their daily existence, by investigating ‘continuity’ as appraised by Lindelof *et al.,* (2017). Again there was relevance with what Genoe and Dupuis (2011) and Brown (2017) conjectured about the continuity of people living with dementia having aspirational, or forward looking elements. Lindelof *et al.,* argue that older people endeavour to sustain continuity in their sense of self and personal image, despite physical challenges caused by ageing, through continuity of their pattern of physical activity. For example, by staying physically active (Lindelof *et al.,* 2017). This is the ‘continuity theory of aging’, where continuity is linked to physical activity. These authors held that embodied memory is an important way that people living with dementia stay in touch with their former selves.

Whilst I was becoming aware of the significance of embodiment, I felt this phrase might be inaccurate, because these are not ‘former’ selves. Participants in Lindelof’s research wished to improve their physical performance and achievement, but my speculation was that they might not be seeking elements of former selves through physical activity. Rather I conjectured this might be an opportunity to look ahead, in an aspirational manner, in relation to their sense of self. The article discusses the rediscovery of body competencies as part of understanding continuity. I thought more than this might be possible. For example the discovery and enjoyment by a person living with dementia of new competencies.

Finally, Lindelof *et al.,* (2017) identified factors that potentially impact upon motivation and compliance with exercise provision, i.e. instructor qualities, staff and facility barriers, and family support. These were matters I anticipated being relevant to the setting for my research based upon my conclusions from Chapter 1. For example, understanding what might hinder engagement in activity needed to be prioritised, because feeling disempowered by others, and stigmatized is part of the prevailing context people living with dementia face (Alzheimer's Society, 2017). The scholarship of Brown (2017) and what she wrote about relatedness appeared to have congruence with this, for example, through relationships with others enabling barriers to engagement in activity to be more easily overcome by people living with dementia.

In concluding this section review of the literature indicated that, in the context of great complexity and uncertainty post diagnosis, the leisure setting can offer simplicity and clarity in identity formation (Dupuis *et al.,* 2012). Leisure is where people living with dementia can express agency and develop their sense of identity (Genoe, 2010; Genoe and Dupuis, 2011; Lindelof, *et al.,* 2017; Brown, 2017). Identity formation remains fluid (Brown, 2017), but continuity in the sense of one-self and one’s self-image can be a personal goal (Lindelof *et al.,* 2017). What ‘continuity’ means for a person’s sense of themselves is unclear, but leisure provides opportunities to grow as a person and citizen, and place will be influential in this (Phinney, *et al.,* 2016). Attachment and relationships with others matter in the formation of identity for people living with dementia as they negotiate their sense of identity over time (Phinney *et al.,* 2016; Brown, 2017). The experiential and embodied self becomes more important to people living with dementia as they negotiate their identity (Brown 2017; Wright, 2018).

The question of whether and how far engagement with activity at Centres enables this is thus important. However, from this selection of papers I concluded that despite growing interest, the topic of my enquiry remained an under researched area. In particular there was a dearth of material that investigated vigorous physical activity, of the sort on offer at Centres, and its potential influence upon identity. Thus, I needed to draw upon literature from a wider range contexts.

2.3.3 Participation in leisure by people in related contexts, and its role in their identity.

My discussion turns to the review of literature I completed which encompassed scholarly publication addressing participation in leisure by people with lived experience of other contexts, in particular disability and older age, and how this has a role in identity. I proceeded in this way because of the gap identified in the literature, because I needed to understand more from published material relating to the sort of engagement in activity I was interested in, and because I felt this literature could provide me with enhanced understanding of relevant theory. No one conceptualisation of life experience can be directly equated to another, because of the heterogeneity of individuals and their circumstances.

However, based on my discussion in the opening chapter, I judged that age and disability were useful concepts to embrace. Therefore, this section critically reviews nine articles that explore the experiences and insights of physically disabled and older people, as well as people who had had a stroke, engaging in sport/ physical activity.

Tregaskis (2003) afforded value in particular by providing insight into the experience of using a Centre from the perspective of a disabled person, and its relationship with identity. In the absence of comparable published accounts by people living with dementia this was insightful. For example she related, “I loved…being able to turn off my mind and simply enjoy my physicality, and through my participation I rediscovered the fact that I need to have a space where I can be all of me, and not just a talking head” (Tregaskis, 2003, p.37). The author continued that Centres should be places, “where people can be themselves” (Tregaskis, 2003, p.39). This alludes both to physical spaces being places where identity can be realised, and to my earlier reflections about embodiment, based upon the scholarship of Brown (2017), and Wright (2018). Tregaskis’ work, therefore, supported Centres being the location for the study, and that people be enabled to communicate meaning they held about their identity in ways beyond the verbal.

Tregaskis also concluded that where disabled and non-disabled people came together with common interest in participating in leisure activities, their similarity of intention enabled co-existence with individual difference (Tregaskis, 2003). Her article considers the merits of what the author referred to in the nomenclature of the time ‘segregated’ and ‘mainstream’ activities and groups. No overall conclusion is reached, however, this enabled me to reflect further on aspects of the discussion by Phinney *et al.,* (2016), and whether people living with dementia prefer bespoke activity to mainstream alternatives. This reinforced my belief that this would be a relevant matter to investigate in relation to my research.

Oliver, Hudson and Thomas (2016) explored the impact of an exercise referral programme upon older people. I was interested in its conclusions about identity developing through engagement with physical activity, and that identity remains dynamic throughout later life. This added to my developing understanding about the nature of continuity of identity, gathered via the publications of Dupuis *et al.,* (2012), Lindelof, *et al.,* (2017); and Brown, (2017), which were based upon the perspectives of people living with dementia. Within the context of their work Oliver and colleagues’ indicated a transition was possible, from a physically impaired and negative self towards a more future-orientated, capable and integrated self-identity. This highlighted again how continuity might involve aspiration and evolvement of identity rather than something inert and unchanged, and how the conceptions offered by Oliver, Hudson and Thomas (2016) might help me frame analysis and discussion.

Lundberg *et al.,* (2011) was noteworthy because of its focus upon identity and identity formation, addressing the context of disabled people engaging in physical activity. It added valuable theoretical constructions to help inform my research, for example, introducing me to the concept of ‘opportunity structures’, which play a role in shaping identity (Lundberg *et al.,* 2011). The authors explain these can include leisure activities, or individuals, and work through self-discovery, and / or feedback from others as individuals engage in activity. Lundberg and colleagues' article draws upon the work of Erikson (1995), and the psychosocial growth model, encountered in Chapter 1. This caused me to reflect upon the setting of a Centre, and how opportunity structures might be pertinent to people living with dementia. After all there appeared to be synergy with the work of Phinney *et al.,* (2016) and two themes in their study relating to place, i.e. 'creating a place of belonging', and 'claiming a place in the community'.

Of interest also within Lundberg *et al.* (2011) was the concept of 'negative disability identity', which includes characteristics such as helplessness, abnormality, isolation, and dependence. The authors link this to what is known as 'identity crisis'. Lundberg *et al*., (2011) considered how, due to negative labelling and stereotyping people with disabilities reconsider the subjective sense of who they are. Stigmatisation was the precursor to this. I noted the potential relevance of this to my own enquiry because, as Genoe (2010) reflected, people living with dementia experience such oppression.

The study by Son, Kerstetter, and Mowen (2009) was relevant and useful because of its focus on exploring how self and social identity influenced continued engagement with physical activity. It argues that identity is self-perceptions of one's behaviour within various physical and social environments (Son, Kerstetter, and Mowen 2009, p.97). Drawing upon earlier scholarship by

(Dionigi, 2002) the article identifies the phenomenon of ‘physical activity identity’. Son, Kerstetter, and Mowen (2009) argue that this represents an individual’s identification with physical activity as being meaningful to how one sees oneself. The concept is important to my study because such an identity links to a person’s interpretation of the meaning physical activity has to themselves (Son, Kerstetter, and Mowen, 2009). This encouraged me to consider how through engaging in physical activity research participants might ascribe aspects of their sense of self, for example, by illuminating aspects of their identity by how they did what they did. This concept is interesting in comparison with Lundberg’s, ‘negative disability identity’, as it appears to offer a constructive notion of identity in comparison to a deleterious one.

Son and her colleagues relate physical activity identity is something that can be fostered in later life. Arguing that an older adult who views herself/himself as active will probably be more likely to make substantial efforts to participate despite constraints. Of interest, therefore, because of the potential setting of my research was the argument that physical activity identity had the greatest association with vigorous activity (Son, Kerstetter, and Mowen, 2009, p.98). Meanwhile, leisure constraints are, “anything that limit or prohibit participation in desired leisure activities” (Son, Kerstetter, and Mowen, 2009, p.98). The authors highlight that leisure constraints can be intrapersonal, interpersonal, or structural. Reflecting upon my earlier discussions about the stigma and oppression facing people living with dementia I anticipated this concept as being significant too. This was not least because such adversity could be encountered through prejudices held by others, as individuals with dementia engaged in activity in public settings.

Anderson and Whitfield (2013) explored the experience of people who had experienced a stroke. The authors argued that stroke involved a loss of cognitive function, and feelings of stigmatisation. Additionally, they examined the effects of social interactions on stroke survivors' sense of identity. This enabled further understanding about the value of identity negotiation through interaction with others, highlighted as significant, for example within the 'opportunity structures' advocated by Lundberg *et al.,* (2011). Anderson and Whitfield discuss how people surviving a stroke felt they had lost their social position. Social positioning and respectful social relationships can play a part in developing a positive post stroke identity. This echoes Brown's hypothesis that people's sense of self is fluid, Anderson and Whitfield arguing this is particularly so following a health-related life-changing event. However, they go further by stressing the importance of the sense of social position within one's identity, and how this can be impinged by a traumatic reduction in cognitive ability and the reaction of others towards that. They also suggest that being part of a social group, treated as 'us' rather than as the 'other', provides individuals with a sense of belonging and purpose. This had resonance with the social identity theory of Wearing (2011), and Stevens (2017), which I recognised in Chapter 1. Anderson and Whitfield arguing that in such ways, people with stigmatising illness can reject negative stereotypes, and construct more positive views of themselves and their potential.

Snyder and Spreitzer (1979) contributed understanding of theory underpinning social identity and sport. Their article explored the socialisation process through which a person develops an identity via athletic endeavour. It discusses the cultural meanings associated with sport participation for identity construction, arguing that it is through an ongoing process of social interaction identities are created and transformed (Snyder and Spreitzer, 1979, pp. 57-58). The authors take a symbolic interactionist perspective, maintaining identities are shaped by social interaction and the meaning attributed by individuals to what occurs within the contexts of those. Of note also is the identification of the cultural meanings and expectations associated with being a participant in sports. I valued the authors' explicit notification they were exploring this from the perspective of participation as a leisure pursuit, rather than on a therapeutic basis, which accorded with thinking linked to the dementia context set out by Dupuis *et al.* (2012).

Additionally this article highlights again the fluid nature of identity, as advocated in Brown (2017), and Anderson and Whitfield (2013) for example. Snyder and Spreitzer contribute by suggesting that individual identity as an athlete is not a permanent personality trait; rather it is informed by the sense that sport may be more or less important within one's self-image and resultant roles within one's life. Finally, their article considers the degree to which participation plays a part in the person's life, especially in comparison to other activities. The authors argue the more extensive this is, the more relevant those activities are to the person's sense of themselves. This suggests personal biography is important, because what has formed part of a person's life hitherto will influence their sense of self, looking ahead. This was demonstrated too by the findings in Allen-Collinson and Hockey (2007), set out in my discussion of identity in Chapter 1. The importance of biography to identity formation is recognised within another of my retained articles, Williams (1994), as I will describe below.

Weiss (2001) also draws upon symbolic interactionism to progress the discussion about how role adoption is a constituent of identity reinforcement. Discussing 'socio-psychological assumptions', Weiss argues that role adoption enables participants in sport to confirm their identities (Weiss, 2001, p.398). In synergy with Anderson and Whitfield (2013) he suggests that identity reinforcement can be facilitated through membership of a group. However, here via groups of people involved in sport, including, through the sports role (e.g. as a player), or type of sporting performance (e.g. a person who exerts maximum physical energy when playing) an individual deploys. Weiss highlights how participation in sport is simple and clear in the context of modern society, which in contrast, is a complex structure necessitating ability in role playing. Dupuis *et al.* (2012) argued this in relation to leisure activity when considering the identity of people living with dementia. However, the article also notes that 'performance in sport is a quantifiable dimension' (Weiss, 2001, p.401). Thus, sporting failure is a clear as success. Whilst sport enables the creation of an identity, this might not always be a positive one in the face of reduced ability caused by the progressive symptoms of dementia. The potential negative consequences of this for people living with dementia will be exacerbated by the stigmatising context facing them, as alluded to through this review and previous chapter. In positive contrast, however, Weiss also advanced social recognition as being an aspiration for engagement in sport, especially because, through the reaction of others, one can seek affirmation of sense of self.

The article by Kissow (2015) is a review of the literature, appraising the situation of physically disabled people engaging in physical activity. The focus upon a different type of impairment, offered me an alternative perspective for considering my research context. I noted Kissow argued that, what she refers to as, an athletic identity could be perceived by the individual concerned as empowering, and could thus challenge identity based upon disability. This might then offer opportunity for altered self-understanding, alongside enhanced feeling of personal power (Kissow, 2015, p. 157). This aligned her work with my earlier discussion about agency and aspiration (Genoe, 2010; Lundberg*, et al.,* 2011; Oliver, Hudson and Thomas, 2016; Brown 2017; Lindelof, *et al.,* 2017). For example, linking with the hypothesis highlighted by Genoe (2010), that a changed self-understanding might play a role in addressing stigma. In doing so this argument had similarities with what Lundberg *et al.,* (2011) said about negative disability identity, and its potential amelioration via physical activity within social settings.

Kissow draws upon the earlier work of Williams (1994), which argued engagement with sport enables people with impairments to strengthen their sense of social identity, as social beings. Williams (1994) is over twenty years old, however, the article was helpful in enabling me to understand how socialisation within physical activity settings might contribute to identity formation. This also encouraged me to consider how this might take place for people living with dementia within the particular settings of Centres, because of the focus upon how relationships might be influenced by place.

Williams (1994) was valuable too because it focused upon identity formation by disabled people within sporting contexts, using two theoretical concepts. Firstly, structural-functionalism, where identity was inculcated by individuals through engaging with the social culture prevailing within the group with whom they participated alongside in physical activity. Secondly, via interactionism, where individuals shaped their identity by drawing upon their biography, and through interpreting the meaning of situations encountered alongside others in their group. This resonated with the work of Snyder and Spreitzer (1979).

Williams reflected upon the ‘social role-social system approach’ (Kenyon and McPherson, 1981) to help explain this. Here he identified the influence of significant others, socializing situations, and personal attributes as key features in what he referred to as disability sport socialization. I noted the possible synergy with ‘opportunity structures’, discussed earlier, which can play a role in shaping identity, through self-discovery, and/ or feedback from others (Lundberg *et al.,* 2011).

Different strands highlighted within Williams’ theory resonated with my study’s context. For example, ‘significant others’ could incorporate those whom people with dementia participated alongside, including carers and centre workers. This would be important in light of what Brown (2017), and Phinney *et al.,* (2016) had articulated about relationships and attachment being important to identity formation for people living with dementia. ‘Socializing situations’ could link with the places where the person with dementia engaged in physical activity. This was potentially synergetic with the arguments of Phinney *et al.* (2016) that ‘creating a place of belonging’, and ‘claiming a place in the community’ held relevance to identity formation. Further, there were similarities with conceptualisation of place as articulated by Lengen and Kisteman (2012), and detailed in Chapter 1. For example, that ‘socialising situations’ might contribute to the places of my research as concentrations of social relations and social practices, and/ or, zones of experience and meaning. What Tregaskis had said about places enabling people to be themselves added emphasis (Tregaskis, 2003).

Together the papers discussed in this section enabled me to explore what is known about participation in leisure by individuals in related contexts, and how this has a role in their identity. This added details relevant to my review, for example, that an individual’s identity is fluid, it can change over time (Snyder and Spreitzer, 1979; Weiss, 2001; Oliver, Hudson and Thomas, 2016). Additionally, physical activity enables participants to realize and confirm their identities, because it is culturally understood and visible (Weiss, 2001). The notion of theoretical conceptions could be helpful, for example, whether negative disability identities (Lundberg, *et al.,* 2011), and more positive ‘physical activity identities’, might help increase participation and address stigma (Son, Kerstetter, and Mowen, 2009; Kissow, 2015). However, more needs to be known about the subject matter of my research, and opportunity structures for the redefining of identity might help understanding (Lundberg, *et al.,* 2011).

Finally, the work of Williams (1994) sustains value by shedding light on helpful elements of theory which the author uses to help illustrate disability sport socialization (Williams, 1994).

2.3.4 Methodological insights

In addition to the merit the retained articles offered in terms of content, I also reflected on their value for how I might progress my own research. This was advantageous, for example in helping me understand how I might go about my enquiries (Jones *et al.,* 2013). For example, whilst Genoe's 2010 article was not primary research, it included robust and comprehensive discussion of published research relevant to the article's purpose. Its presentation of a potential research agenda, whilst not identically aligned to my own, contributed to my understanding of how research must look forward to consider how to challenge insights that are apparently understood.

The methodology employed by Genoe and Dupuis (2011) was more closely aligned to the approach I was potentially considering, in that a relatively small number of people living with dementia were engaged in ways enabling them to share rich evocations of their experiences. The study's phenomenological basis was of interest to me. For example, through utilising phenomenology to explore the meaning of existence in the world (Valle, King, and Halling 1989). The scholarship of Genoe and Dupuis also confirmed that the role of leisure in sustaining or creating identity among people living with dementia had received relatively little attention, in particular investigation of vigorous physical activity, and its potential role in identity formulation.

Brown (2017) did not conduct primary research, and this meant the article offered less value with regard to my developing plans relating to research methods. However, it remained valuable as being a well-informed philosophical, peer-reviewed reflection upon personal and professional experiences, supported by the literature.

The research conducted by Phinney *et al.,* (2016) was based upon a two-year ethnographic study. This was a longer timescale than I could devote, rendering an identical approach impossible. However, the study was valuable because it helped inform my decisions relating to research methods. For example, participant observations and go-along interviews were used to good effect to understand matters pertinent to the research, from accounts offered by people living with dementia. Data were analysed interpretively and inductively, offering rich insights. In addition, the article suggested that participants were able to enjoy the engagement in their physical activity (and thus the research), in large part because they were physically fit enough to take part. This caused me to reflect, and note that insight gained through my study could be drawn only from people whose health enabled their participation in physical activity within Centre settings, if that was where I chose to locate the research.

Dupuis *et al.,* (2012) employed action research, with an emphasis upon partnership between researchers and participants throughout the process of enquiry. The aspiration was that such a distinction need be noted only where absolutely essential. However, the authors related that early on in the research the voices of people living with dementia were obscured by those of others –

notably family carers and professionals. This served as a warning to me to take care to avoid or mitigate this risk. The article reported that thematic analysis began immediately the first data were gathered. I noted that because it offered an opportunity to build knowledge and insight that might help to inform later parts of the study. Other ideas relating to methods included, creating visual representations of themes drawn from data analysis, and employing a photo representation of each theme to help facilitate dialogue with participants about it. This highlighted the potential value of visual aids within methodology.

The methods utilised by Lindelof *et al.,* (2017) were also helpful in enabling me to consider my approach. For example, researchers undertook qualitative interviews with twenty-one participants living with dementia. Interviews were held directly after people completed an exercise session, with notes about those sessions recorded then too. These techniques aligned with my own developing thinking, because close proximity to the engagement appeared to enhance opportunity for participants to recount aspects relevant to their activity. Indeed, it was reported that methods worked well in enabling participants living with dementia to offer deep and rich accounts of their experiences (Lindelof *et al.,* 2017, p.9). However, transcription was by a person not involved in the study. I tended to favour transcribing myself. This would be in order to gain as much sense of the research encounter as possible, and to begin the process of analysis through hearing again and reflecting upon the interview. I noted the value the authors accorded from a systematic approach to their analysis, which they perceived as adding to the quality of analysis.

Tregaskis (2003) engaged in a qualitative ethnographic observation of relationships at a leisure centre. To do so she immersed herself in the research recounting that, as a disabled person, she was both the investigator and tool of the research (Tregaskis, 2003, p.28). However, as far as I know I do not have dementia, and so my ability to adhere to a replica of that format would be limited. In fact, Tregaskis reflected that her identity as a disabled researcher might have influenced responses, suggesting participants may have “censored” their comments about disabled people as a result (Tregaskis, 2003, p.31). Additionally, I perceived the fact that only staff were interviewed as a limitation of this study. It did, after all, aim to enhance understanding about leisure provision for disabled people. The fact no disabled people were research participants detracted from this therefore. The study also lacked a rigorous method of analysing its findings. However, these potential detriments were outweighed by the value it afforded to the context of the review. In particular via the insights gathered relating to identity formation within the setting of a leisure centre, a rare account based upon the findings of my review, but one published within a peer reviewed journal.

Wright’s 2018 study employed both participant observation and interviews. Observations were utilised to assist researcher understanding of the embodied communication of participants, as it related to identity. This was a feature I noted, anticipating the potential significance such communication might hold within the context of my study. Additionally, I noted the author’s comment that interviews held after activities carried with them the risk that participants had forgotten aspects of their experience, and were thus less able to contribute insight as fully as they wished. This accorded with the warning articulated by Lindelof *et al.,* (2017). Wright suggested, however, that participants living with dementia could express their views whilst engaging in activity, and this could help counter the risk.

Meanwhile, Oliver, Hudson and Thomas (2016) used methods which included asking participants to complete weekly measures of their physical activity-related cognition and identity, alongside in-depth interviews. I noted the significance and value of hearing the original voice of research participants. This related to the emphasis I placed upon building empathy and rapport with others, believing within the context of potential research that this would enable interaction and dialogue. However, I was not inclined to introduce measures requiring participants to engage with my research every week. This was because participants in Oliver and colleagues' study were engaged in an exercise referral falls prevention programme, whilst participants in my research would not be attending on a formal basis. I judged, therefore, that an approach that emphasised empathetic engagement by the researcher, rather than methods requiring active regular and frequent input by participants would be more appropriate.

Lundberg *et al.,* (2011) incorporated qualitative open-ended interviews with seventeen disabled people engaged in adaptive sports. Additionally interviews were held with practitioners providing these activities. The research sought an explanatory model, utilising grounded theory. In this way it differed from my plans at this formative stage because I was not seeking to identify a theoretical model as an outcome. My literature review had confirmed the scarcity of research pertaining to my specific area of enquiry. I noted, however, the additional focus upon those providing activities, which could afford additional context to the experience and insights of the person living with dementia.

This article was of interest also because it used phenomenology to analyse its findings, in particular considering ‘stocks of knowledge’ brought to the activities, and how these were utilised to understand personal experiences. These were based upon participants’ ideas, values and attitudes, built by their social associations over time. The authors constructed ‘typifications’ from participant accounts, drawn from those ‘stocks of knowledge’. This helped with their analysis. The phenomenological approach I was considering at this early stage in my thinking was less prescriptive, however. This was because phenomenology appeared to offer a way in which life could be understood, as individuals experienced it, from moment to moment (Bakewell, 2017). Thus, I was not inclined to introduce complexity which might obfuscate such insight. However, I noted the importance of recognising what participants already brought to their engagement in activity, and endeavoured to keep this in mind.

In the article published by Son, Kerstetter, and Mowen (2009) the methods employed were different from those I was contemplating. This was particularly because their study relied upon questionnaires alone. However, three hundred questionnaires were completed. I could understand that by reaching a relatively large number of respondents these authors gathered information that helped their enquiry. However, no dialogue was engaged in with respondents. I felt more could be understood about matters of relevance, in particular relating to physical activity identity and leisure constraints, from methods that enabled such dialogue.

Anderson and Whitfield’s 2013 article used grounded theory to explore the experiences and understandings of nine adults described as ‘stroke survivors’ as they re-engaged with activities of daily life. However, only one interview was held with each participant and no contact was made with others relevant to the study’s aims, for example, family members. I believed I might understand more from contact with participants on more than one occasion, especially because identity is fluid (Snyder and Spreitzer, 1979) and thus elements relevant to my research might change over the course of the enquiry.

I outlined earlier that the article by Atherton *et al.,* (2016) was retained because of what it represented about the engagement of people living with dementia engaging in vigorous activity within community settings, rather than because it offered substantive insights into identity. The article’s research methods, founded upon a randomised controlled trial, were also very different from an approach I envisioned for my study. For example, I did not think this technique would lend itself to discovering what I wished to know, particularly about how people’s experiences can influence their identity.

Other retained articles similarly offered less of value in terms of their methodological approach. For example, Snyder and Spreitzer (1979) was not concerned in any way with contexts where people with cognitive or physical disabilities were involved. However, it was an insightful academic discussion of matters relevant to my study, contained within a peer reviewed journal. Similarly Weiss (2001) was not based upon findings from primary research, but was also a peer reviewed article, and one retained because it progressed understanding of social identity and sport in ways that were helpful to me as detailed above.

The study by Kissow (2015) was a literature review. It was helpful in enabling me to consider my research methods. For example, it suggested that qualitative approaches had succeeded in illuminating essential elements of lived experience relevant to understanding identity for people with physical disabilities. It called for a move beyond the standard interview to enhance this (Kissow, 2015, p.162-163), whilst observations and study of what went on in everyday life were recommended to deepen understanding (Kissow, 2015, p.163). However, the article had less to offer with regard to the context of my research. For example, the literature it reviewed was on a different topic to my own, i.e. personal experiences gained through participating in physical activity, and how those might influence participation in other contexts of life for people with physical disabilities (Kissow, 2015). Additionally, only qualitative studies, and qualitative components of mixed-methods research articles, were included as data, and appraised by the author.

Finally, whilst elements of the content of Williams (1994) were of value, its methods were less so. This was because it did not rely upon the gathering of new data through primary research. There were also matters relating to how the literature review was carried out that also caused me concern. In particular, it did not include a clear account of the system through which it appraised literature, and the process therefore appeared to lack rigour.

2.3.5 Gaps in the literature requiring further investigation

Following the process of search and selection of relevant articles, and the resultant synthesis and discussion of matters relevant to the review question, I identified gaps in the literature, and matters potentially requiring further investigation. These were:

- Research investigating engagement in the sort of vigorous physical activity by people living with dementia available as part of the offering of Centres, and its implications for their identity.
- More could be known about the nature of interaction between people living with dementia and others within the context of engagement in activity of Centres, and how this might influence identity.

- In light of what Phinney *et al*., (2016) reflected was the privileged position of people physically well enough to engage in leisure in the community, understanding the perspective of people with dementia who are physically frailer and/ or less well able to contribute insight. Such accounts are under reported but essential to understand the context of people living with dementia engaging in sport and physical activity.

- Understanding of how spaces within Centres, and their physical locations might play a role in identity formation.

- Genoe and Dupuis (2011) suggested that identity for people living with dementia continued to be constructed through leisure activity in ways that were forward looking and aspirational. Lundberg *et al.,* (2011) suggested similar relating to participation in physical activity by disabled people. More could be known about how the identity of people living with dementia engaged in activity at Centres might be influenced in such ways.

- In light of Brown’s 2017 discussion about how self-identity alters over time for people living with dementia, more needs to be known about the potential importance of the passage of time and the continuing life-course in relation to identity for people with dementia engaging in physical activity.

- More needs to be known about constraints to leisure people living with dementia experience (Son, Kerstetter, and Mowen, 2009), and the impact of these upon experiences, and how they might influence ongoing identity formation.

- Additional insight is required about the preferences for activities people living with dementia have in relation to the potential opportunities provided by Centres.

Thus, gaps remained, and my study would attempt to address these.

There were also limitations to my literature review. For example, it was not a full systematic review, meaning articles of potential relevance might not have been found and included. Additionally, aspects of diversity such as gender, and ethnicity were not interrogated as part of the review. This was potentially detrimental given my study took a social citizenship lens. In response I endeavoured to keep these features in mind as I progressed other aspects of my enquiry.

2.4 Review of the literature: concluding remarks

My review of the literature achieved an important function by contributing significantly to the rationale for my study (Jones *et al.,* 2013), specifically its position within the milieu relating to people with dementia engaging in leisure/ physical activity. I expand upon this, below. The review had other significant outcomes, however. For example, as Jones *et al.,* (2013) argue should be the case, through establishing the state of knowledge in the field, identifying gaps in that understanding, and helping clarify the sort of research that might unpick key insights relevant to my subject. However, whilst recognising the need for ongoing dialogue with the literature throughout, as Jones (2015) advises in relation to an exploratory study such as mine, it was necessary to construct a programme to ascertain new knowledge relevant to the research. Thus, in subsequent chapters I address the underpinning philosophy of the project, which informed the research at every stage, then its methods, and the findings of the research. Before doing so I will set out the aim of my study, its objectives and the research question. My literature review, and reflections upon topics discussed in Chapter 1, had placed me in a position to confirm these.

2.5 The aim of the study, its objectives and the research question

2.5.1 Synthesis of arguments made in Chapter 1 and 2; the rationale for the research

Detail contained in my opening chapters led me to conclude that research exploring identity formation for people living with dementia, within the context of Centres, was important. The harm dementia can impose upon individuals, families and communities can be significant, and responses have been found to be lacking. The rationale for the research was based upon this, because insight might contribute new ways through which individuals living with dementia could be supported, and/ or continue to forge their life, in ways they wished.

Identity would be the focus because of maintaining a sense of oneself is a fundamental part of being human (Kitwood, 1997). The complexity and pace of life in contemporary western society makes retaining this challenging (Spracklen, 2013). Whilst the sense of identity endures for people living with dementia (Caddell and Clare, 2010), societal influences, alongside the symptoms of the illness, can demean and erode aspects of life that sustain identity (Moran 2001; Sabat; 2001; Patterson *et al.,* 2018). This serves to diminish or deny individuals opportunity to express and enact preferences in daily life, hindering people being who they wish to be. Additionally, whilst adjustment to living with dementia is difficult (Cheston, 2013; Brooker and Latham 2016), successful readjustment is essential to enable individuals to feel they are living well as well as possible (Bunn *et al.,* 2012; Cheston 2013; Brooker *et al.,* 2017). Identity formation remains fluid throughout the course of life (Snyder and Spreitzer, 1979), and therefore forms a key component within the context to adjusting to dementia.

Leisure is an important part of the life of western societies (Hill, 2002), and offers opportunity for individuals to manifest their identity through engagement with it (Spracklen, 2013). It is more than the fulfilment of tasks, leisure potentially offers individuals meaning to their lives (Torkildsen, 1999; Spracklen, 2013). Participation in physical activity is part of this, as it is thought through engagement identities form or current identity strengthens (Perras, Strachan, and Fairley and Gammon, 2005; Fortier, 2015; Evans *et al.,* 2016; Bennett *et al.,* 2017). The social context of identity formation is important, as people interact with each other, and such interactions contribute to the formation of identity (Wearing, 2011; Pittman *et al.,* 2011; Spracklen, 2013). The role of others significant to individuals living with dementia is important in influencing the formation of identity (Dupuis *et al.,* 2012).

Interest in the significance of identity within leisure contexts for people living with dementia has progressed understanding (Genoe and Dupuis, 2011; Dupuis *et al,* 2012; Phinney *et al*, 2016). However, research must continue to explore and challenge matters that are apparently understood (Genoe, 2010). The meaning individuals accord to their engagement in leisure is important to their experience of it, and potentially their identity (Stebbins, 1992).

More needs to be known because individuals living with dementia wish to understand ways in which they can play an active role within their communities (Swaffer, 2016), and in turn how those communities can support and enable this (Bartlett and Brannelly, 2019a). There is interest too in understanding more about how places are important to people living with dementia (Ward *et al,* 2018), and could play a role in identity formation (Phinney, *et al,* 2016), in particular because people develop identities through the relationships they have with places (Maersk, Cutchin, and la Cour, 2018).

Centres are located within neighbourhoods and are thus part of this context. However, how identity formation might operate for people living with dementia engaging in these settings is unknown. There is also a lack of evidence about how engagement in vigorous physical activity, of the sort offered at these venues, might contribute to the formation of identity of people living with dementia. This is intriguing particularly because ‘physical activity identity’ has the greatest association with vigorous activity (Son, Kerstetter, and Mowen, 2009). Centres are potentially places of special significance because the experiential self (Brown, 2017) is an important way through which people living with dementia express their identity. Such embodied communication is used by people living with dementia to support their identity (Wright, 2018). The nature of activities on offer at Centres means this can be investigated to heighten understanding of identity formation for people living with dementia.

2.5.2 Study aims, objectives and research question

Study aims, objectives and the research question were as follows:

Aim:

To understand the influence engagement with Centres has upon the sense of identity of people living with dementia, through exploration of their experiences in those settings.

Objectives:

1. To discover what, if any, are the key factors in participation within the activities of Centres that influence the identity of people living with dementia.
2. To learn more about the lived experience of dementia in the context of activity within Centre settings.

3. To distil understanding of how Centres can position their offering to promote opportunity for people living with dementia to participate within their lives and within their local community.

Research Question:

How does engagement in activity within Centres influence the identity of people living with dementia?

Chapter 3: Methodology

3.1 Introduction

In this chapter I set out and justify the research methodology, and underpinning philosophy. In addition, I clarify my ontological, epistemological and axiological standpoints that influenced my research design. The chapter will outline the phenomenological ideas of four philosophers that provide the methodological foundation: Martin Heidegger (1889-1976), Hans-Georg Gadamer (1900-2002), Edith Stein (1891-1942), and Maurice Merleau-Ponty (1908-1961). My approach was not wedded to a particular thinker. This was because ideas of each enabled me to make sense of how these phenomenological underpinnings informed the methods I employed. Those methods are discussed in detail in the subsequent chapter.

3.1.1 How the chapter builds the foundation of my methodology

The following table illustrates the foundation upon which my methodology was built. This is a summary of the structure I use within the chapter to develop the arguments providing the foundations of my research methodology. It is included to aid navigation through the chapter.

Table 2: Showing how the discussion in this chapter builds the foundation of my methodology.

My paradigm, or worldview	I consider that humans consistently search for understanding of their social world. This helped me interpret the meaning research participants gave to their experiences, and understand how I might co-construct knowledge with them.
My ontological standpoint	I believe what people perceive as real can change over time, influenced by their experiences. This enabled me to

<table>
<tr><td></td><td>understand how participants perceived themselves, and how interaction with others influenced that.</td></tr>
<tr><td>My epistemological standpoint</td><td>I know my world through understanding my experiences, and by co-creating understanding with others. Thus, interactions with participants were central to how research findings were created.</td></tr>
<tr><td>My positionality</td><td>How I know and understand my world meant I was present within the enquiry, and a part of it. My understanding was therefore subjective, and advantageous in the sense my previous experiences strengthened my comprehension of participants’ contributions to the research.</td></tr>
<tr><td>My reflexivity</td><td>By regularly reflecting upon my position within the research I was able to understand what my presence meant for participants, and how this influenced findings.</td></tr>
<tr><td>My axiology</td><td>My personal values informed how I approached the research. For example, incorporating empathy to endeavour to ensure that interactions with participants enabled them to offer the insight they wished to contribute.</td></tr>
<tr><td colspan="2">The phenomenological ideas of four philosophers that provided the methodological foundation:
The interpretive phenomenology of Martin Heidegger: his ideas enabled me to consider and understand better what being-in-the-world meant, in particular for the four research participants living with dementia.
The interpretive phenomenology of Hans-Georg Gadamer: his ideas informed my approach to gaining knowledge that was co-created between myself and research participants. His phenomenological philosophy also helped me determine how I would analyse the data.
The phenomenology of empathy developed by Edith Stein: her ideas helped me understand the meaning of empathy, and its significance in enabling me to understand the experiences of research participants.
The phenomenology of perception, pioneered by Maurice Merleau-Ponty: his ideas enabled me to consider the role the body has in making, and communicating meaning for participants. Aspects of his philosophy also helped me understand the significance for participants of engaging in activity within spaces and places, often alongside others.</td></tr>
<tr><td colspan="2">Justifying the research methodology:
These phenomenological ideas enabled me to understand better what being-in-the-world meant for participants. This was essential because understanding what the experiences of people living with dementia meant, as they engaged in activity within the spaces where the research was located, was integral to my enquiry. The tenets of these ideas were congruent with my worldview and its components, in particular my focus upon understanding what being-in-the-world means for individuals through comprehending their experiences and meaning derived through interactions. Thus, together, these formed the basis of my research methodology, as the chapter will now explain in more detail.</td></tr>
</table>

3.2 Paradigmatic approach

A paradigm is a, “set of basic beliefs. . . a worldview that defines, for its holder, the nature of the ‘world’, the individual’s place in it, and the range of possible relationships to that world and its parts” (Guba and Lincoln, 1994, p.107). How I see the world played a formative role in the nature and construction of my methodology. This is because methodology is dependent upon the exploration and gathering of knowledge from the world of which individuals are a part (Denzin and Lincoln, 2018; Creswell 2009). Whilst the term paradigm can be overused in a research context (Holloway and Biley, 2011), it is of significance within my study because of the importance the enquiry attaches to identity. Therefore, my worldview fundamentally informed the approach taken in my research and, as explained below, my identity was incorporated within the methodology.

My identity has been constructed through my experience within a variety of intergroup contexts, in the manner integral to the work of Martin and Vitali (2011), which have shaped my worldview or paradigm. These include life experiences (professional and personal), my own socialisation, education and training (Sparkes and Smith, 2014; Gill, 2011). I have articulated these experiences in Chapter 1, and so will return to them only briefly. My paradigm was shaped by my career as a social worker with its inherent values and practices, and how I transferred this experience and underpinnings into teaching on related matters within higher education. My involvement with sport and physical activity also contributed, having been a coach, player and teammate. As accounted in Chapter 1, these experiences and their impact upon my view of the world, along with my academic study, led me to social citizenship, in particular its focus upon the participation by people living with dementia (Bartlett and O’Connor, 2007 & 2010; Bartlett, 2016). Additionally, I placed value upon the framing of citizenship as a status, founded upon rights; for, example, to have opportunities for growth, camaraderie and purpose, personal recognition beyond being a person living with dementia, and to live without discrimination (Bartlett and O’Connor, 2007 and 2010).

In summary, my paradigm identifies the following features as being important to how I understand and approach the world: empowerment, critical appraisal, inquisitiveness about others, empathy, agency, anti-oppression, co-production, and person-centred approaches. How my paradigm mattered to my research topic, and enhanced the quality and meanings I drew from my enquiries, are issues to which I now turn.

3.3 Compatibility of my ‘worldview’ with the research methodology

The methodology was congruent with my paradigmatic position. It enabled exploration of the complexity inherent in identity negotiation within a physical activity context, in the manner recommended by Tulle (2015) and Oliver, Hudson and Thomas (2016). This was because my worldview is constructivist or interpretive, believing that humans consistently search for understanding of the social world of which they are part (Crotty, 1998). Every person will gain different meanings about their experiences, and these meanings are subjective in nature. Thus, there are multiple possible meanings that exist in relation to experiences. Additionally, meaning is not simply interpreted by individuals, interaction between individuals plays a key role in the formation of meaning (Cresswell, 2009; Crotty, 1998).

The researcher’s role within such a paradigm is to interpret the meaning others give to their experiences within the world. This is congruent with the key principles influencing how I interpret the world. It is in combination with how I learned to appraise information critically, via my experience within professional employment contexts. Utilising this gave me a strong perspective from which I approached the complex subject matter of my research. In this position I was also aware of structural features of society that shape identity, for example, age and gender. This was important because researchers often minimise their importance, which is to the detriment of their inquiries (Williams, 1994). My worldview aligns with a qualitative approach to the research. This is because as the researcher I am a co-constructor of knowledge, understanding and interpreting the meaning of lived experiences (Smith and Sparkes, 2016; Denzin and Lincoln, 2018).

I will now explore how the different components enabling me to understand the nature of the world are incorporated into, and inform, my worldview. Firstly I address my ontological standpoint.

3.3.1 My ontological standpoint

My worldview, with its emphasis upon empathy and inquisitiveness about others, meant my ontological standpoint was relativist. I believe there are multiple realities that offer understandings of the social world, and that these understandings are constructed and co-constructed via interaction with and between people (Denzin and Lincoln, 2018). These realities will be different as they depend upon the individual offering their unique experiences (Denzin and Lincoln, 2018). What is perceived as reality by people can change over time, dependent upon their experiences of the social world (Sparkes and Smith, 2014). Ontologically this enabled me to understand the significance primary participants had for their perception of themselves. For example, identities constructed from the physical activities they engaged in, ‘physical activity identities’, where that person’s association with physical activity was meaningful to how they viewed themselves (Son, Kerstetter, and Mowen 2009). The significance held by people living with dementia for their identity when engaging in leisure activities can be powerful and immediate, for example through the nature of activity engaged in and the meaning this has for the person (Genoe and Dupuis, 2011).

However, I also recognised the nature of being-in-the-world for research participants would be influenced by constraints upon them (Son, Kerstetter, and Mowen 2009). These might emanate from environmental features such as a lack of facilities, or from inter-personal relationships which stigmatise and undermine (even unintentionally) the sense a person has of their own ability.

My ontology helped me understand the nature of reality for primary participants resulting from the influence of others. I have related how identity negotiation in a physical activity context is an ongoing process, owing much to the interpretations others within that situation offer the participant in relation to their identity – i.e. through verbal and non-verbal cues (Snyder and Spreitzer, 1979). What the reality is for a person living with dementia in terms of their identity will depend on such interactions (Lindelof *et al.*, 2017). My paradigm assisted me to recognise the potential such interaction might have for reframing of identity, i.e. into an athletic identity rather than one focusing on impairment (Kissow, 2015). However, whilst I understood matters relevant to dementia and physical activity, I had limited insight into the experience of living with dementia because, as far as I know, I do not have such an illness. It would be incorrect, therefore, to claim I could understand the reality of living with dementia (Swaffer, 2016).

Adherence to my worldview, especially the value it places upon recognising diversity and the significance of person-centred approaches, meant that I could not presume that framing an athletic identity would be positive for every person. For example, if physical activity played an important role for a person's sense of themselves throughout their life, reduced levels of ability might have a negative impact upon their sense of self. Thus, I considered that it was preferable to view the nature of being-in-the-world as encompassing a holistic context for people living with dementia, beyond the exclusive focus on the medicalised discourse of the disease (Brooker and Latham, 2016). In other words, one where the person's sense of self was developed over time and included meaningful recollections of formative experiences pre-diagnosis (Williams, 1994). To do so was a recognition of primary participants' social citizenship, and to presume otherwise, without clear evidence to the contrary, would feel oppressive. As

Bartlett and Brannelly (2019a) suggest, people living with dementia must be recognised as people, complete with skills, abilities and aspirations.

3.3.2 My epistemological standpoint

Epistemology is the theoretical approach to knowledge that focuses upon its nature, in particular understanding *how* one knows the world (Smith and Sparkes, 2016; Denzin and Lincoln, 2018). My epistemological standpoint is subjectivist, recognising that it is through my understanding of my own experiences, and the co-creation of understanding with others that I know my world. This meant that the relationships between me and research participants were fundamental. Relationships between researcher and participants, and the nature of their interactions, inform how findings can be created (Smith and Sparkes, 2013). For example, my data included discussions held with each primary participant shortly after we had taken part in an activity together. Conversation about what went on, and how that felt for both of us, helped generate unique knowledge informed by both our perspectives. This was pertinent because, as Lundberg, *et al.,* (2011) suggest, such approaches are important to understanding how identity is negotiated within sporting contexts by people with cognitive disabilities.

Additionally, I will demonstrate later how the phenomenologies which underpinned my methodology emphasised holistic understandings of being-in-the-world, for example, at the expense of propositions such as an absolute distinction between body and mind (Davis, 2004). Therefore, I rejected an epistemology that mandated rigid objectivity. The value to my research was being able to align my approach to attempt to know the world utilising the perspectives of people living with dementia. Understanding perceptions in this way is a fundamental part of working alongside people with dementia, particularly in a research context (Kitwood, 1997; Brooker and Latham 2016; Bryden, 2012; Bartlett, 2012; Robinson, 2002).

3.3.3 My Positionality

Positionality is the recognition a researcher within a constructivist paradigm must have of their own position and role within the enquiry (Thomas, 2013). Whilst a constructivist paradigm offers researchers opportunity to gain a rich understanding of the social world, it is essential for anyone using the approach to accept the subjectivity that this will bring (Thomas, 2013). Critiques of research adopting a constructivist paradigm highlight the negative implications of this subjectivity, and the influence it will have upon the research. Recently, however, such subjectivity has been reframed positively (Finlay, 2002). The phenomenon has come to be seen as possibly accentuating the virtue and benefit that a greater understanding of the research context can have for the quality of interpretation. Thus, my previous experience of working alongside people living with dementia, and its contribution to my worldview, meant that I was aware that research participants would bring a unique perspective to the enquiry, and that this could offer far reaching outcomes. For example, I had worked alongside colleagues in higher education settings who were living with dementia. This reinforced to me the importance of enabling people to offer their holistic experience of life, rather than being categorised exclusively as people with understanding only related to their illness.

3.3.4 My Reflexivity

To justify my position in the research, and to utilise it effectively, I engaged with another concept – reflexivity (Sparkes and Smith, 2014). Reflexivity involves examining how the researcher and elements of the research work together and relate to each other to influence the enquiry and potentially its findings (Finlay, 2002, p.210). In practice, I was critical of myself as a researcher, and the potential myriad elements of my identity I brought to the research setting (Denzin and Lincoln, 2018). Engagement with reflexive analysis was an essential component, to maximise the integrity of my enquiry (Finlay, 2002). This was not least because, as advised by Day (2012), it enabled me to consider and address the power dynamics relating to my position as a researcher alongside the primary participants, as well as contributing to the iterative process of the research. In addition, whilst all human experience involves change, because dementia illnesses are characterised by symptoms which are progressive in nature, the lived experience of dementia involves inevitable additional alteration (Martyr *et al*., 2018). Reflexive analysis was therefore especially relevant to my understanding because change would likely be a core part of primary participants' experience.

Reflexivity has an established history within qualitative research designs, and a variety of approaches have been adopted in pursuance of it (Finlay, 2002). The methods I employed included use of a research diary, to monitor and understand my reflective interventions and techniques (Etherington, 2004). For example, noting details of every research contact as contemporaneously as possible, alongside my initial reflections, and then returning to those entries before future interviews or observations were convened, to reconsider my approach. I also utilised discussions with members of my supervisory team, collectively and separately, on a regular basis throughout the research. Finally, I employed formal presentations I gave during the research process, for example, Leisure Studies Association Annual Conference in 2017, to assess my approach reflexively within the critically constructive academic environment.

Thus, I used reflexive techniques to inform the choice of method employed with primary participants on a particular day, in order to meet their needs and to provide the best opportunity for them to offer their unique insights. For example, with one participant, Ivan, as he struggled with his physical health in the later phases of our relationship, I prioritised observational techniques in favour of those that included more active verbal engagement by him. However, reflexive techniques must be accomplished well to have value, and to avoid having an adverse impact on elements of the research (Finlay, 2002). For example, overemphasis upon reflection might result in the position of the researcher becoming dominant, with the participant’s contribution drowned. Acknowledging power relations between researcher and participants was therefore especially valuable.

Reflexivity strengthened my methodology in other ways. For example, it enabled me to consider the unconscious motives and prejudices I brought to the enquiry. It offered a mechanism, too, through which I could reflect upon the data as they were gathered, and a tool to assess my research study as a whole

(Finlay and Gough, 2003). In addition, reflexive techniques allowed me to consider the ethical dilemmas I faced as a qualitative researcher, for example on the nature and extent of the development of relationships with participants, and deployment of the appropriate practice in response (Etherington, 2007; Brown-Wilson, 2011). I return to this when discussing the phenomenology of empathy (below).

Finally, I employed support through reflective discussions with my supervisors, to help me address situations that may have left participants, or myself, emotionally vulnerable because of the circumstances under scrutiny, in the manner recommended by Bowtell *et al*. (2013) and Gemignani (2011). This is imperative in the context of studies, such as mine, which include matters of personal feeling (Sparkes and Smith, 2014), for example, how people living with dementia anticipate their future (Martyr *et al*., 2018).

3.3.5 My Axiology

Axiology is the philosophical value base which underpins a paradigm and influences the research throughout every stage (Denzin and Lincoln, 2018). My axiology (personal values) played an important part in the methodology of my research, for example, by drawing upon principles within my paradigm. These included valuing empathy, anti-oppression, co-production, and person-centredness. My value base also meant I had already given thought about matters pertaining to a qualitative research project before commencing the research. This was especially relevant in relation to the impact it might have upon participants living with dementia (Bartlett, Milne, and Croucher, 2019). For example, I tailored the interpersonal nature of my interactions with primary participants to anticipate that they were engaging with physical activity at a time when their cognitive skills were liable to be changing (Genoe, 2010; Bell and Wheeler, 2015).

My personal values also led me to incorporate empathetic approaches, and to work alongside participants to seek new understandings about my subject, from the earliest stages of the study. This was because my value base made understanding the experience of my research participants and hearing their voice a priority (Genoe and Dupuis, 2011; Brown, 2017). In the next chapter, I discuss how, in line with good practice (Health Research Authority, 2017), at the outset of the research I sought the views of potential stakeholders and beneficiaries of the research. My main focus was upon people living with dementia, and their close family members. This consultation was motivated by a desire to explore whether this group of people believed that the focus of the study was appropriate. Later, it was driven by my commitment to understanding how the research should be designed and organised. The feedback gathered duly informed my research approach.

The influence of co-production was also reflected in the approach I made to Centres in the primary stages of the research. I used a questionnaire to open a dialogue with this group of stakeholders, whom I perceived as critical to the endeavour because their services offered the context for my research participants living with dementia. Details are set out in the following chapter. However, responses to the questionnaire also provided an invaluable opportunity to shape the project. For example, by allowing me to understand how people living with dementia were engaging with activities offered by Centres.

A further important component of my value base, and indeed a key part of my reflexivity, is not accepting information or supposed insight uncritically. This stems in particular from my training and employment as a social worker (British Association of Social Workers, 2014). This was relevant to my methodology in several ways. For example, reminding me that people may be motivated to engage in physical activity as a result of societal pressures rather than through individual choice (Tulle, 2015). Additionally, being aware that sport and physical activity can be used by policy makers in ways to achieve their organisational goals rather than meet the specific needs of participants (Green, 2006).

I was also wary of the possible unintended effects of my research on participants. This was because participants knew the focus of my enquiry was the implication of the activity they were engaged in. This pre-awareness has been referred to as the Hawthorne effect in experimental research (Fernald *et al.,* 2012). Thus, I needed to guard against taking responses at face value, lest participants, even subconsciously, were offering the sort of insights they felt I might want to hear. The variety of methods I employed in my research (in particular observation alongside interview, and go-along interviews), where I could observe participant activity, as well as discuss it together, helped mitigate against this.

Finally, and as mentioned in my opening chapter, it is the case that citizenship is not always a construct that is exclusively and universally positive. For example, one of the consequences of contributing as a citizen might be the implication that one is also responsible for failings in one’s own health (Collinet and Delandre, 2017). This might be especially pertinent within sporting contexts, where physical health and dexterity are prized assets. For all these reasons, I endeavoured throughout not to accept what I found uncritically. It was through discussion with my supervisors, both collectively, and individually, that I tested remaining personal uncertainty.

3.3.6 Concluding remarks on links between my worldview and research methodology

For me, being-in-the-world involves accepting there are multiple, individualised realities, and these can change. For people living with dementia I believe these realities are often immediate and powerful. Epistemologically I know the world through endeavouring to understand my own experiences of it and those of others. My axiology is closely aligned with my paradigm in that I place importance on a value base promoting empathy and co-construction of meaning with and alongside other people. My axiology also encourages me to be forward looking, anticipating of the future. Understanding what opportunities might give rise to such for people living with dementia was a significant aim of my enquiry. Interpreting the meaning primary participants attached to those opportunities was the fundamental component of my role as the researcher. These were comprehensive and complex matters, and I believed I needed a framework to help me contextualise and understand them better. Phenomenology provided this. In the following sections I investigate how phenomenology supported understanding of my paradigm, and comprehension of my research content.

3.4 Introducing the phenomenological approaches that informed my research

There is no agreement on what phenomenology is, and it comprises many variants (Moran, 2000, p.xiv; Allen-Collinson, 2016, p.11). It has been described as an approach to enquiry; a form of research method (Barkway, 2001; Genoe and Dupuis, 2011). However, phenomenology as philosophy offers more, potentially a means through which individuals can reconsider how they perceive the world in which they live, for example seeking fresh meaning in circumstances where they might have been inclined to take established preconceptions for granted (Allen-Collinson, 2016). As philosophy it articulates how one can move from abstract speculation to engage with life as it is actually lived, and with the tangible experiences of daily life (Moran, 2000; Allen-Collinson, 2016) to describe things in the manner they appear (Moran, 2000, p.xiii and p.4). I perceived my research topic, and the places where I would be undertaking investigation, as ideal opportunities to find out more about life as lived by people with dementia.

To help I drew upon the work and ideas of four phenomenological thinkers: the interpretive phenomenology of Martin Heidegger and Hans-Georg Gadamer, the phenomenology of empathy developed by Edith Stein, and the phenomenology of perception, pioneered by Maurice Merleau-Ponty. Although distinctive in many ways, their phenomenological ideas offered the means of interpreting life moment to moment, as people experienced it (Bakewell, 2017). In the following section I will illustrate how phenomenology contributed to my research.

3.5 The contribution of phenomenology to my research

Phenomenology contributed by providing the means to gain additional and deeper understanding of three aspects of my research:

- The interpretation of human experience.
- How people used their bodies to engage in activities as an expression of meaning in relation to identity.
- Exploration of the role and meaning of the physical environment, or place.

3.5.1. The interpretation of human experience

To answer my research question I needed to put interpretation of the human experience at the heart of my enquiries. Phenomenology offered an authoritative philosophical basis for this as it prioritised the interpretation of human experience (Lindelof *et al*, 2017), for example, by enabling aspects of the human condition that remain poorly understood to be investigated, i.e. the lived experience of dementia. Indeed, Husserl elaborated that phenomenology should probe assumptions that are un-investigated, and not seen as problems in relation to an individual phenomenon or phenomena (Allen-Collinson, 2016, p.12). This was appealing because until my research commenced, the engagement of people with dementia in the ordinary context (Bartlett, 2016) of

Centres had been of insufficient priority to warrant exploration. Phenomenological investigation could redress this by providing “fresh, complex, rich descriptions” of phenomena in the social world as they were being lived (Finlay, 2009, p.6).

3.5.1.1 Hermeneutic phenomenology and the interpretation of human experience

Scholars have frequently employed phenomenology to explore the interpretation of human experience in the context of living with dementia. It is well placed to address experiences which are highly complex, including those of participation in high intensity exercise, and identity negotiation immediately post-diagnosis (Lindelof *et al.*, 2017; Cadell and Clare, 2011). To do so, different iterations of the philosophy have been utilised. For example, Lindelof and colleagues (2017) used a hermeneutic phenomenological approach, which prioritised investigation of the interpretation of human experience, and gained rich, insightful data as a result. Such an approach suggests that reality can only be understood by considering how people interpret their existence and experiences (Moran, 2000). Further, understanding derived from hermeneutic phenomenology relates that all of human existence must involve some form of interpretive quality, and that whilst description is important, part of the human condition will always involve an interpretation of their surroundings and experiences (Finlay, 2009, p11; Moran, 2000, p.235). Hermeneutic phenomenology incorporates a continuous, creative, intuitive, dialectical approach on the part of the researcher, seeking new insight all the while (Crowther *et al.,* 2017). Interpretive phenomenology aligned with my emphasis upon understanding the perspective of others, and the distinctiveness of individual experience and outlook, being fundamental to comprehending the social world.

3.5.1.2 The hermeneutic circle/ spiral and the interpretation of human experience

The phenomenology of Gadamer (2004) contributed to this understanding. His work also influenced my methodology in relation to the dialogical character of comprehending the world, where this resonated with my study's focus upon co-created knowledge. Gadamer built upon earlier thought about what Heiddeger termed the 'hermeneutic circle' (Heidegger, 1962). For Gadamer this concept involved what he referred to as 'the fusion of horizons' (Gadamer, 2004, p.304). This was how Gadamer held that individuals interpreted objects, using written texts as his example. He referred to the preconceptions individuals brought to objects as 'foregrounding' (Gadamer, 2004, p.304), but suggested that an inevitable process of interpretation would take place, where individuals went about testing prejudices about the object and moving beyond a fixed set of opinions, in the manner of looking towards a new horizon (Gadamer, 2004, p.305). The hermeneutic circle is interpretive, using an iterative process. It captured the essence of Gadamer's ideas, involving moving from endeavouring to understand a phenomenon as a whole, to its individual parts, and from there to the whole again (Debesay, Nåden and Slettebø, 2008). Gadamer referred to this as, "…going beyond the historical horizon" (Gadamer 2004, p. 367). The hermeneutic circle has been used within diverse research contexts where meaning is sought, including that of the lived experience of dementia (Tranvåg, Petersen, and Nåden, 2015). Gadamer suggested it could be referred to as a spiral rather than a circle, in order to conceptualise an ongoing search for learning (Lindberg, and Rudolfsson, 2019). The concept has enabled compelling, experiential and existential insights to be identified about the meaning of living with dementia (Fæø, 2019; Lindauer, 2016). The hermeneutic circle/ spiral informed how I sought insight, especially in how I utilised it to support the analysis of my data. The clearest example was how I retained a focus upon the insights provided by each of the four primary participants (set out in Chapter 5), whilst endeavouring to understand what together these might mean for my research question more generally (set out in Chapter 6).

3.5.1.3 Concepts within Heidegerrian phenomenology, and how they assist understanding the interpretation of human experience

Returning to Heidegger's interpretive phenomenology, this encouraged me to think about concepts of relevance in new and different ways. For example, his idea of 'Dasein', literally *being-in-the-world* and understanding one's place within that (Heidegger, 1962, pp.67-69; Crowell, 2006) enabled me to consider being-in-the-world of people living with dementia, and their experiences of engagement with Centres. I was interested in Heidegger's observation that in every day existence understanding of being is not revealed. This is because one is preoccupied with living daily life. It is only with anxiety, or in Heideggerian terms 'Befindlichkeit' (Heidegger, 1962, p.310) or angst, that an understanding of being-in-the-world is revealed (Large, 2008). Angst is the understanding of the possibility of the impossibility of being there (Heidegger, 1962; Crowell, 2016).

‘Dasein’ was a useful concept because being-in-the-world resonated with components of identity discussed in previous chapters; in particular the social facets of one’s identity. It was also congruent with important aspects of my own paradigm, notably my ontology with its emphasis upon the multiple realities of being-in-the-world, and the understanding that these are subject to change. Dasein and related concepts thus helped me think about and conduct my analysis, as I will demonstrate in the chapters that follow. However, I was mindful that a criticism of those utilising such interpretive phenomenologies is to draw inferences that can relate to individuals, because this was not a focus for Heidegger’s work (Bakewell, 2017). Thus, I was cautious not to draw conclusions based on phenomenological understandings alone relating to individuals within my study. Rather I used phenomenology to enhance my thinking and analytical focus.

Heidegger’s interpretive phenomenology, and its notion of temporality provided additional utility. This was because dementia illnesses are progressive, and thus the passage of time, and its meanings to people were of relevance to my research. This was given added significance because people living with dementia are likely to be aware of the progressive nature of dementia causing diseases, and feel the consequences of this deeply (Oliver, 2016; Swaffer, 2016). Heidegger argued that humans are not held to the present, but have a consistent sense of projecting themselves towards the future. He characterised this as ‘authentic temporality’ (Heidegger, 1962, pp.377-379). His argument purported that people draw through aspects of their personal and cultural past they bring with them. In his original text he refers to this as ‘Gewesenheit’, which can be interpreted as ‘I am been’ or ‘having-been-ness’ (Heidegger, 1962, pp. 389-390; Large, 2008; Critchley, 2009). My interest in this aspect of temporality reflected notions that people living with dementia have been presumed to have no future, certainly not one informed by their own agency and aspirations (Kitwood, 1997; Cheston and Bender, 1999). However, identity negotiation through engagement with sport/ physical activity can enable individuals both to accept who they are, but also consider possibilities for their future identity (Mayoh and Jones, 2015, p.248). The Heideggerian concept of temporality and its associated authenticity was aligned to this, and contributed to my analytical focus.

Being able to draw upon one’s personal and cultural past might be difficult for people living with dementia if symptoms include memory loss. However, this is not something that everyone with dementia experiences (NICE, 2018), and there might be other ways in which memory could be recalled, for example, through the contributions of others. My research would include the contribution of others of significance to the primary participants, notably carers and workers at the centres, who might be well placed to support memory recall. Thus, I retained this understanding of temporality, and included it within my methodological considerations.

Heidegger also argues that through ‘resoluteness’ the influence of personal and cultural pasts can be shaken off, and instead progression made towards a different course for the future (Heidegger, 1962; Critchley, 2009). Heidegger saw resoluteness as reacting to uncertainty about one’s future and responding to it (Heidegger, p.463 & 477; Large, 2008). Within his phenomenological conception of temporality the present was referred to as ‘Augenblick’; a moment of vision, something to be seized and made one’s own (Heidegger, 1962, p.396; Large, 2008; Critchley, 2009). This, Heidegger held, was the authentic present (Large, 2008), and this was where and how ‘Dasein’, being-in-the-world, was realised (Critchley, 2009). Such notions were central to how I interpreted primary participants’ experiences within Centres, and what this might mean for their identity.

3.5.1.4 Understanding the interpretation of human experience and the significance of one’s present and future

My discussion about temporality and its relevance to my methodology returns to the significance of, and understandings about, the present and future, drawn from Heidegger’s phenomenology. Here the future is existence, for time is a way of being, and the future is from where existence is found (Mulhall, 2002). Time directs one’s existence towards one’s future and the present is informed by anticipation of one’s future (Heidegger, 1962, p.479; Large, 2008). As I identified above, anxiety heightens awareness of one’s potential for non-existence, and this serves to accentuate the power of the present, acting as a moment of vision (Heidegger, 1962, p.396; Large, 2008).

Reflecting on the experience of living with dementia scholars have identified the significance of the immediacy of being in the moment (MacPherson *et al.,* 2009; Smith, Mountain and Hawkins*,* 2018). The immediate moment was of importance to how primary participants would understand their identity. This was especially relevant to the contexts within which they were engaged; places where physical activity took place, when activity would happen moment by moment. My methods consequently had to capture these moments.

Gathering the sense of how primary participants might feel at these times would be important. However, it is also notable that Heidegger termed as ‘authentic temporality’ (Heidegger, 1962, p.479) the notion that the present drew its meaning from the future. He rejected it being a stand-alone moment, and held that this offered humans a sense of freedom they would not otherwise have (Large, 2008). Thus, the extent to which primary participants might conceptualise their future, and what influence this might have upon their identity, would be important to my understanding of findings. This resonates with the Heideggerian notions of freedom (Heidegger, 1962, p.485) mentioned above. For example, individuals demonstrate personal agency through engagement in sport (Mayoh and Jones, 2015) but all the while within the context of that present moment being influenced by considerations about the future. These matters informed the choice and design of my research methods, as I will show in chapter 4, and how I analysed my findings, in particular cross-cutting themes which I explore in Chapter 6.

3.5.1.5 Interpretive phenomenology and social interaction

I conclude this section by addressing a fundamental part of the human experience, that of social interaction with and between ourselves. Interpretive phenomenologists following Heidegger recognised this and included it as a core part of their philosophy. For example, Gadamer evolved interpretive phenomenological thinking to emphasise the significance of this dialogical character in understanding the social milieu (Moran, 2000). Such an approach was congruent with my ontology and axiology and epistemology, and thus, this strand of interpretive phenomenology contributed to my thinking as I formulated my research methods. It could also empower primary participants, through emphasis upon the co-construction of knowledge between researcher and participant. This was co-construction as a ‘fusion of horizons’ (Gadamer, 2004) where it is insufficient only to enter the research participant’s world. Instead one must aspire to co-produce new knowledge from the combined perspectives of participant and researcher (Holloway and Biley, 2011). I believed this was an approach compatible with researching the lived experience of people with dementia in the context of my research, not least because it accords with values grounded in social citizenship (Genoe and Dupuis, 2014).

This is also relevant to the methodological arguments I made earlier relating to positionality and reflexivity. In relation to the former, as I have shown the interpretive phenomenology of Heidegger asserted that people are a part of the world which they inhabit and experience (Moran, 2000). It is thus pointless and impossible to try to remove the understandings and viewpoints a researcher or participants bring to any enquiry into the nature of the social world. This has been interpreted as the phenomenological basis for placing the researcher as an active participant in spaces where data are gathered and meaning is made (Koch, 2006).

This was an appropriate technique within my study that explored elements of the lived experience of people with dementia, and valuable also because co-produced knowledge equalises power imbalances endemic to researcher - participant relations in such contexts (Bond and Corner, 2001). However, co-production must be genuine, for example, through the valid fusion of horizons, with each person being able to share their reality of ‘being’ and having it recognised (Gadamer, 2004). Otherwise the practice risks becoming oppressive, with the researcher’s voice predominating (Holloway and Biley, 2011).

3.5.1.6 The phenomenology of empathy and how it contributed to understanding the interpretation of human experience

Utilising this personal reflexivity accorded with my empathetic values, and I concluded that to realise coproduction of data and of knowledge I had to strive to achieve empathy. In pursuance I drew upon the scholarship of Edith Stein. Stein’s phenomenology of empathy counselled understanding of oneself as a holistic, experiential entity, whilst seeking insight from others. Stein believed that empathy is fundamental to discovering truth (Sullivan, 2002). It depends upon feeling concern for a person, demonstrating this, and endeavouring to understand what experiences might mean for them. It is also necessary to seek cognitive understanding of the situation of the other person. This has been summarised as “…imagining and explicating a rich understanding of the experiences of this very person I am facing” (Svenaeus, 2015, p.243). As a researcher this presented challenges because forming too strong a bond might create contained risk. For example, in the manner suggested by Dickson-Swift *et al.,* (2006), blurring boundaries between being a researcher and a friend, which might leave participants confused and potentially upset as the research concluded. It might also prove counter-productive, for example unduly influencing the clear-sightedness of participant responses (Fernald *et al.,* 2012). However, building rapport and empathic relationships are a key part of good practice when working alongside people living with dementia in a research context (Brooker and Latham, 2016). Furthermore, empathy of the kind articulated by Stein would assist me to identify angst within the context of my research (Stein, 2000). I believed empathy could build the confidence of primary participants to contribute. I also considered that my professional background would enable me to construct arrangements to facilitate this. How I incorporated the phenomenology of empathy into my research methods, and how I addressed the concurrent ethical and practical risks, are detailed in the following chapter.

3.5.2 Embodiment as an expression of meaning

The fourth phenomenological strand of value concerned the contribution it makes to knowing more about how people use their bodies to engage in activities as expressions of meaning. Such phenomenology lends itself to research settings such as mine, where there is a “nexus of mind, body and environment” (Allen-Collinson, 2016, p.11). Thus, investigating the sensorial implications for the identity of the primary participants in my research as they engaged in activity was a priority. Additionally, because language tends to filter and distort the ability to present people and their experiences as they really are (Murdoch, 1954), these strands of phenomenology were useful in enabling me to get closer to representing the experiences of participants in my written account.

3.5.2.1 Aspects of phenomenological philosophy relevant to understanding embodiment as an expression of meaning

In his later work Husserl was interested in how one exists alongside other people, immersed all the while in sensory experience (Bakewell, 2017). Husserl held that we exist within a ‘Lebenswelt’, or ‘life-world’. This is the social, historical and physical context where all human activity happens, where a key component is physically sensing ourselves within this world (Bakewell, 2017). This is barely noticed, it is taken for granted. However, through ‘proprioception’, the perception of self, humans sense and experience themselves in the world (Bakewell, 2017).

Maurice Merleau-Ponty, a pioneer of the phenomenology of perception, was another guiding scholar. Of significance was his premise that the body has its own sense of agency, and that its actions can express meaning in relation to identity, the phenomenon known as ‘embodiment’ (Merleau-Ponty, 1962). Merleau-Ponty used understandings of embodiment to provide full descriptions of how humans live from moment to moment, and the implications of this for who we are (Bakewell, 2017). I have established the value of ‘the moment’ to my study. Thus, the phenomenology of perception (even though perception can be fallible) was important to my methodology, because it enabled me to draw upon embodied communication, and consider methods to allow understanding of insight offered by participants in moments significant to the shaping of their identity.

Merleau-Ponty’s concept of ‘embodied consciousness’ recognises that we are always with our body, and simultaneously we are our body (Hockey and Collinson, 2007), additionally, we are always “bodily in the world” (Merleau-Ponty, 1962; van Manen, 1997, p. 103). Thus, people reveal and hide elements of themselves, often unconsciously, via their physical presence, through their bodies and how they use them (Merleau-Ponty, 1962, p.74). At the same time Merleau-Ponty held that ‘embodied cognition’ considers consciousness holistically as social and sensory phenomenon, and not simply abstract processes in sequence (Merleau-Ponty, 1962, p.73 & 78; Bakewell, 2017). This moves understanding of the body from it being an object to an entity of ourselves, capable of making interpretation and judgments about the world around us, independent of conventional consciousness.

Understandings of these ideas embrace what is known as ‘carnal sociology’, which advocates that through embodied consciousness the body has an active role within social life (Crossley, 1995). This was relevant to my research because of the manner embodied consciousness might be realised in social situations, when primary participants engaged publically in physical activity. For example, it has been argued movement and the rhythm of movement can trigger feelings in oneself which one interprets and/ or are interpreted by those with whom one participates alongside.

Additionally, seeing, hearing, and even smelling ourselves (and or others), whilst engaged in physical activity, contributes to enabling individuals to draw meaning from such engagement (Merleau-Ponty, 1962, p. 232); Hockey and Collinson, 2007). This might involve recollection on past sporting related activities which in turn contribute to meaning. However, such nostalgic reflections must be treated with care, lest they inadvertently temper the veracity of recollection (Hughes, Kohe and Purdy, 2019).

3.5.2.2 Embodiment as an expression of meaning within the context of the lived experience of dementia

Merleau-Ponty argued the appreciation of ones senses and what this means comes from understandings learned in childhood, and modifies as life progresses (Merleau-Ponty, 1962, p. 361-362; Bakewell, 2017). Such movement from uncertainty to understanding, back to uncertainty and the search for understanding was everlasting. Merleau-Ponty’s scholarship attuned this to what happened when faculties were lost or damaged (Merleau-Ponty, 1962, p.233; Bakewell, 2017).

I anticipated that primary participants might show me meaning about themselves through what they did in ways they might otherwise be unable to do, because symptoms of dementia had either made speech difficult, or had reduced their confidence to try to express themselves verbally (Wright, 2018). Indeed, as it becomes less easy for participants to express themselves verbally, conceptions of dialogical engagement between researcher and participants must be broader, more flexible and include emphasis upon non-verbal encounters (Bond and Corner, 2001; Genoe and Dupuis, 2011).

Such embodiment has been applied to research contexts involving people with dementia, wherein scholars argue that the body has agency, expresses meaning, and through actions and gestures contributes to identity negotiation (Phinney, Choudry and O'Connor, 2007; Wright, 2018). Because the body can be considered interpersonal in a phenomenological sense, it is therefore capable of expressing meaning within contexts where people with disabilities negotiate identity via physical activity (Kissow, 2015). The methods I chose to investigate my research question were thus designed to capture insights offered by primary participants via the use of their bodies, for example, observations whilst participating in physical activity.

3.5.3 Understanding the role and meaning of the physical environment or place

Phenomenology helped me develop my methodology and guide my choice of research methods. My account demonstrates how inter-related and entwined the phenomenological underpinnings were. This connection extended to the third area in which my methodology sought to help me answer my research question. This was exploration of the role and meaning of the physical environment, or place, within the shaping of identity for primary participants. Place can be important in identity negotiation, particularly with regard to sports and physical activity environments (Wise, 2015). Phenomenology contributes to understanding about this process by enabling close engagement with research participants, i.e. offering the mechanism to enter the social world of the person. Indeed, individuals with cognitive disabilities use familiar environments and places to negotiate identity (Phinney, Choudry and O'Connor, 2007) and phenomenology has been employed to help understand this in a sports and recreation context. For example, by using it to explore the significance of the previous experiences participants hold of place and activity, and their immediate perception of the experience (Lundberg, *et al*., 2011).

Considering the above example, and recognising interconnectedness across strands of phenomenology, this understanding was relevant through its argument that we are sensual beings and experience comes to us via colours, shapes, tastes, smells, noises and touch (Bakewell, 2017). I linked this to notions of 'sensuous' geography (Rodaway, 2002), where people create meaning within familiar spaces through use of their senses. In the sporting context this has been used to explore whether venues familiar to participants influence how they express themselves physically. For example, using their understanding of the terrain to determine how they balance and position themselves whilst engaging, or even how participants might use sporting equipment (for example racquets) within spaces (Hockey and Collinson, 2007). A similar argument can be made that habituated bodily action (Bakewell, 2017), made familiar through lifetimes characterised by playing sport, can be transposed into venues where physical activity takes place, even when the places themselves are new to participants (Hockey and Collinson, 2007).

Crucial to the effectiveness of this would be the research methods, which had to align with and support a phenomenological approach (Kusenbach, 2003). I selected go-along interviews and participant observations as two of my research methods because I was keen to understand if and how primary participants might utilise previous experience of sporting endeavour within the spaces where they now engaged in physical activity to help shape their identity. In the following chapter I will explain their nature in detail. However, these methods were phenomenologically aligned, because the go-along interviews provided opportunities for participants to recall with more ease their previous experiences, through repetition of physical activity in familiar spaces. Participant observations gave me the chance to explore individual's perceptions of the experience by observing them in situ, within the place that was potentially impacting upon their sense of self.

3.5.4 Making the case for my phenomenological approach.

In the preceding sections I have detailed how phenomenology helped inform my methodology. However, in recent times the discipline has come in for criticism, with novice researchers, such as myself, being identified as especially vulnerable to making wrong assumptions about the value and appropriateness of phenomenology to their research (Paley 2016 and 2018). The most significant and consolidated criticism emanates from the nursing philosopher and scholar John Paley (2016; 2018). He argues that phenomenology has frequently been adopted by researchers who have given insufficient consideration to what it can offer them within their empirical activity, when in reality this is too little to be rigorous and useful. Paley states phenomenology is too vague to be precisely applied as a method in qualitative research contexts; it relies too heavily upon analysis of text (in particular interview transcripts); knowledge gathered through its use cannot be analysed because of its vague nature; and it is often misread and/ or misrepresented by authors who are straying from the original texts of phenomenological philosophers (Paley, 2016; Paley, 2018; Zahavi and Martiny, 2019).

However, rather than using phenomenology primarily as a method, I utilised it to assist me to understand what opportunities might arise for the shaping of identity within community based contexts for people living with dementia, and the meaning that arose from these. Additionally, I engaged with the original scholarship of the pioneer scholars I identified above. Their philosophy is frequently difficult to comprehend and therefore required reading with care (Mulhall, 2002). I tried not to accept uncritically what was argued but employed it as the basis to seek new understanding (Crotty, 1997). This was where the works of later authors contributed significantly. This mix of phenomenological resource can prove effective and useful for research, including the exploration of the experience and meaning of living with cognitive impairment, if clearly articulated and justified (Zahavi and Martiny, 2019). By incorporating a range of phenomenological thought, taking care all the while to explain how it resonated with the context of my enquiry, I believe my methodology enabled me to better understand the social world in which people with dementia live. It thus sharpened the perspicacity of my research (Bakewell, 2017), enhancing the rigour of the analysis of my findings (Jensen *et al.,* 2019).

Potentially the most harmful criticism of phenomenology is that it is impossible to apply it when endeavouring to investigate the lived experience of dementia (Davis, 2004). This critique centres upon the assertion that ‘Dasein’ for a person living with dementia is improbable, especially in advanced stages of the syndrome, because the self has been dismantled by symptoms to the extent that being is irrevocably destroyed (Davis, 2004). Criticisms here withstanding, I had seen from my own professional experience evidence of people’s sense of self enduring to the point when dementia caused death. Social citizenship also acted to counter censure. It can never be fully realised, and must always be revisited, discussed and reconstructed to be effective (Bartlett and Brannelly, 2019a). Thus, being-in-the-world must never be discounted, no matter what the circumstances of individuals.

3.6 Conclusion

My study involved an exploration of the lived experience of dementia within Centres, and investigation of how engagement in those places influenced the identity of participants living with dementia. In pursuance of this, I have explained what informed my research design, and introduced my research paradigm. I explored this and its component parts, i.e. my ontological, epistemological and axiological positions, and described how these informed the methodology, and dovetailed with it to maximise the effectiveness of my enquiry. Subsequently I introduced the phenomenological ideas of four thinkers, and articulated how these added intellectually and philosophically to the research, and also helped me begin to frame the subsequent methods. In the following chapter I turn to an account of these research methods.

Chapter 4: Methods

4.1. Introduction

This chapter describes how I put my methodological orientation into practice. Firstly, I discuss how I enabled the voice of participants to inform and shape what I did from the outset of the project, through consultation with people living with dementia, family carers and people involved in the delivery of sports and physical activity. The chapter then details my participant recruitment. Subsequently I articulate the rationale for my choices of research methods, and then address how I understood my data through analysing it thematically. Latterly, the chapter discusses my engagement with relevant ethical considerations.

4.2. Consultation with people living with dementia and family carers

People with dementia and family carers, scholars argue, must be involved in the design of any research project that sets out to explore the lived experience of dementia for it to have integrity and credibility (Robinson, 2002; Bartlett, 2012). Indeed, it is irresponsible for research not to aspire to responding to the needs and wishes of people living with dementia, and improving their experiences, as essential goals (Bartlett, Milne and Croucher, 2018). Thus, consultation with people living with dementia, and their closest family members took place throughout my project. It was motivated by my desire to explore whether the focus of my study was right in the opinion of people living with dementia. It was also driven by my commitment to understand how the research should be designed and organised, and how my findings should be disseminated. The insights gathered shaped and informed my research approach.

From January until November 2017, at an early, formative stage of the research process, I consulted with people living with dementia and family carers with twin aims. Firstly, to enlist their assistance in developing and refining my proposed research topic and question, and secondly, to seek their view on my intended approach to the design and conduct of the research. I visited five meetings, convened as part of the provision of the Alzheimer’s Society, located across the county where I was based.

At this stage I was uncertain whether the research would focus upon a distinct societal group (for example, younger people with dementia). Thus, I actively sought the views of people of different ages by visiting meetings that were likely to be attended by people with dementia from across a wide age range. Three meetings comprised younger people with dementia, two were at dementia cafes, where attendees were likely to be sixty-five years of age or older. However, these groups were not fully representative of people with dementia across society. For example, attendees were almost exclusively white. I had travelled widely across my locality, endeavouring to reach as diverse an audience as possible, but was restricted by budget in the scope of geographic engagement for consultation. However, on reflection, sacrificing some of the engagement with those in my locality, and replacing that with meetings further afield in more ethnically diverse communities, would have added to the quality of my research approach. This was because it would have offered me opportunity for fresh thinking, based on the diverse audiences I engaged with (Moriarty *et al.,* 2007). At the same time, however, there would have been a risk of tokenism (Di Lorito *et al.,* 2017). I return to this complexity in my study's conclusions.

At four of the meetings family carers also took part in the consultation exercises. In addition to providing an approach to co-constructed knowledge (Denzin and Lincoln, 2018), this was also helpful to comprehending the relationships and wider social systems within which individuals with dementia live (Kitwood, 1997; Brooker and Latham 2016; Adams, 2008; NICE 2018). It was also possible, however, that on occasions the voice of the carer predominated, because of the format of the meetings. People frequently sat together in familial groups. Whilst recognising the valuable insights carers can offer, it is essential this is in addition to the knowledge of people living with dementia (Stockwell-Smith, Moyle, and Kellett, 2019; Fletcher, 2019). Thus I took care to personally engage with as many people living with dementia as possible when attending meetings that comprised a mixed group of attendees.

Consultation enabled me to crystallize my thoughts on the proposed research topic. It confirmed that a sense of identity was important to people living with dementia, and that the contexts of leisure, physical activity and sport were ones within which respondents felt it was important to seek meaning in relation to identity for people with dementia. I noted that this was consistent with the research literature, that solidifies linkages between sport, physical activity and identify construction (Perras, Strachan and Fortier, 2015; Fairley and Gammon, 2005; Spracklen, 2013).

Later in the year I completed two further meetings with people living with dementia to help inform and plan how my research would be conducted. Such careful planning, alongside people living with dementia, was essential to ensuring successful progression of the research, and the needs of participants living with dementia, in particular cognitive difficulties (Abendstern, *et al.,* 2019), could be recognised and addressed. One meeting was hosted by Dementia Voice, part of the Dementia Engagement and Empowerment Project (DEEP), with a focus on younger people with dementia. I organised the second meeting with the assistance of the local Alzheimer’s Society, where attendees with dementia were older. At the first meeting no family carers were present, whilst at the second carers attended and participated.

This part of the consultation recommended that my approach to the research must pay attention to environmental factors that would enable participants with dementia to feel as comfortable as possible in order to offer their insights. It also highlighted that the approach must prioritise the building of rapport with participants and attempt to equalise power dynamics in the researcher/ participant relationship. This is congruent with dementia research (Scottish Dementia Working Group, 2013; Clarke *et al.,* 2018). My analysis of the consultation recommended that an approach whereby the researcher would join in the activities at the Centres with the participant would be helpful in assisting to build rapport and trust, and potentially enable easier recall of significant information by participants.

4.3. Consultation with Centres

I defined the term leisure and fitness centres in Chapter 1. These were the places where my study would be based. I anticipated they were attractive venues within which to locate the research, because of their availability, the diversity of activities on offer, the fact potential support for participants is close at hand (via Centre Workers), their all-weather availability, and because other facilities which operate within them (e.g. cafes). Centres also have links to public and charitable organisations with whom they work in partnership (Ping Kung and Taylor, 2010), and may be, invariably, better employed within care pathways to help support people living with dementia and carers.

As my thinking progressed, however, I was struck by the advocacy of people living with dementia, calling for better-informed and more progressive use of such public spaces (Bryden, 2016). Indeed, there is little information about whether and how well Centres are inclusive of people living with dementia, and whether they can assist people to retain aspects of their identity, and perhaps negotiate new identity formation and social configurations. Their inclusion seemed especially timely because, in the context of funding shifts in community resource and sport and leisure space provision, their permanency and effectiveness cannot be guaranteed or be immune from politicisation (Local Government Association, 2017; Findlay-King *et al.,* 2018).

This influenced the adoption of one alternative type of location for research with one primary participant, Ivan. This setting described itself as a ‘fitness gym’, being privately run, without links to public or charitable partners, and providing a narrower range of activity compared with the other sites. It offered my study opportunity to investigate the engagement in activities by a person living with dementia in a slightly different setting. This was pertinent in light of the uncertainty relating to the future nature and provision of leisure services. Additionally this type of offering is becoming ever more prevalent (Andreasson and Johansson, 2014; Andreasson and Johansson, 2018). Ivan, had a rare, progressive, neurological disorder causing his dementia, corticobasal degeneration. I believed that exploring his insights in relation to the research question would be of value, and this was another motive for selecting that site. Incorporation of this type of setting led to me adopting the term leisure and fitness centres (referred to throughout as ‘Centres’) to describe the sites of my research.

Prior to the PhD my knowledge of the sports and leisure sector was minimal. I sought assistance from staff within the School of Sports and Exercise Science at the University, and colleagues within my local sports partnership charity to understand the strategic context. I judged that to be important to enable me to comprehend the contemporary nature of service provision, relevant to centres, within the United Kingdom. These conversations led to contact with the leisure centre membership organisation, Community Leisure UK (https://communityleisureuk.org/). They assisted me co-produce understanding relevant to my research by acting as the gatekeeper for a questionnaire I sent to

140 Centres in England. As well as enhancing my perception this provided a means to network, which was beneficial to the project - for example, with participant recruitment, as I will relate more fully below.

4.3.1. Questionnaires sent to leisure centres

I used a gatekeeper in order to maximise opportunity to reach respondents, and selected that organisation as it offered a broad geographical spread from across England. I used the questionnaire to open a dialogue with Centres. It was a scoping exercise that sought insight on whether people living with dementia were engaging with the activities Centres offered, and enabled me to begin to build relationships with colleagues in such settings to support the progression of the research (for example, through initiating dialogue with colleagues to seek further information on the context of their responsibilities and priorities as they related to dementia). The questionnaire was an advantageous method because I was able to design it based upon the requirements of the research (Thomas, 2013). Thus, it aimed to ascertain what Centres offered to people living with dementia, and the priority they believed such an offering should hold. It also explored the levels and nature of training received by the Centres in relation to dementia, and the sources of support they drew upon to underpin their offering. Additionally, as explained later in this chapter, this early dialogue enabled me to identify the people living with dementia who became research participants.

4.3.2. Responses to my consultation with leisure and fitness centres

Please see Appendix 3, where responses from my questionnaire are set out, with summaries relating to these. Twenty-six completed questionnaires were received, which contributed insight that was useful. However, there were limitations in my approach. For example, those Centres who responded to the questionnaire were a self-selecting group. It is possible, therefore, that respondents were interested in the subject. However, I believed that the merits of the method substantially outweighed deficiencies, not least because of the congruence the approach had with my constructivist paradigm. In keeping with the literature (Scottish Dementia Working Group, 2013; Murphy *et al.,* 2015), the method was designed to seek insight from others better placed to understand the context of my research than me, and to build, at the earliest possible stage, arrangements that would support relationships characterised by partnership and mutual understanding. For example, through the lifetime of my research I was able to keep in touch with respondents who agreed to do so. Fifteen colleagues expressed their desire to maintain contact. This informal network enabled sharing updates on the latest policy developments relevant to the research context.

I recorded responses to each question onto an Excel based template. I was also able to record dialogue from respondents relating to each question. In combination this allowed me to review the consultation and to draw from it matters most relevant to the shaping of my study. The consultation enabled me to identify the following as being relevant to my research, because they added to my understanding of the contemporary context of engagement of people living with dementia within Centres, and provision related to that (please see Appendix 3 for full detail of consultation outcomes based on questionnaire responses).

1. Recognition of dementia as a phenomenon that is of significance to the potential offering of Centres, and one they wish to engage with constructively.

2. Confirmation that people living with dementia participate in a wide range of services and activities offered within Centres, for example, swimming, exercise classes and in the gym, but also including social activities – such as use of the café. Participation happens within classes and activities for people living with dementia, and mainstream classes/ activities.

3. The physical spaces inherent to Centres were used flexibly, for example to offer activity not related to physical activity for people living with dementia. Comments indicated this included what was described as arts and crafts.

4. The feeling of respondents that Centres could offer people with dementia more, but that what they offer is insufficiently communicated/ publicised to attract participants.

5. High value placed by respondents upon working arrangements with partners such as health services, and the charity/ voluntary sector – particularly because they offer Centres support with knowledge provision about dementia, and links to other local services.

6. Although dementia is viewed as important by respondents it competes with other policy and practice priorities of Centres.

7. Staff based within Centres tended to have some knowledge about dementia, but this was limited to basic awareness briefings, rarely linked to the context and role of their workplaces.

The questionnaires also allowed me to contact respondents seeking more information. I had designed it to enable this dialogue, and it duly helped me shape my project (Sarantakos, 2013). Examples included identifying topics of relevance requiring more detailed investigation, such as exploring the value people with dementia placed upon non-physical activities, e.g. board games and use of café facilities within Centres. The dialogue also enabled me to recruit three out of the four primary participants (full information upon participant recruitment follows below). Essentially respondents offered information about the research and my contact details to people living with dementia who regularly used their Centre. This was helpful because I had anticipated difficulty in finding and recruiting primary participants, believing there would be very few people in this situation, certainly within my geographical area.

4.4 Participant recruitment

When I began my preparations to recruit participants I knew of no-one living with dementia who was engaging regularly in sport or physical activity, within the places I wanted to investigate. To enhance my understanding I carried out scoping exercises locally. I visited two Centres within twenty miles of the University and spent time talking about my research, and its aims with senior colleagues who had good knowledge of their community base. They knew anecdotally of people living with dementia who engaged with their offering but had no specific details.

At this point my recruitment criteria were relatively few and widely drawn (i.e. a person living with dementia, regularly engaging in sport/ physical activity at a leisure centre, who held mental capacity to participate in my research). I drafted the criteria thus, in part, because I felt it might be challenging to find and recruit people living with dementia who were engaging at Centres. Study of the literature indicated that whilst people might engage in leisure activity in spaces inhabited by the public (Dupuis, *et al.,* 2012), participation in vigorous physical activity in the context I also planned to investigate was rarer (Atherton, *et al.,* 2016). Additionally, having mental capacity to participate was a pre-requisite because I wanted to hear from participants themselves in as comprehensive fashion as possible about their experiences of engagement, and reflections upon that. As far as I could ascertain this study was unique, therefore I wished to hear from people who could offer the fullest informed account possible of relevant matters.

The desire to gather accounts that were as rich and comprehensive as possible lay behind my decision to recruit 4 primary research participants living with dementia. I conjectured that this sample size would offer opportunity to collect in-depth, meaningful, nuanced data collection, borne out in several interviews and observations over a long period. The richness of the data, and also the 'fit' with the nature of the phenomena/case study approach being followed, would provide the testimony to help answer my research question, and shed light upon this under-researched area, in the manner suggested by Smith (2017). Additionally the geographical context of my study, the potentially small general cohorts of accessible participants living with dementia, who also met the criteria for engagement in the activity of Centres, influenced my decision, and meant my project was set toward a small sample by nature. The actual scope went well beyond this, however, because family carers and Centre Workers were also recruited (see below). Whilst the enquiry focus was upon insight offered by participants living with dementia, these individuals contributed original understanding too, and their accounts supplied valuable contextual detail to the engagement of the primary research participants.

Early in the recruitment stage I considered an extensive approach to maximise opportunity of gathering participants living with dementia. For example, I enrolled in the ‘Join Dementia Research’ programme run by the Alzheimer’s Society, and sought help and advice from the Dementia Engagement and Empowerment Project (DEEP) – the charity which promotes and coordinates initiatives led by people with dementia in the United Kingdom. Additionally I made contact with local charities whose interest included dementia.

As mentioned above I had used the questionnaire as a vehicle through which I publicised my need for participants. Responses to the questionnaire were encouraging, particularly because respondents indicated that they knew of people with dementia engaging at their Centre. Thus, at the point of my application to the Ethics Committee for the substantive research, I designed a flow diagram of the recruitment process of participants with dementia for interviews and observations (Appendix 4). This was included as part of the ethics application which is described in detail at section 4.10 (below). Gatekeepers publicised my research at their Centre and made my contact details available to people who might have an interest in being recruited.

To support recruitment I created a flyer (Appendix 5) to enhance participant recruitment, and offer people information they could study and reflect upon. The flyer set out my recruitment criteria. I retained those set out above, but did not include reference to mental capacity. This was because until a potential respondent came forward I could not conduct an assessment of mental capacity (Department for Constitutional Affairs, 2007). I also added to the flyer a requirement to meet with other people important to the person’s situation, such as their partner (if they had one), and/ or staff members at the Centre fundamental to their engagement there.

It was essential that respondents were required to make contact with me. This was because underpinning principles of ethical research include autonomy for, and nonmaleficence towards participants at every stage (Artal and Rubenfeld, 2017; Sobočan, Bertotti, and Strom-Gottfried, 2019). In the event, all the primary participants I recruited in this manner elected that the employee at their Centre who knew them best make contact on their behalf.

One primary participant, Ivan (see above), I recruited in a different way. I became aware of Ivan as part of the discussions I had with my student peer group as we provided informal mentorship for each other. My colleague knew of him through familiarity with her local community. On an occasion when we were discussing my project and research criteria she related that she knew of someone who aligned well. My colleague took a flyer and offered to share it with Ivan. Within a few days he had contacted me via email and we agreed to meet to discuss the project.

I completed initial meetings with each of the four primary participants. At their request these were held at the Centre each attended with the exception of Ivan’s meeting, which he elected to have at his home. Ivan asked me to make arrangements with his wife for the meeting, which I did via the email address the couple provided me with. The other three primary participants asked the employee at their Centre, who had originally contacted me, to agree arrangements.

Based upon the principle of autonomy, and allied with my desire to promote co-production throughout my research, the primary participants identified those others whom I should approach with the intention of including them as participants within the research. Thus, with their informed consent, the family carer of each primary participant, and Centre Worker most closely involved with the primary participant’s engagement at the Centre, were formally engaged as research participants. One participant, Jacqui, lived alone, and was estranged from her family, thus no family carer was recruited. This also had implications for my contacts with Jacqui, where and how these took place, as I will explain below.

4.5 Arrangements for visits

The location for the majority of the research were Centres. These were buildings that were open and accessible, providing their services to the general public. However, to ensure my safety as a researcher lone working arrangements were followed, adhering to the University's policy (University of Worcester, 2012). In particular a nominated member of my supervisory team was aware of my whereabouts throughout the data collection process. Arrangements were agreed for action to be taken should I fail to notify this colleague of successful completion of visits. I also complied with the health and safety requirements of each of the three Centres that were research sites. For example, by completing an induction with a member of staff, which enabled me to engage in activity alongside every primary participant safely.

Measures were agreed to enable me to debrief after each interview, or later if required. This was important because qualitative research can place the researcher in a position where they are engaging with matters of a deeply personal or distressing nature (Morse, 2000). In the event the subject matter discussed did not result in the need for this arrangement to be activated. However, I utilised regular supervision meetings to discuss such matters. For example, the personal history of Jacqui was unsettling, due to the abuse she had experienced from family members. Discussion with my supervisors helped me make sense of what this meant within the context of the research, but also supported me in comprehending what were unpleasant details of her life. I also valued the support of my supervisory team in the decision not to visit Jacqui at home. I was concerned this was potentially oppressive. This was because it was treating her differently, as she was a single female living alone, unlike the other three primary participants who were male, living with a partner. Lone working practice forbade visits in such circumstances, however.

4.6 Qualitative interviews

Completion of participant recruitment meant I could turn my attention to seeking insight from those living with dementia, and those closest to them. In the course of my research interviews and observations were held with the four primary participants between December 2017 and September 2018. I address observations in detail below, where I also discuss the rationale for their inclusion. However, part of the reason for utilising them was because, together with my approach to interviews, they enabled me to gain an in-depth, and fuller understanding of the phenomena I investigated, and comprehension of the meaning of experiences for participants (Leverton, *et al.,* 2019).

I convened up to four interviews at intervals of approximately six to eight weeks, with each primary participant. Please see Appendix 6 for the record of data collection events with participants, and the detail and amount of data collected (which also includes time spent engaged in observations). At least one interview was conducted in the ‘go-along’ format, whereby I facilitated the interview alongside the participant whilst they were engaged in physical activity at their centre (Kusenbach, 2003). This involved me playing and/or participating in a range of sports and/or physical activities with each. These included badminton, table-tennis, darts, chair-based exercise and gym classes (both in group settings), and individual weights sessions alongside an instructor. The activity was determined by what the person chose to do. As mentioned above I also interviewed those others relevant to their engagement within the Centre (on one occasion each) within each primary participant’s social network or system. This was because understanding a person living with dementia’s lived experience is only possible if these wider social systems are explored (Adams, 2008).

The qualitative approach I used in every interview aligned with my methodology, which took a naturalistic approach and explored participant’s lives in reality (Sarantakos, 2013, p.280). The naturalistic approach adds detail and texture to the research findings (Smith and Sparkes, 2016, p.382). In the context of my research this meant that I could endeavour to really understand the experience research participants had, when engaging with activities within the Centre settings, and the meanings they drew from that. This had aspects of an ethnographic approach, rather than being ethnographic research. This was because my immersion as a researcher within the settings and alongside participants was for a relatively short period of time, and contacts were intermittent rather than being prolonged and sustained (McClelland and Giles, 2016).

The personal contact afforded by face to face interviews enabled me to build rapport with primary participants (Thomas, 2013). This was appealing as the method corresponded with my philosophical approach. It also resonated with the priorities and tenets of the phenomenology discussed in the previous chapter. For example, it was dialogic, affording opportunity for co-constructed insights. This was also true of the narrative approach I took to the first long interview I held with each primary participant. This was characterised by endeavouring to enable the story of the each participant to emerge and develop (McCracken, 1988; Hopf, 2004; Kullberg and Odzakovic, 2018). It was attractive because it enabled me to engage in active listening with participants. This is empathetic, a core part of my methodology, and is an important part of good practice when working with people living with dementia (Mason and Wilkinson, 2002). It afforded time for primary participants to gather thoughts and respond, and enabled me to recognise and note communication offered non-verbally (Scottish Working Party on Dementia, 2013).

Thus, Ivan's verbal communication was affected by symptoms of corticobasal degeneration, to the extent it sometimes took up to one minute for him to articulate a short sentence, I endeavoured to listen attentively to enable him to offer his insights as fully as possible. The reflexive techniques, detailed in the previous chapter, meant I anticipated the need to ensure I practised in this way. This was also compatible with the social citizenship focus the study took, ensuring Ivan's rights to contribute as fully as possible to the research (Fisher, 2012).

I concluded the data collection phase with primary participants, with a final interview. Through re-visiting topics covered in earlier contacts I tried to ascertain from each participant whether I had recognised the sense of what they offered. For example, feelings about participation in different activities at their centre and thoughts on how interaction with others influenced their experiences there. Once again this aligned with my paradigm, in particular elements relating to social citizenship stressing the requirement to afford people with dementia opportunity to participate as an active agent within interactive contexts (Bartlett and O’Connor 2007; Bartlett and O’Connor 2010).

I was denied opportunity to complete a final interview with Ivan, following his sad death in June 2018 (please see Chapter 5, below). I was able to attend to the purposes of concluding his involvement, however, via a meeting with his wife Jemma in the months following his passing. Indeed the significance of final interviews with primary participants was not, in the event, as great as I had anticipated. This was because, in accordance with recommended practice (Bartlett, 2012; Bartlett, Milne, and Croucher, 2019), I had placed emphasis throughout the data collection process upon understanding participant priorities. Thus, I had consistently endeavoured to recognise these within every research contact.

4.6.1 Secondary data or source consultation

Other components of my paradigm, particularly those relating to empathy for and inquisitiveness about others, led me to utilise resources produced by people with dementia and advocacy groups throughout the research. This is good practice because it enables learning already provided by people living with dementia in a research context to be incorporated (Cridland *et al.,* 2016). Thus, for example, I consulted guides produced by the Dementia Engagement and Empowerment Project (DEEP), available at, http://dementiavoices.org.uk/resources/deep-guides/. I utilised in particular their publications relating to involving people living with dementia within initiatives.

Another invaluable resource was the ‘Core Principles for involving people in research’ publication, produced by the Scottish Dementia Working Group (available at http://www.sdwg.org.uk/wp-content/uploads/2014/06/Core-Principles.pdf). This approach was especially useful in my preparation for and facilitation of interviews and observations. It meant that I arrived for each properly organised, having anticipated what was required (Bethell *et al.,* 2018). This enabled contacts to progress smoothly, resulting in stronger rapport between me and participants – a feature conducive to achieving better outcomes in research involving people living with dementia (Genoe and Dupuis, 2014). I perceived the rapport to be genuine, my belief was supported by insights offered by primary participants. For example, this comment made by Jacqui:

“Long catch up this time, and you impressed the others within the class…They were pleased with your suggested undertakings and around the togetherness we feel during these various sessions…”

Jacqui: Email from her to C.R., 48 hours after research contact at her Centre, June 2018

Jacqui’s unsolicited contact was encouraging and I felt reflected the manner with which she perceived I had engaged alongside her and the group with whom she partook in physical activity. The following comment from Paul suggested I had established rapport with him also. He said:

“It’s good when you’re here. I like seeing you”.

Paul: Go-along interview at his Centre, 8th January 2018.

4.6.2 Ensuring interview quality

Despite this positive context, the assumption that interviews can elicit respondents’ ‘experiences’ and ‘perceptions’ effectively and with integrity is one that must be treated with caution (Silverman, 2017; Thompson, 2017). Responses must be supported and complemented by the use of naturalistic data (Silverman, 2017; Kullberg and Odzakovic, 2018). Furthermore, interviews that include a focus upon the social process of interaction between interviewee and interviewer strengthen the reliability of the interview method (Silverman, 2017, p.146 and p.153). Equality between interviewee and interviewer should be the goal, even though this may not be entirely possible (Digby, Lee and Williams, 2016). I heeded this as part of my strategy to include meaningful reflexivity within my methodology.

The initial interview with each primary participant contained a greater element of structure than later meetings. This was because I wished to seek biographical detail at an early point. A strength of the unstructured interviews, of the sort I conducted later, is that its flexibility allows participants to collaborate with the researcher to identify and shape the focus of data collection (Dallos, 2012, p. 348). I endeavoured not to bring too structured an approach even to the initial interviews. I was keen to build rapport and gather biographical detail, but was aware that too much structure could impede the sort of conversational comment that would reap reward in the form of verbal insights from primary participants

(Abendstern, *et al.,* 2019). This also corresponded with the ambition to build research where findings were drawn from co-produced approaches, and aligned with the earlier discussion about the balancing of power dynamics within the research environment.

However, there is a risk that *insufficient* structure and focus may mean findings are too disparate and random to have integrity (Thomas, 2013, p.222). Thus, I had to hand written prompts prepared before every interview to ensure I was aware of what had been covered, and to alert me to omissions. Appendices 7 and 8 detail the prompts I utilised to help me structure the initial interview for each primary participant (Contact 1), and the subsequent interview (Contact 2), which was convened very shortly after each primary participant had concluded an episode of physical activity at the Centre.

4.7 Go-along interviews

I employed go-along interviews in part to try to address some of the aforementioned potential deficiencies. Their aim was to elicit data that was embodied and multi-sensorial, which the go-along method is well placed to do with people with dementia (Phinney *et al.,* 2016; Wright 2018; Kullberg and Odzakovic, 2018). Such bodily methodology engages with movement and senses to produce knowledge (Springgay and Truman, 2018). Additionally, the technique can have efficacy in the stimulation of memories and emotional responses, offering insights into participants' contexts (Smith and Sparkes, 2016). Thus, go-along interviews provided opportunity to draw upon naturalistic data to assist me answer my research question. They also enabled the interactions between myself and participant to form a social process. Congruent with my phenomenological underpinnings, both of these approaches improved the reliability of data collection from my interviews (Crotty, 1998; Moran, 2000; Cresswell, 2009).

A study, published by Hung *et al.,* (2017), employed go-along interviews to explore first-person perspectives from patients living with dementia in hospital. The article highlights how the method enables groups usually marginalised by societal attitude to be given *participant* status enabling them to contribute insight, rather than simply being passive subjects to be studied. Simultaneously, they contribute as experts by lived experience, which assists in addressing power imbalances that often characterise the accounts of the experience of those living with dementia. Engagement with a familiar environment during the interview enables participants to discuss experiences and give their views in more detail and depth (Porta *et al.,* 2016). Set against this though, the approach does not lend itself well to use in areas requiring more privacy, such as changing rooms (Hung, *et al*., 2017).

The environmental elements noted here have relevance to earlier discussions about identity and space. Thus, I tried to anticipate possible difficulties in advance of each go-along contact. For example, recognising it would be more difficult and inappropriate to seek potentially sensitive personal information from a participant within a space shared by others. My experience confirmed this was the case, particularly on the badminton court, and I adjusted my approach accordingly (see the section on Ethical Considerations, below). However, the flexibility provided by go-along interviews and the ability of the method to enable understanding of individual’s contextualised experiences were strengths. They offered opportunity to build rapport to facilitate conversation, and to tailor the interview to individual physical and cognitive abilities (Digby, Lee and Williams, 2016). The interviews also provided an effective means to help articulate identity construction and spatial experiences. This example, demonstrates Jacqui’s interaction with her environment, and how it held meaning, as we prepared for a go-along interview. Here, in relation to her social citizenship being exercised in ordinary places:

…I witnessed Jacqui coming and going across the barrier into the areas where participants would be expected to pay for activities, from where the café is…she clearly knows and is well known by the Centre team. They are on first name terms.

Jacqui: extract from research diary, 13th June 2018

Finally, as the following excerpt from an interview with Leonard illustrates, the quality of data can be enhanced via utilisation of the go-along method with people living with dementia (Kullberg and Odzakovic, 2018). I was asking him, while we played badminton, whether he was finding the method helpful in enabling recall of information relevant to my questions:

Leonard: *Yeah, cos I’m doing it.* (Leonard laughs).

Leonard: Go-along interview at his Centre, 3rd May 2018.

An additional strength of the go-along approach, shown here, is that it draws upon both verbal and paraverbal communication (Kullberg and Odzakovic, 2018).

4.8 Participant observations

There are different ways to gather data using observation, but all have in common the necessity for the researcher to watch with care what is going on in the social context they are investigating (Thomas, 2013). I used unstructured observation, where what is to be observed is not specified in detail before the study begins. These were participant observations, and as such I was part of the setting to witness and record what went on (Sarantakos, 2013). In pursuance of my constructivist research paradigm the method enabled me to gain knowledge of how participants understood their social world. It offered me opportunity to observe participants within relevant contexts, and participate alongside them within relevant activity, as recommended by Thomas (2013). One example was a session I completed alongside Ivan within an exercise class. Observations, such as this, enabled me to complement those other qualitative methods of data collection to enable fuller understanding of the phenomena under investigation (Dallos, 2012).

Observation could not directly help me explore the attitude or opinion of participants, but it did offer opportunity to observe body language and social interaction (Sarantakos, 2013, p.244). This links directly to the phenomenological underpinning discussed earlier, especially as it relates to the use of one’s body to express and negotiate meaning (Merleau-Ponty, 1962; van

Manen, 1997). This was valuable to my research particularly because two primary participants, Ivan and Paul, had reduced ability from the outset to communicate verbally due to the symptoms of dementia. The manner in which they engaged with the gym based activities (Ivan), and table tennis (Paul) enhanced my ability to understand what these experiences meant to them and for their sense of self, as suggested is the case by Bond and Corner (2001), and Kissow (2015).

Reflection upon my consultation with people living with dementia (see section 4.2, above) and upon relevant literature (Scottish Dementia Working Group, 2013; Clarke *et al.,* 2018) informed my approach to the process of data collection through observations and also go-along interviews. This meant my priorities were a minimisation of any public distinction between researcher and participant as activity took place, and the capturing of insights as close to the moment of engagement as possible. My intention was to forge relationships so that I engaged alongside participants as a fellow player as fully as I was able, and to enable my focus to be upon recognising comments and incidents to my enquiry. This presented challenges related to how data were recorded. For example, I could not carry notepads with me as I took part in observations or go-along interviews. Also, I did not wish to attach recording equipment to my person, anticipating this would influence my own approach to play, and also feeling uncertain about the quality of sound captured within physical venues whose acoustic qualities were unreliable. Thus, my technique involved engaging in activity, whilst observing and/or conducting a go-along interview, and using breaks in play to make brief bullet point notes on small ‘post-it’ notes that I kept with my spare clothing, close by. By utilising the natural breaks taken in play I did not disturb the rhythm and flow of a game. At the conclusion of every research episode, but only as soon as the moment felt right in terms of showing respect for the participant in question, I left the immediate setting with the intention of refilling my water bottle. I then found a quiet space close by within the Centre and added detail to every bullet point I had previously made, this time using a larger notepad. If I was unsure of any detail I reflected upon this with the participant in in conversation on my return. Finally, at the end of every visit, after I had taken my leave of everybody, I sat quietly in the car, or on the train home, and reviewed my bullet points and fuller notes in order to complete a final record of the observation/ go-along interview.

Having discussed how my research methods enabled the gathering of information, I now turn to the discussion of how I analysed my data, and the rationale for my approach.

4.9 Data Analysis: Thematic Analysis

4.9.1 My approach to the analysis of the research data

I utilised thematic analysis because it offered a mechanism through which the insights and experiential wisdom of participants could be scrutinised, considered, and understood. Thematic analysis is a well-regarded method for analysing qualitative data, and can be applied in a flexible manner to suit the requirements of projects such as mine (Braun and Clarke, 2006; Braun and Clarke, 2013). The approach also aligned with the phenomenological basis of my study, particularly because the theoretical flexibility of Braun and Clarke’s thematic analysis (2006) fitted with hermeneutic phenomenology. This was because my understanding developed as the analysis process made progress (Fleming, Gaidys and Robb, 2003). It also meant I could consider my data in its totality and also in its component parts iteratively throughout analysis, in the manner of the hermeneutic circle (Debesay, Nåden and Slettebø, 2008). The systematic approach to thematic analysis has been shown to be beneficial within research involving people living with dementia (Lindelof *et al.,* 2017).

I had some limited experience of using thematic analysis for a previous small-scale project in a related area (Russell, 2016). However, I did not accept this approach to analysis naively and without due consideration. Thematic analysis has been criticised for a lack of rigour (Boyatzis, 1998). To help address this, following the advice of Braun and Clarke (2006), I designed and employed an approach that included transparent stages that could be audited by others. I created an auditable process for my analysis at the point it began, and maintained it throughout. Giving insufficient attention to explaining and presenting how analysis is carried out is a major criticism of qualitative studies (Jones, 2015), and I was keen to avoid this.

Critique of thematic analysis highlights a risk that the researcher can be beguiled into affording undue authority to codes, i.e. units of meaning assigned to data (Jones, 2015), which reoccur often, to the detriment of those which appear less frequently but carry important meaning (Buetow, 2010). To help address this I utilised an approach known as saliency analysis (Buetow, 2010). This places emphasis upon codes that progress understanding but might not be repeated frequently throughout the data (Buetow, 2010). As I planned my approach this technique was reassuring because my research was interested in understanding the unique insights of every participant. Thus, if perception was only offered fleetingly, or rarely, I had a means to consider it.

4.9.1.2 Discounting the use of a qualitative data analysis software package

I discounted the use of a qualitative data analysis computer software package, for example NVivo, to assist with analysis. In light of the volume and complexity of my data it was possible that this might have helped me manage and thus analyse what I had gathered.

However, I desired to stay as close to the data as possible (Jones *et al.*, 2013), because my study was about identity, a significantly personal concept in understanding our existential selves. Allied to this, my phenomenological approach meant I consistently set out to understand the data holistically and in as much detail as possible. In large part this was to enable new knowledge to be co-created between me and my participants. This meant taking an open phenomenological stance to comprehend the nature of participants' experience in the fullest context of their lives (Fleming, Gaidys and Robb, 2003; Starks and Trinidad, 2007; Finlay, 2011). Thus, I wanted my analysis to take account of all the sources of data, and be sensitive enough to register and utilise the nuanced articulation of participants, including their body language and paraverbal communication. I was seeking true dialogic engagement with the data (Hoskins and White, 2013). The following entry from my research diary illustrated my reflections on the significance of this:

“…*I note body language and facial expression are playing a more significant part in Ivan’s data context than I anticipated…in terms of… the depth of meaning and insight I believe these afford. I am also struck by the significance of accentuation placed on certain words by Jacqui, for example, when she said in relation to her approach to life, “I did it because it was* <u>*there*</u>…”

Extract from research diary, November 2018

Being sensitive to the meaning offered by participants also included personally identifying any raw data that appeared to run contrary to what I might have expected to find (Jones, 2015), to avoid subconsciously seeking only positive reflections from individuals on their engagement. For example, during one interview Paul said he had found playing table tennis boring. This contradicted what I had observed of his body language during the game. Reflecting on this, I noted that his comment came immediately after he had disagreed with a statement his wife had made. I believe Paul was cross in that moment, and used his response to show that. I was not confident a software package could address these features and distinctions, when compared to my own endeavours

Additionally, I had transcribed every interview. This had taken time I might have utilised differently had I decided to employ a colleague to complete this task. However, I had been determined to complete transcription personally to add to my ability to become familiar with the data. Thus, it made little sense at the point of formal analysis to introduce a mechanical process which might serve to distance myself from the research (Jones, 2015). Therefore, despite recognising merits of mechanised approaches I analysed my data manually.

4.9.1.3 Phases of Analysis

The six phases and articulation of the actions I took in pursuance of the thematic analysis of my data, are now presented.

Phase 1: Familiarising self with the data

I began construction of the record of the data through completion of what I termed, the ‘Data Analysis Phases 1 and 2’ document’ (hereafter referred to as Analysis Document). Here I noted down the sections of data relating to individual participants and the aims of the research, as suggested by Braun, Clarke and Weate (2016). This also enabled me to familiarise myself with the data. The document was completed through a time-consuming and rigorous process of highlighting and recording extracts from the data for every research participant (including the participants who were family carers or Centre Workers) which might have relevance in terms of the research question. Writing and re-writing in this way is part of hermeneutic phenomenological analysis, and it helped me distil meaning (van Manen, 1997).

Thus, I began phase 1 by reading and re-reading all interview transcripts and accounts of observations and copies of my field notes I had kept throughout data collection. This entailed trying to immerse myself as deeply as possible in the data, endeavouring to familiarise myself intimately with the content (Braun *et al.,* 2016). Such early stages of analysis have been described as naıve reading (Ricoeur, 1976; Dreyer and Pedersen, 2009). However, I was already considering the matters I was noting critically (Braun, Clarke and Weate, 2016). For example through designing the Analysis Document so that its structure leant itself to my developing analysis. Thus, setting out its main heading to encourage me to note what interested me in relation to the data for each primary participant, in line with practice articulated by Braun, Clarke and Weate (2016).

I also listened again to every interview and checked every transcript for accuracy against this original record. Additionally, I re-read my research diary. This enabled me to re-visit aspects of analysis I had engaged in as data collection had progressed. I had used my research diary to reflect on each interview and/ or observation, recording insights I felt might be relevant to the research question, and/ or examples relevant to the experiences of people living with dementia engaging in activity within their Centre. As data collection progressed this had allowed me to refine and construct questions and areas for enquiry in dynamic fashion. Now, however, the approach offered opportunity not only to familiarise myself with my data but also contributed to analysis, for example, through enabling me to be alert to theory that might help interpretation of the data (Jones *et al.*, 2013).

Through actively and analytically engaging with the research question, transcripts of interviews, accounts of observations, field notes and passages of my research diary, a large amount of qualitative data was produced. I used the Analysis Document to make note of every tract with potential relevance, adding

‘Initial Reflections’ (‘I.R.s’). These were one, sometimes more, tentative and speculative reflection(s) on how this particular chunk of data might add to my understanding of the research question. Subsequently I gathered all of the I.R.’s relating to each participant living with dementia. I listed those notes towards the conclusion of each primary participant’s section of the document. Finally, I re-read all those chunks of data, and their accompanying I.R.’s, and used my reflections to construct a section in the ‘Analysis Document’ for each participant with dementia entitled, ‘Summary Of Ideas and concepts that can help address my research question’. This enabled me to enhance my familiarity with the data, and begin to sharpen the focus of my analysis by considering some of the broader strands of content that I had noted as part of the first phase of analysis.

The process of recording potentially relevant insights from chunks of the data, and trying to offer provisional reflections on what they might mean enabled me to begin the process of data reduction. This was through the generation of codes from the data. I noted reflections upon my experience of analysis to this point within my research diary:

“…phase 1 and phase 2 of analysis have moved together as analysis continues. This dynamic overlay and blending is anticipated by the literature”.

Extract from research diary, April 2019

Phase 2: Generating initial codes

As I began phase 2 of analysis I re-read the entire Analysis Document and the data transcripts and records for every participant. I did so because the process of analysis and passage of time meant I had not studied participant data in depth for a short while. Reflecting on the data thus, and upon my I.R's I created a new set of summary notes for each primary participant. This activity assisted my familiarisation with the data set, enabled me to begin to sharpen my understanding of the insights of research participants, and think how these might be relevant to the coded data.

As previously indicated 'codes' are labels or units of meaning that can be given to pieces of data (Jones, 2015). Because of the phenomenological foundations of my study I had planned to use participants' own terms for the title of each code. In reality I did so where I could. Frequently this was impossible because the symptoms of dementia had impeded participants' ability to articulate phrases succinct enough to be used in this way. Where I could not use participants' phrases I attempted to employ alternatives that my knowledge of the person implied they might have used, or a form of my own words I judged communicated the meaning the participant had offered. I based these upon the vocabulary that I had heard that person use over the months that I got to know them. My priority, though, was to capture the essential meaning of what had been said by the participant. This aligned to my emphasis in the study upon co-created data, and meant that I adhered to practice that was data-driven rather than risk over-emphasis upon my own pre-conceptions of findings (Fleming, Gaidys and Robb, 2003). In addition, whilst theoretical considerations could be considered and applied to the analysis, the voices and insights of participants would have priority.

I utilised a system of coding that set out to gather insights offered by research participants drawn from their experiences of engaging in activity at Centres, and reflections upon those (Morse, 2010). Every line of my transcribed text for each of the qualitative interviews was numbered, and for those go-along interviews where the participant offered a significant level of verbal data. Phase 1 allowed me to record both small parts of the data referred to by Braun and Clarke (2006) as ‘data items’ and at other times larger chunks of data, referred to as ‘data extracts’. During phase 2 I progressed analysis and data management by re-reading the Analysis Document and began an electronic ‘cut and paste’ exercise from its contents. A system of ‘open coding’ was utilised to help facilitate this.

To ensure I achieved the rigorous and auditable process required I gave each research participant a unique number. This number was attributed to the same participant throughout analysis. Additionally, every interview was accorded a number that related to the order it occurred with the participant in question. So, for example, the first interview with Ivan (Participant 1) would be recorded as ‘1’ and when recorded alongside him within the analysis process it would be titled as 1/1. Finally, any salient point accruing from each interview would be coded with a unique third number, drawn from the line number(s) of the transcribed interview. Therefore, for example, for Ivan, the first point of potential relevance to the research question in his first interview, if it came within the first line of that, would be coded 1/1/1. In this way an auditable trail could be followed throughout the coding of data (Braun and Clarke, 2006). Data that were irrelevant to the research question were not coded and left out of analysis (Braun and Clarke, 2013).

There were difficulties related to this process. For example, determining what data to retain amongst a voluminous amount of information. Doing as Holloway and Galvin (2017) recommend, however, and keeping a focus upon the research question, assisted me make decisions relating to this.

With regards to more informal data capture, for example go-along interviews where little was said/ or where my notes were more general than specific, and in my observations, I adopted a less structured approach. Here, I recorded and included chunks of textual notes I had made within the overall record of data that I thought might have relevance to the research question. This was because potential insights had emerged organically as part of data capture.

Observational notations, and brief passages of dialogue did not lend themselves well to the more rigid break down, as characterised by my approach to the formal transcripts, thus they were not coded in the same numeric manner with line numbers. A structured, formulaic approach to coding would not work well in relation to what were essentially ethnographic conversations and observations. However, I carefully went through this data, sorting passages manually and recording each extract clearly so that I was then able to correlate these excerpts to the codes from my formal transcripts. They were given titles so I could do this. For example, ‘From Observation, with Ivan at his gym, 16.12.17’, and were recorded in the Analysis Document.

This approach allowed me to pull out and group my observational notes accordingly. To some degree this data was approached as a form of narrative analysis, where I let data speak for itself, through fragments of the stories told by participants of their experiences (Floersch, *et al.,* 2010). I also incorporated ‘snap-shots’ from my research diary notes to help illustrate the way such data was captured and richness of the data. The advantage of this included allowing at points in the thesis a confluence of participant experience and my own researcher reflexivity.

By utilising the system of coding detailed earlier I was able to follow a data-driven approach to analysis (Braun and Clarke, 2006). The merits of this included adhering to and prioritising the participants’ voice and their interpretation of experience. I also utilised my understanding of social citizenship, and the phenomenological philosophy that I adopted to enable me to understand better the meaning of experiences and of embodied communication. Thus, as the researcher I continued to keep this in mind as I made progress with my analysis, all the time trying to be mindful that it was the meaning participants gave to their experiences rather than my own pre-judgements that must be the priority. Taken together this approach meant I was able to maintain a systematic engagement with the data and offer a clear and auditable account of my analysis (Jones, 2015).

Phase 3: Searching for themes

Themes are core ideas in the data, linked by a common thread, which bring meaning to what is being investigated (Jones *et al*., 2103; Nowell *et al*., 2017). They move beyond the understanding provided by codes because their construction requires evaluation and judgement by the researcher. This is informed by the researcher's understanding of the phenomenon being investigated (Jones, *et al.,* 2013). During Phases 3 and 4 I completed the process of data reduction. In a similar fashion to earlier phases of analysis this took time. However, I was assisted because what I had already achieved in phases 1 and 2 meant I was familiar with my data, in its entirety and component parts.

In Phase 3 I retained emphasis upon hearing and recognising the insights offered to me by every participant, as well as their interpretation of their experience. However, I also used my own professional understanding of the lived experience of dementia, knowledge of relevant literature and theory to guide me in the creation of themes. In particular my understanding of the significance of participation within, and contribution to the society of which participants were a part, and the societal barriers they would face as they did so (Genoe and Dupuis, 2014; Birt *et al*., 2017; Bartlett and O'Connor, 2007; Bartlett and O'Connor, 2010; Bartlett, 2016; Bartlett and Brannelly, 2019a). Social citizenship, for example, offered me a holistic understanding of how people living with dementia should expect their personhood, agency and rights to be enacted and celebrated within the communal spaces and activities I was encountering them.

In Phase 3 I organised potential first-order and then higher-order themes via a cut and paste sorting exercise which I completed electronically utilising my Analysis Document. I structured this so that themes were created in relation to each of the four participants living with dementia. This was done to adhere to a person-centred focus of the research, i.e. to understand the perspective of the individual, which is essential to ensure unique insights are not disregarded (Thomas and Milligan, 2018). I applied techniques of saliency analysis at this point (Buetow, 2010). For example, where participant, Paul, demonstrated his sense of humour through action rather than speech, and thus instances of his humour were not reflected in the number of codes.

Braun and Clarke (2006) counsel that recoding might be necessary during later phases of analysis. Indeed this might be expected as the researcher's understanding of the data improves. This was my experience. For example, an entry from my research diary related my revised judgement regarding research participant Jacqui. It recorded how upon re-familiarising myself with aspects of her second interview (i.e. 4/2) I had initially missed the potential significance of a sense of aspiration she held in relation to engaging in physical activity. It was only after my familiarity had increased with the data, and my understanding of what that might mean for participants in relation to the research question, that I understood the potential significance and importance of this example and others like it.

In order to create themes that aligned well with both the data in its particular parts and also as a whole, I reread both summary sections from the Analysis

Document relating to each of the four primary participants. I made notes on what impressed me as significant in terms of the broad data topics captured within the summaries. For example, I noted that for participant Ivan, “The social side of Ivan’s life registers most strongly.” After reading both summaries and making these notes for each of the four participants I re-read the codes I had created for each, and the accompanying informal data captures. This assisted me check the alignment between codes and data. In this way I was better able to identify deficits and take remedial action to ensure information of relevance to the research question was included. I used reflections such as these to revisit the themes I had constructed for each participant, and to ensure as far as I possibly could that the themes contributed to the analysis of my participants’ narratives. At this point I also noted that my own knowledge and experience were playing an important part in the analysis.

“…there is no way I can divorce what I bring…I believe I should not attempt to do so either, because what I can contribute (through previous experience and theoretical awareness) is relevant and helpful to my understanding...”

Extract from research diary, May 2019

All of this allowed me to construct an initial thematic map for each of the four primary participants (the final version of which is set out in the following chapter).

Phase 4: Reviewing themes

During Phase 4 I refined the initial thematic maps of the data for each of the four primary participants, and themes underpinning them. At this stage of a thematic analysis it is possible to include other themes too if they relate directly to the research question, but I chose not to do so judging this was unnecessary. I carried out an audit to gauge dependability by checking whether higher and first-order themes made sense, were coherent in terms of the research question, and had been drawn from the experiences of participants. In triangulation with the research literature, detailed within chapters 1 and 2, and my theoretical understanding of social citizenship and phenomenology as outlined above, I felt that every theme was manifestly distinct in its own right. I was thus able to confirm its title, define it, and be able to describe its content and scope. To note, I did not organise themes hierarchically. This was because there was overlap between them. Additionally I believe that analysis of a phenomenon as nuanced as identity legislates against arbitrarily compartmentalising its components. The principles of saliency analysis also guided me to place emphasis upon themes that progressed understanding related to my subject matter.

Phase 5: Defining and naming themes

In phase five, I finalised the name of every theme. Once again I attempted to employ the words of primary participants, or phrases that might communicate their desired meaning. This accorded with person centred and phenomenological approach, i.e. in particular to demonstrate uniqueness.

Two themes, loss and continuity, I classified as ‘over-arching themes’. Additionally, as the researcher, and the ‘instrument for analysis’ (Starks and Trinidad, 2007), I utilised my knowledge of participants, and of the literature and theory (especially as it related to identity formation, personhood and social citizenship in dementia), alongside my analysis, to create one word themes applicable to individual primary participants: sociability, freedom, resilience and authenticity. These I classified as ‘core identity themes’. They epitomised what people had always valued about themselves, and how that continued through their engagement in sport/ physical activity. They represented aspects of primary participant identity strongly from my analysis (Thomas and Milligan, 2018). However, every one of the four primary participant accounts reflected the significance of each core themes to some extent. My discussion of the analysis over the subsequent two chapters explores this.

Phase 6: Producing the account

My goal was production of a textual account that formed a coherent picture of the whole of the data for each primary participant. To achieve this I revisited the research question and linked it back to my analysis of the data (Mason, 2002). At this final stage of analysis the congruence of the design of the study, alongside its theoretical and philosophical frameworks, methods and data analysis of data must synergise to result in a robust and trustworthy report (Mason, 2002). My account is set out in the following two chapters.

4.10 Ethical considerations

Ethical approval for my study was gained from the Health and Science Research Ethics Committee at the University of Worcester (reference numbers: SH16170011-R & SH16170025-R1). Chronological and distinct applications were made so that the questionnaire (first application) would precede, and thus help inform, the interviews and observations (second application). See Appendix Numbers 11 and 12.

In relation to the second application, I clarified and confirmed arrangements relating to the awareness others might gain within the public spaces, that Centres constitute, that primary participants had dementia, and ways I would safeguard this knowledge. My belief, extending from the recruitment of participants living with dementia, throughout the data gathering phase, was that it could not be my role to disclose a diagnosis of dementia on behalf of a participant to any third party if this was not their wish. Offering research participants with dementia choice and control in relation to such matters is an essential part of good practice, thus this was necessary and important within the ethical context of the study (Murphy, *et al.* 2015; Rivett, 2017).

I discussed the issue with local gatekeepers at the recruitment stage. Arrangements were agreed so that potential research participants could contact me discretely in these circumstances, so that I could offer reassurances that they would not be identified by me as having dementia during the research. I undertook not to disclose anyone’s illness during any part of the research. In fact, every primary participant related that their happiness to be open and transparent about their diagnosis throughout, so this did not prove to be an issue.

The public nature of the spaces within which I conducted my research gave rise to a second key ethical issue. This related to the observational and go-along components of the research. I understood that I must inform other attendees in my vicinity that I was carrying out research, and offer them opportunity to consent to my presence (Steinsbekk, Kåre Myskja, and Solberg, 2013), for example those others within exercise classes. To address this I drafted a half-page document entitled, ‘Summary of Research for Observations’ (Appendix 15). This gave broad details of my research, but did not identify any research participant. It highlighted the focus my study had on understanding people’s experiences of attending centres. I asked each of the primary participants their opinion on the document’s content, giving opportunity for amendment to be made. No one wanted changes and were happy for me to use it.

What transpired as more pertinent to ethical practice was what I experienced once the go-along interview component of the research was underway. I found that when playing badminton, for example, it was difficult to have conversations with participants without the risk that others might overhear. The literature had warned me to anticipate this (Hung *et al.,* 2017). However, until I undertook the interviews I did not fully understand the impact. Conscious of the essential ethical principle of beneficence I did not want to compromise the personal information being shared (Pesonen, Remes, and Isola, 2011). Thus, on occasion, I had to curtail conversation, saving verbal enquiry for the next convenient moment, usually a drinks break. Because these were interspersed frequently, I do not believe this impeded the quality of these research encounters.

Throughout, I gave considerable thought and attention to the ability of each primary participant to make informed decisions. A criterion for recruitment was that participants entering the study should have full mental capacity in relation to it, for reasons I detailed above. This meant close adherence to law and policy relating to mental capacity throughout the research, in particular the Mental Capacity Act 2005, and its Code of Practice, which includes safeguards and controls in relation to research participants with dementia (Department for Constitutional Affairs, 2007). The Code of Practice offered guidance on practice should a participant relinquish mental capacity to engage during the research. Once I had recruited participants living with dementia I did not want to lose their insight and contribution. I anticipated the value the participant would have already brought to the study and I did not want to surrender their ongoing input unless unavoidable (Cridland *et al*., 2016; Brooks, Savitch, and Gridley, 2016). Thus, I instituted arrangements to involve a consultee should a participant lose mental capacity, whereby a person close to the participant would help determine whether they wished to remain involved and to what extent (Department for Constitutional Affairs, 2007). In the event this proved unnecessary, because every participant retained capacity to make decisions relevant to the research throughout.

There was one primary participant, Paul, with whom I felt matters relating to mental capacity were especially pertinent, because the symptoms of Alzheimer’s disease had an impact upon his memory. Thus, when with him I took additional care to abide by the provisions of the Code of Practice, and reflect upon my experience of working with people with dementia, to ensure I never progressed research activity for which Paul lacked the mental capacity to engage in.

The final ethical consideration arose during the process for the second application. The committee were concerned that consent was gained from participants living with dementia in a manner that accorded with their procedure. This meant I was obliged to supply participants with paperwork that complied with such regulations. I had concerns about this, because in several respects I felt this hindered the ability of potential primary participants to understand what I was asking them (especially the use of very long participant information sheets), and thus reduce the likelihood they might participate. See Appendix 13.
This was a social justice issue as well as an ethical one, because the research process should work in ways that encourage people living with dementia to feel they want to participate in research (Mann and Hung, 2018; Bartlett, Milne, and Croucher, 2019).

In addition, the committee insisted that consent forms were initialled in multiple places by participants with dementia (See Appendix 14, where the consent form is presented). I anticipated this might cause difficulty if a person had problems with manual dexterity. I took advice from my supervisory team and from a senior researcher at the University. Despite their support the Committee were not persuaded, however, to enable me to make changes, such as using a more succinct information sheet for participants living with dementia, or video recording consent.

Thus, I took particular care to make sure that every primary participant did indeed understand what was contained on the information sheet. We discussed the requirements and consequences of participation together in as much detail and for as long as each participant needed. I made sure this was done on each occasion I met with every participant. When one participant, Ivan, signed his consent, he did experience difficulty with dexterity. Thus, we took several breaks, and I endeavoured to reduce any feelings of pressure he might feel. However, this remained uncomfortable for everyone involved. These complexities within the ethical approval process, rooted in bureaucracy rather than in meeting the needs of participants living with dementia (Bartlett*, et al.,* 2018), appeared unnecessary to me, and potentially harmful to participants. Thus, I return to this matter in my study's conclusion, setting out recommendations to improve practice.

4.11 Conclusion

In this chapter I have discussed how I consulted with people living with dementia, family carers and people involved in the delivery of sports and physical activity, in order to inform and shape my project. I then detailed how I went about recruitment of research participants. The chapter continued with the rationale for and application of my chosen research methods, and progressed to discuss how I analysed my data, and the reasons I adopted that approach. Finally, the chapter explored my engagement with the ethical considerations within my research. In the following chapter I introduce the participants in the research, and relate primary participants’ experience of engaging at their Centre. I then analyse how this may have influenced each in the maintenance and development of their identity.

Chapter 5: Findings: Primary Participant Stories

5.1 Introduction to the chapter

In this chapter I present the study findings as they relate to the four primary research participants Ivan, Paul, Leonard and Jacqui[1]. I introduce each person in turn, with a summary of their life story up until my research commenced. The focus of interest is to understand whether and how engagement with the Centres each attended, and the activities on offer there, influenced their identity. I use this focus to help me explore what each person told and showed me, and what we discussed together concerning their identity, often when alongside each other engaging in physical activity. Finally, I provide a summary for each person, which draws together my analysis of the data relating to them. To aid understanding, the presentation of my analysis includes a thematic map illustrating analysis for every primary participant. I begin the chapter with an overview (Table 3, below) summarising key information about the primary participants, their relationship with other research participants, and their engagement with the offering of the Centre they attended.

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[1] Each participant is given a pseudonym, as are the names of every place mentioned.

Table 3: Detailing primary research participants, their relationships, Centre details, and basis of engagement.

Primary Participant, age at start of data collection, and dates engaged in data collection	**Diagnosis**	**Family Carer**	**Centre Worker(s)**	**Leisure and Fitness Centre, and its offering**	**Basis of engagement at Centre**
Ivan, 64 years old 12 December 2017 - 10 April 2018	Corticobasal Degeneration	Jemma (wife)	Kyle	Situated in Krowle (West Midlands of England). Gym, exercise classes, swimming pool.	1:1 fitness and conditioning, twice weekly. Group exercise classes, twice weekly.

Primary Participant, age at start of data collection, and dates engaged in data collection	**Diagnosis**	**Family Carer**	**Centre Worker(s)**	**Leisure and Fitness Centre, and its offering**	**Basis of engagement at Centre**
Paul, 79 years old 11 November 2017- 3 May 2018	Alzheimer’s Disease	Connie (wife)	Martin and Jane	Situated in Arby (South-West England). Gym, exercise classes, swimming pool, multiple sports (e.g. badminton), café.	Weekly group facilitated at centre for people living with dementia.

Primary Participant, age at start of data collection, and dates engaged in data collection	Diagnosis	Family Carer	Centre Worker(s)	Leisure and Fitness Centre, and its offering	Basis of engagement at Centre
Leonard, 59 years old 19 December 2017 – 2 July 2018	Posterior Cortical Atrophy	Caroline (wife)	Martin and Jane	Situated in Arby (South-West England). Gym, exercise classes, swimming pool, multiple sports (e.g. badminton), café.	Weekly at group for people living with dementia, including badminton. Additionally, badminton and swimming through week. Meals at café.

Primary Participant, age at start of data collection, and dates engaged in data collection	Diagnosis	Family Carer	Centre Worker(s)	Leisure and Fitness Centre, and its offering	Basis of engagement at Centre
Jacqui, 63 years old 7 December 2017 – 4 October 2018	Dementia with Lewy bodies	None	Patrick	Situated in Warkham (West Midlands of England) Gym, exercise classes, swimming pool, multiple sports (e.g. badminton), café.	Group exercise classes twice weekly. Occasional swims and use of gym in the week. Organised walk, weekly.

5.2.1 Ivan

Early Family Life

Ivan was born in 1953, and he was sixty-four years old at the time the research started. He grew up in a city in the West Midlands of England, Denham. An only-child, he described a happy and settled early-life where he was raised by his parents and extended family. His mother ran a hairdressers' business, his father a newsagents. Ivan spent time in both establishments as he grew up, and therefore got to know people well within his local community. Ivan moved to University in his early twenties, located within twenty miles of his home. He lived there during term-time, but retained regular contact with friends and family in Denham. Upon graduation his employment took him only a little farther afield, as I will detail below.

Leisure and Physical Activity

Participating in and spectating at sporting events were constants in Ivan's life from childhood. Initially this involved being part of school football teams, progressing to playing in University standard football, rugby and cricket teams, the latter providing the opportunity to engage with a county level trial with his local team, Blakehamshire, whilst at University. He was unsuccessful but continued playing sport, in particular five-a-side football, into his late fifties. Ivan supported his local professional football club all his life, Denham United. By coincidence this was the same club I have always supported, and we chatted about our shared experiences at points during the research. Ivan was taken to watch the team by uncles when a child, and he continued as a season ticket holder throughout his life; initially with family members but increasingly with friends, several of whom were lifelong companions.

Adulthood and Employment

Ivan graduated from University as a dentist. He practised in the same urban community, which was twenty miles from where he grew up, until he retired on grounds of ill health (caused by dementia) in his late-fifties.

After his first marriage ended in divorce when he was in his forties, he married Jemma. The couple had a shared interest in sports and physical activity, which included running after work and attendance at the gym of his local fitness centre. During these years Ivan attended football matches with his daughter, from his first marriage. She was a similarly dedicated Denham United fan, and the only child Ivan had.

Dementia and Contemporary Life

Diagnosing Ivan’s dementia was difficult, partly because concerns arose when he was relatively young, fifty-seven, and because his symptoms were unusual. Diagnosed as corticobasal degeneration, the illness meant that Ivan had increasing difficulty with speech, and with his movement and dexterity. Ivan remained able to remember events with relative clarity, but struggled to articulate them in detail because of the significant problems with verbal communication caused by the corticobasal degeneration. For example, when we met Ivan knew what he wished to say, but often could not provide more than one word answers to questions. If he attempted to offer longer explanations his sentences would frequently be characterised by words which were jumbled and made little sense together.

Following diagnosis he continued to engage in physical activity, usually alongside Jemma, at the fitness centre in Krowle he had attended for over ten years. This was the context for the research. Here he trained with Kyle, a personal fitness trainer, often on two days every week, and also attended up to two group fitness classes on a weekly basis, which were available to the membership of his Centre. Kyle was a participant in the research because of his involvement with Ivan at the centre. Additionally Ivan attended a local professional rugby club which offered weekly exercise and social activities for people living with dementia. I met him there often in my role as a volunteer. Ivan passed away four months after his sixty-fifth birthday (in June 2018) for reasons linked to his dementia. He had continued to engage in physical activity and attend Denham United matches until the final weeks of his life. He had made a fulsome contribution to the research, by participating in several observations and interviews.

5.2.2 Ivan's thematic overview

The thematic map in Figure 3 illustrates my analysis of Ivan's data. This incorporates his core identity theme (shown in the green box, in centre), two higher order themes (blue, larger circles), and the eight first-order themes (orange, smaller circles) which inform the analysis. The commentary which follows addresses both higher-order themes in turn and sets out my analysis in detail.

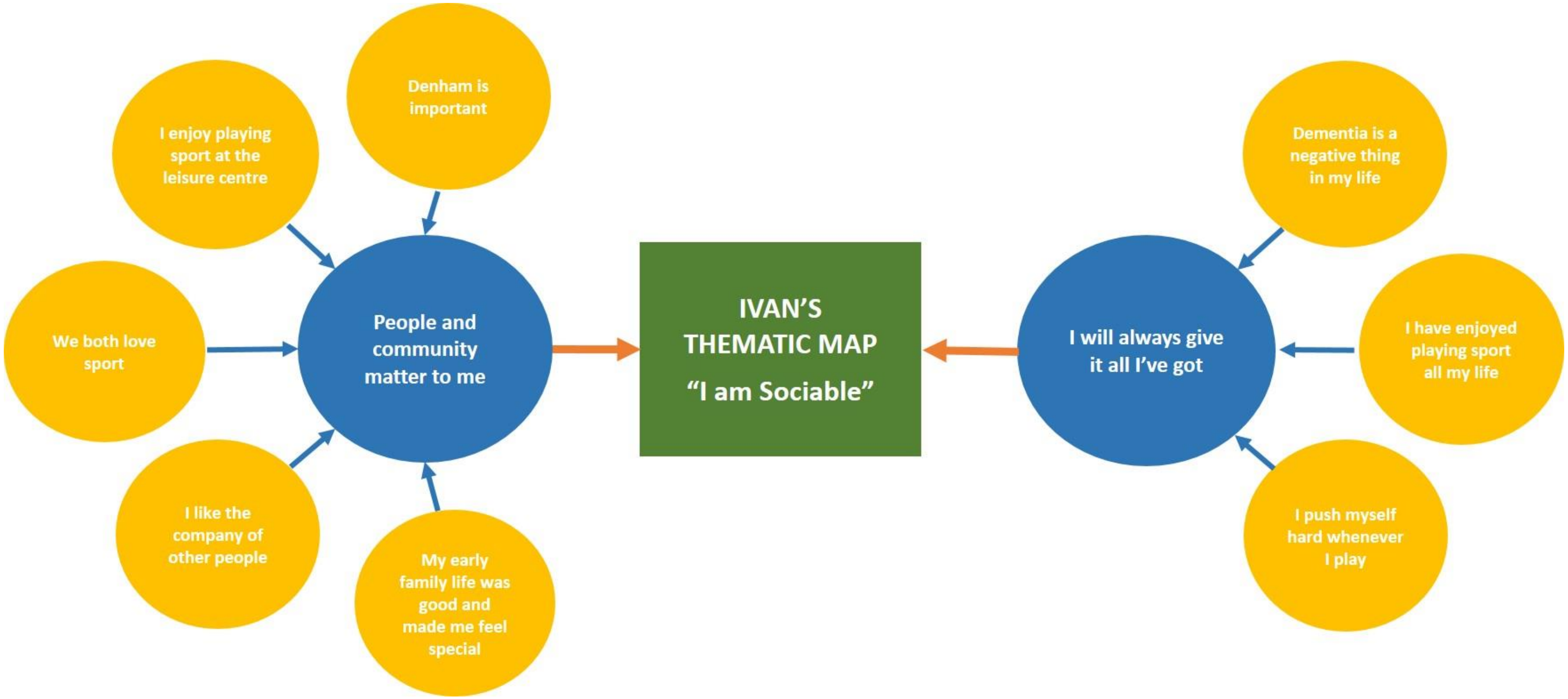

Figure 3: Schematic representation (thematic map) of core, higher order and first order themes for Ivan in the maintenance and development of his identity.

The impact of the corticobasal degeneration meant that how Ivan experienced the world through his senses and his body was significant to shaping his identity. The observations I recorded help illustrate this, as I will show as the sections relating to Ivan continue, below. The ideas and arguments put forward by scholars, detailed in Chapter 3, relating to corporeal meaning making and embodied consciousness, (Merleau-Ponty, 1962; van Manen, 1997; Bakewell, 2017; Hockey and Collinson, 2007) pertained to this. The importance of one's experiential self was highlighted by Tregaskis (2003), Brown (2017), and Wright (2018). The former discussing this in the context of physical disability, the latter authors with a focus upon dementia.

5.2.3 'People and community matter to me'

This was the first of the two higher-order themes relating to how Ivan's identity was influenced by his engagement with the Centre he attended. It is underpinned by five first-order themes:

1. My early family life was good and made me feel special
2. I like the company of other people
3. Denham is important
4. We both love sport
5. I enjoy doing physical activity at the fitness centre

This higher-order theme demonstrated how important the relationships Ivan had with people, and the settings within which these took place, had been to how he has constructed his identity. Engagement with activities at his Centre had enabled this to continue in important ways since he became unwell.

5.2.3.1 My early family life was good and made me feel special

Ivan's physical and emotional experiences had contributed to how he perceived himself as far back as childhood times. For example, here he is describing how playing football with his friends was a regular and significant part of his formative life:

"…it was a bunch of people…to play with…because there was always a lot…you come during the holidays and you never went without something…so they would come from school…so brilliant."

Ivan: interview at home, 12th December 2017.

The symptoms of the corticobasal degeneration had made speech very difficult for Ivan, but he discussed how being with people in his home community had mattered. For example, recounting here time spent playing sport with childhood friends in his neighbourhood.

CR: *Was it good fun?*
Ivan: *It was*.
CR: …*being with the others and*…
Ivan: *Yeah* (very long pause, Ivan is reflecting)

Ivan: interview at home, 12th December 2017.

5.2.3.2 I like the company of other people

Enjoying the company of others extended from his earliest times into later phases of Ivan’s life. Many times I observed Ivan doing what Tregaskis (2003) described; through physical activity dispensing with speech and being himself. Brown (2017) related that symptoms of dementia mean people increasingly rely upon experiences to demonstrate and inform their identity. I witnessed that he was able to do this, and, as Weiss (2001) suggested, utilise his embodied skills to support his identity. For Ivan this was through what he did within the gym and exercise classes. For example:

‘…one other gym user greeted Ivan warmly as they passed with a big smile. Ivan nodded to her in recognition.’

Ivan: observation at his Centre, 16th December 2017.

In his contemporary life the corticobasal degeneration necessitated use of this embodied engagement, and enhanced its significance to the shaping of Ivan’s identity. However, Ivan had always enjoyed the company of others, and even in earlier times had also utilised non-verbal to demonstrate this. For example, Jemma reflected upon the use of his laugh. This example was from when Ivan was working as a dentist, and spending time with his patients.

Jemma*: …I could hear great guffaws of laughter…So I think he liked. Am I right..?*
Ivan*: Yeah* (Ivan is smiling).

Ivan and Jemma: interview at home, 12th December 2017.

Continuity is something that people living with dementia have been shown to strive for in terms of their identity, and embodied memories contribute to this (Lindelof *et al.,* 2017). Ivan's data show that from his earliest days he had valued experiences and the feelings attached to them, and these had shaped who he was. His Centre and what it offered enabled him to continue to do this, even despite the challenges dementia presented.

5.2.3.3 Denham is important

The significance of place in informing Ivan's identity saturated this higher-order theme. Finding a sense of community through regularly and routinely being in certain places is another feature reaching back to his earlier history. This is not necessarily unique feature of peoples' sporting experiences of course. However, being in Denham alongside family and friends, often watching football, or playing sport in the street, had always meant a great deal to Ivan. For example, he reflected on his affection for where his father's shop still stands:

"…if you go to a match you to have to virtually almost, you can, just on the side…away from the (city) centre."

Ivan: interview at home, 12th December 2017.

That affinity was replicated with his engagement at the Centre. This reflects what Sabat (2018) relates about places where a shared interest in what goes on bonds individuals with others. It also resonated with what Phinney, *et al.,* (2016) identified as creating a place of belonging. Ivan used such connection to his Centre to help continue to define who he was.

5.2.3.4 We both love sport

Those with whom Ivan connected as he engaged in the activity of the research were important to him and his sense of self. However, in common with other people living with dementia (Bosco *et al.,* 2019b) Ivan's agency, his ability to continue to make what he wanted to do happen, having his decisions acted upon, was reliant upon those closest to him. In particular, this was Jemma, who through her actions was in a position to ameliorate intrapersonal, interpersonal, and structural constraints to leisure (Son, Kerstetter, and Mowen 2009), such as those Ivan faced.

For example, where once Ivan was proactive, here in earlier times together, when attempting to learn to ski:

Jemma: *"…he was determined…I would say, "oh don't do that!" But he was determined to do it…"*

Jemma: interview at home, 20th March 2018.

Now, this aspect of his identity was tempered by dementia, and the constraints related to its context. Ivan needed support to continue to manifest his identity. This was where Jemma's input was invaluable, as this example demonstrates:

"…I've always told the instructors… my husband's got dementia so he'll keep up as much as possible…some people think that he's had a stroke…and I'll say, no he's got dementia, and…that gets round, and people…are very, very kind…"

Jemma: interview at home, 20th March 2018*.*

Relatedness is important because what lies between people is significant in enabling personal agency for people with dementia (Brown, 2017). In the case of Jemma and Ivan I recognised 'couple identity', the combined identity of two people in a relationship, where one has dementia (Hernandez *et al.,* 2019).

As (Bosco *et al.,* 2019b) argue must happen in such circumstances, Jemma encouraged Ivan's engagement in tasks requiring perception and understanding, in synergy with his capabilities and aspirations. Their relationship and how both engaged in physical activity as a couple had evolved in light of the impact of dementia. This example, where Jemma describes how she enabled Ivan to continue to go walking, illustrates this. It demonstrates how Jemma kept him connected to physical activity, and thus to whom he felt he was and wanted to be.

"We went for this walk today…he really, really struggled, but he wants to go, he wants to do it…I say struggle, he's practically staggering. He feels…you've got to stay as fit as you can…he just likes the feeling of getting hot and sweaty…in sport…To feel you've had a work out, and come off thinking I feel so much better…"

Jemma: interview at home, 20th March 2018.

5.2.3.5 I enjoy doing physical activity at the fitness centre

People and communality mattered to Ivan therefore, and he liked being alongside the attendees at the Centre. Engagement enabled him opportunity to participate within sociable activities identified as so valuable to social health by Dröes *et al.*, (2017). He continued to relish physical activity. Lindelof *et al.,* (2017) indicate this continuity enables individuals to demonstrate who they are as they age.

Ivan's experience of engaging in activity at the Centre was also congruent with what Wearing (2011) argues is the enactment of social identity theory. Self-contextualization for Ivan occurred within his gym and exercise classes. Thus, as Stevens, *et al.,* (2017) suggest happens, Ivan defined himself as a group member, as a fellow fee-paying member of the facility. Weiss (2001) argued that self and social recognition occur in such a manner. For Ivan this meant he was an insider, alongside others whom he would encounter as part of their membership of the same Centre. Witness, for example, the instance detailed above of Ivan and a fellow gym user greeting each other, apparently on equal terms. A further example comes from an observation of Ivan's participation within a fitness class:

"At one point another member of the class subtly and sensitively handed Ivan back his weight when he dropped it. She used his name. Ivan clearly appreciated the gesture and, I think, how it was done. In other words discreetly, without fuss…"

Ivan: observation at his Centre, 23rd March 2018.

There was no bespoke provision for people living with dementia at his Centre. Ivan was happy to engage in mainstream activities, and, was accepted as a 'co-insider' by fellow participants. Later I will detail how other primary participants chose to do physical activity in groups provided for people living with dementia. However, Ivan felt connected to others by the place in which he participated in physical activity, he did not want or need bespoke opportunity. This example taken from an interview with Jemma illustrates this. I had asked her how engaging in exercise classes made Ivan feel:

"…included…people aren't sort of shying away…"

Jemma: interview at home 20th March 2018.

For Ivan to demonstrate who he was through physical activity required others to connect him to these opportunities. Kyle did this well. Unlike Ivan's relationship with Jemma, the men had only known each other for a short time, just over two years. However, Kyle was also adept at what Bosco *et al.,* (2019b) identified as important, encouraging Ivan to participate in activity that necessitated his cognitive engagement, in harmony with what he was able and wanted to do. For example:

"Ivan was concentrating hard…He listened attentively to the instructions Kyle gave him. His face was set in a determined expression throughout."

Ivan: observation at his Centre, 16th December 2017.

Earlier I discussed how dementia friendly environments must enable social connectivity on the basis of personal preference, as suggested by Glicksman, Ring and Kleban (2016). This was what Ivan wanted. It was only thus, however, because Ivan's preferences were recognised, Kyle's approach incorporated them, Jemma supported his agency, and other attendees were empathetic.

It is a complex milieu, and William's (1994) helps understanding, as Ivan called upon the influence of significant others, socializing situations, and his own personal attributes as key features, as he expressed whilst engaging at his Centre. I return to these matters and their role in identity formation in the following chapter, as I explore cross cutting themes demonstrated by my analysis.

5.2.4 'I will always give it all I've got'

This is the second higher-order theme illustrating how Ivan's identity was influenced through engagement at his Centre. It is underpinned by three first-order themes:

1. Dementia is a negative thing
2. I push myself hard whenever I play
3. I have enjoyed playing sport all my life

Ivan perceived a sense of loss about himself and what he could still do, caused by the symptoms of dementia. However, simultaneously, he marshalled long-standing elements of his identity to counter this and forge an on-going sense of himself.

5.2.4.1 Dementia is a negative thing

Ivan felt restricted by dementia as it meant he was less able to do the things he enjoyed, for example engaging in conversation. This was part of who he felt he was and the corrosion of this aspect of himself felt painful as Jemma told me:

"That's the heart-breaking thing…when he goes into a shop…or a pub…he has the inclination to…say a witty comment, and…he'll try and say something, and people look, and of course he can't say it…"

Jemma: interview at home, 20th March 2018.

The ability to engage and converse socially was an important part of Ivan's identity. As Ivan confirmed:

C.R: "*Do you like the sport because of the social side, being in a team?*

Ivan: *"I would say yes to that because you've got to go, because there's one thing you could have done …and that's the only thing…"*

Ivan: interview at home, 12th December 2017.

He wanted to retain the feeling of sustaining a position within his social environment, in the manner articulated by Anderson and Whitfield (2013), but dementia had impinged upon his ability to do so. Losses, such as these, negatively impact upon people living with dementia (Brown, 2017). Ivan felt this, and he also resented his dementia because he led a healthy life and was physically fit. For example:

CR: “*How do you feel about having dementia?”*
Ivan: “*I* (short gasp/ tut)… *You just think, oh no, not me...I…be…you shouldn’t say, you shouldn’t say, oh why can’t…but I did all the right things…erm but* (pause)*...”*

Ivan: interview at home, 12th December 2017.

5.2.4.2 I push myself hard whenever I play

Ivan desired to push back against dementia by utilising life-long identity traits, and these included engaging enthusiastically with physical activity.
Ivan had always pushed himself hard when doing this. He had a clear physical activity identity, of the sort described by Son, Kerstetter and Mowen (2009), which was meaningful to how he saw himself. He illustrated elements of this when we met and were discussing engaging in physical activity. For example,

Ivan: “*Yeah. Well, I tell you what I’ve got”* (Ivan is smiling and pointing to his knee).
Jemma: “*Oh, he broke his knee, that’s what he’s trying to tell you.”*

Ivan and Jemma: interview at home, 12th December 2017.

Ivan’s physical activity identity involved significant physical commitment to the sport and activity he was engaged in, wholehearted participation. This extract from my research diary, reflecting on the interview I had recently held with Ivan, illustrates his feelings about this in relation to his times playing football socially.

‘I related that from what I had heard Ivan’s identity on the football pitch was in the style of Liam Main or Martin Dixon, two physical players. This made Ivan smile broadly and he nodded.’

Extract from research diary, 16th December, 2017.

Ivan continued with this approach in his contemporary circumstances. For example:

“…when undertaking the exercises Ivan’s face was set in an expression of extreme concentration. He was taking what he did very seriously.”

Ivan: observation at his Centre, 16th December 2017.

A few months later I observed the following during an exercise session Ivan was engaging in alongside Kyle:

“Ivan works hard physically and mentally throughout. He concentrates completely…”

Ivan: participant observation at his Centre, 1st February 2018.

For Ivan, physical activity felt substantial, interesting, and fulfilling, very much as Stebbins (1992) described serious leisure. It also meant, therefore, he could continue to hone related skills. It was affirming and rewarding, providing him with feelings of self-development, self-expression, and accomplishment, in the sort of ways described by Cohen-Gewerc and Stebbins (2013). It enabled Ivan to work towards successful readjustment to dementia, in the manner suggested by Bunn *et al*., (2012) and, Cheston (2013). Through continuing with his life-long love of physical activity, and choosing to engage so whole-heartedly, Ivan was able to express agency (Genoe, 2010), and make personal meaning (Habermas, 1990; Spracklen, 2013).

5.2.4.3 I have enjoyed playing sport all my life

In a manner suggested by Allen-Collinson and Hockey (2007), and Williams (1994), Ivan's progress and self-perception had been interrupted by the unexpected arrival of a debilitating illness. Personal adjustment in such circumstances is important (Bunn *et al*., 2012; Cheston 2013; Brooker *et al.*, 2017). Ivan utilised long-standing aspects of his identity and contemporary approach to physical activity to adjust. He was not motivated to respond through stigma and shame. As Spracklen (2013) suggests this sometimes happens as individuals try to counter preconceived stereotypes relating to how they might perform. For Ivan this was about how much involvement in sport and physical activity had meant to him from the earliest years of his life. The value he accorded to it had continued into his adult life. For example, as Jemma related, Ivan played football with friends regularly into his adult life:

"I wish some of his friends were here because they would tell you some of the tales…they used to play a couple of times a week".

Ivan and Jemma: interview at home, 12th December 2017.

Ivan attempted ‘to keep the focus off dementia’, in the manner suggested by Phinney, *et al.,* (2016). Ivan’s history was steeped in involvement in sport and physical activity, and he was utilising this heritage to continue to forge his sense of self as his life continued, albeit is dramatically different circumstances.

5.2.5 How I conceptualised Ivan’s core identity*: “I am Sociable*”

Ivan engaged wholeheartedly with physical activity at his Centre. He had always been someone who played hard in this way. The meaning Ivan drew about himself, from his contemporary engagement with physical activity, emanated from his personalised endeavour, alongside his priority to maintain active social links with those around him. His sense of identity, therefore, continued to blend the individual with the communal. Thus, Ivan’s sociability provided a strong theme borne from my analysis of his data.

Freedom was another concept that emerged from my analysis of Ivan’s transcripts and observations. Earlier I related how the challenge of being free has been defined as the combination of being an individual without constraint, within a ‘safety net’ of community, with its accompanying duties and commitments (Cohen-Gewerc and Stebbins, 2013, pp. 6-7). This reflected Ivan’s freedom, drawn from the personal and communal. He used personal encounters to find out more about himself. However, Ivan was not an individualist, as it was not exclusive personal freedom he was seeking. Being part of a social group mattered because it provided that sense of belonging and purpose threatened by illness, as articulated in the findings of Anderson and

Whitfield (2013). This was not about Ivan locating himself amongst peers with dementia, though he was happy to do this too, as I saw when we met at the rugby club. Ivan was keen to continue to engage with the mainstream. His identity was rooted in that part of freedom linked to community. He had always drawn positively upon being a team-mate in sporting settings, from the social side of his work, and the communion he enjoyed at his Centre. The fact that physical activity offered him opportunity to maintain and progress this sense of himself, despite his symptoms which rendered vocal communication very difficult, was a significant part of the attraction for him.

Role adoption enables people to confirm their identities (Weiss, 2001, p.398), and this is what Ivan did alongside others at the Centre. In Ivan’s situation this was so because he could engage without feeling the need to consider himself against others outside of that group context. Observing Ivan’s positive reaction to the acceptance and affirmation of the community he had come to know within his Centre showed me the value this freedom had for him. How to create spaces that are amiable to freedom seeking is an important question. Ivan’s experience indicates there are potential implications beyond his own context of identity maintenance and development. I will return to this in the following chapter, therefore, as part of my analysis of what my findings mean more generally for people living with dementia.

Now I turn to the second of the primary participants, Paul.

5.3.1 Paul

Early Family Life

Paul was born in 1938, and was seventy-nine at the time the research started. From the age of two Paul lived in a market town, Burchester, situated within a rural part of south-west England. He described a happy upbringing. He was one of a large family, the second child of seven. Three of his brothers moved to North America when Paul was a young adult, one of his sisters relocating to the United States a little while later. An older sister resides in north-west England. Paul's younger brother stayed in Burchester and remained in close contact with him.

Leisure and Physical Activity

Paul was involved in sport, close to where he lived, throughout his life. He played regularly for his town's amateur football and cricket teams, and in later years held administrative responsibility with the cricket club. He was a supporter of the professional football team nearest to his home, Rockton City, and frequently travelled to watch them play, with the same group of male friends, until his late fifties. Subsequently he spent part of his leisure time watching his local county cricket team, Nostershire. Paul took part in half-marathons in his middle-age. He completed his final race, his ninth in total, when in his mid-fifties. Paul retired from running, feeling he was no longer physically fit enough to compete.

Adulthood and Employment

Paul has been married to Connie for over fifty years. The couple have one adult daughter, who lives in the U.S.A. Paul was in employment until retirement, initially in factory work, then as a technician with a quarry company and latterly as an assistant to a financial advisor. During early adulthood he undertook three years of national service in the Royal Air Force, serving in Cyprus at the time of the Cyprus Emergency, in the late 1950s.

Dementia and Contemporary Life

Increasing difficulty with memory led to a diagnosis of Alzheimer’s Disease approximately two years before the research began. Paul’s symptoms included short-term memory loss, and anxiety (possibly as a result). They did not affect his speech. He had, however, lost confidence in consistently being able to follow his train of thought, and this impeded his willingness to speak in public. Paul had some difficulty remembering details about recent events, but retained the ability to recall things that happened longer ago.

Paul engaged in physical activity, primarily table-tennis, on a weekly basis at a Centre in the next-door town to Burchester, Arby. This was in a group he attended with Connie, facilitated for people living with dementia. The couple joined just over one year before data collection for the research began, after reading about it in a solicitor’s office. Two Centre Workers, Martin and Jane, hosted the group and were participants in the research because of their regular and frequent interaction with Paul.

5.3.2 Paul’s Thematic Overview

The thematic map in Figure 4 illustrates my analysis of Paul’s data. This incorporates his core identity theme (mauve box, in centre), four higher order themes (blue, larger circles), and the ten first-order themes (orange, smaller circles) which inform my analysis. The commentary which follows addresses each higher-order theme in turn, and sets out my analysis in detail.

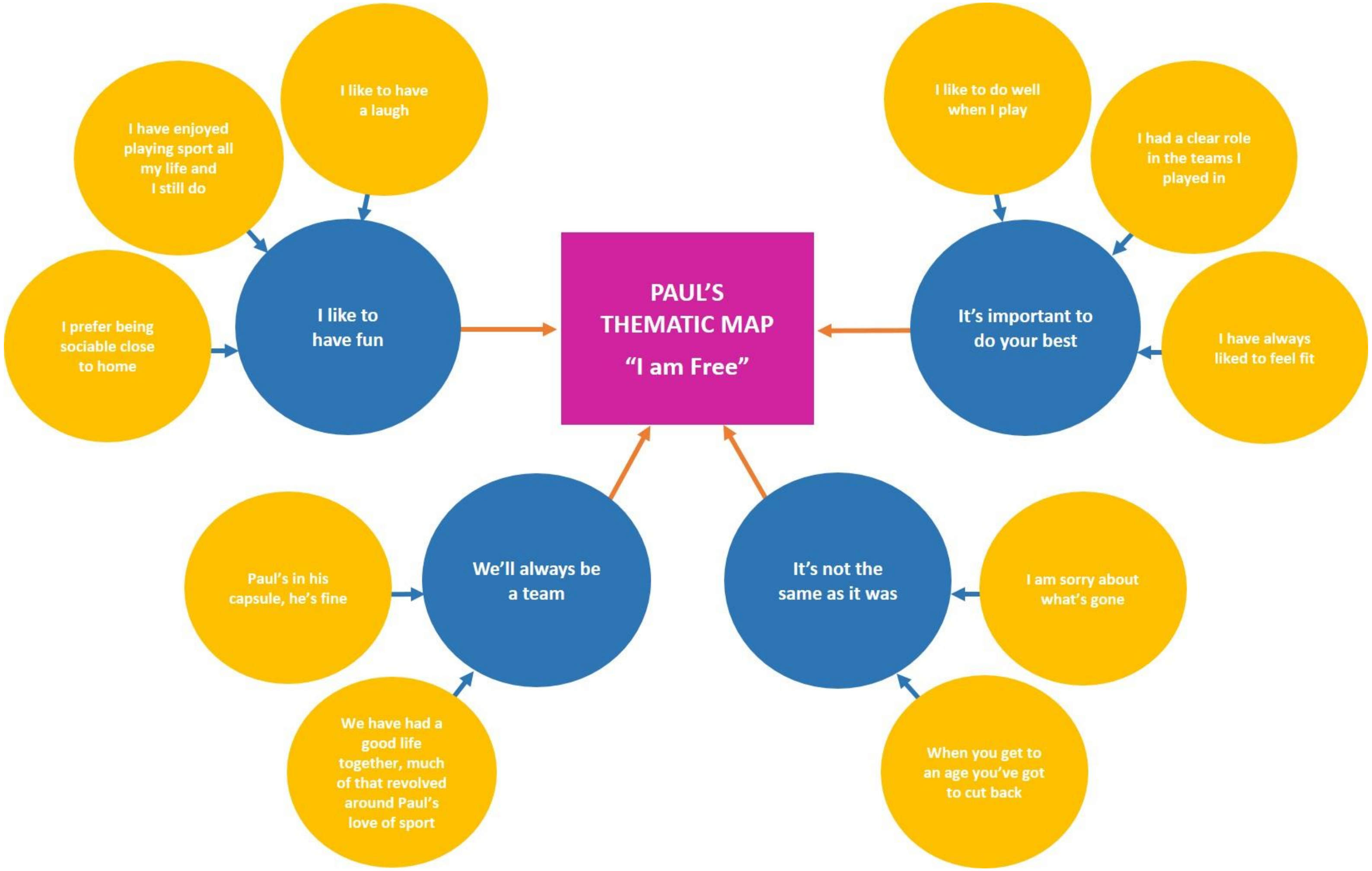

Figure 4: Schematic representation (thematic map) of core, higher order and first order themes for Paul in the maintenance and development of his identity.

5.3.3 ‘I like to have fun’

This is the first of the four higher-order themes relating to how Paul’s identity was influenced by his engagement at his Centre. It is underpinned by three first-order themes:

1. I have enjoyed playing sport all my life and I still do.
2. I like to have a laugh.
3. I prefer being sociable close to home.

This higher-order theme demonstrated how important Paul’s personal history as a sport’s player was to his contemporary sense of identity, despite his difficulties with memory.

5.3.3.1 I have enjoyed playing sport all my life and I still do.

Paul was aware that he was losing his ability to remember details. In such circumstances difficulty with memory can have a negative impact upon identity (Alzheimer’s Society, 2014; Yokoi and Okamura, 2012). However, engaging in physical activity enabled Paul to maintain links with the sense of himself steeped in life-long involvement in sport. Over many years, through cricket, football, and long-distance running he had developed a physical activity identity with significant personal meaning, of the sort described by Son, Kerstetter, and Mowen (2009). This was often how he was known by others, as exemplified from what Martin told me:

“*…he was quite a sportsman in his day… he was very high in sport.”*

Martin: interview at the Centre, 3rd May 2018.

Paul had fond memories of these experiences. For example he said:

“…I used to enjoy my sport.”

Paul: interview at home, 11th December 2017.

Paul continued to make personal meaning from leisure and maintain an identity, in the way Spracklen (2013) suggests, via ongoing engagement in physical activity. Although specific details might only be remembered fleetingly (Cabillas, 2014; Bryden, 2012; Conway *et al.,* 2004), new memories were shaping and reshaping Paul’s identity. Paul remembered the Centre and attending regularly, and he enjoyed himself when he participated there in physical activity. For example, when playing table-tennis against me.

CR: *“I think…when you realised that I could hit the ball back…”*
Paul: *“Yeah, you were, he can, he’s awake now!”* (Paul laughs)
CR: *“…you were sending me some faster shots I think then.”*
Paul: “*Yeah, nasty!”* (Paul laughs)

Paul: interview at his Centre, 23rd April 2018.

5.3.3.2 I like to have a laugh

Having fun comes when personhood is strong, and people living with dementia feel they can flourish (Brooker and Latham, 2016). I believe Paul’s sense of himself was strengthened by continuing to be able to engage in physical activity at the Centre, and having fun whilst doing so. The sense of being able to flourish through playing offered Paul a feeling of freedom, as described by Torkildsen (1999). Indeed, well-being through engagement in sport can be experienced by individuals as feelings of freedom (Mayoh and Jones, 2015). Freedom was something Paul had always valued from playing sport. Having fun and a sense of freedom felt personally positive for Paul therefore, and motivated him to return to play every week.

Paul's sense of enjoyment was communicated by his embodied actions. How he played table-tennis, for example, allowed him to communicate what he felt about continuing to play. For example:

'Paul smiled for most of the time we played. He appeared to be enjoying himself a great deal'.

Paul: reflection upon observation and go-along interview, 8th January 2018, from researcher's field notes.

Whilst his confidence in using speech publically had diminished, the way Paul played table-tennis demonstrated the love he had for engaging in physical activity. Embodied communication, such as this, can enable disabled people to demonstrate their identity (Tregaskis, 2003). My observations of such an experiential self (Brown, 2017; Wright, 2018; Lindelof *et al.,* 2017) by Paul were of someone having fun, who retained his love for playing sport.

5.3.3.3 I prefer being sociable close to home

Notable also, was that place mattered to Paul, because it was integral to the enjoyment he had at the Centre. He had only spent rare moments away from his local community during his life, and valued his affinity with it. For example Connie reflected that at the conclusion of his national service Paul:

"…couldn't wait to get home…"

Connie and Paul: interview at home, 11th November 2017.

Of course, being glad to return from national service might have been for other reasons than missing home. However, indications of how much he valued the environs of his local neighbourhood were numerous. For example, here Connie explains aspects of the involvement Paul had in Burchester's cricket and football clubs, and how his presence was tied to this:

Connie: *"When he didn't any longer play he was on the selection committee…he would go on the Monday and he would watch… we've talked to people, and one of the chaps up at Burchester…said…when I played…we had this big centre half… and Paul said, "well that was me!""*

Connie: interview at home, 14th March 2018.

Having fun engaging in physical activity in the heart of his community was therefore an important part of his identity. In the past Paul's time with local teams involved being alongside his team-mates. The symptoms of dementia had reduced Paul's ability to engage socially, but the Centre gave him the opportunity to do so. It was a ‘geographic space’ (Cohen-Gewerc and Stebbins, 2013), where Paul pursued the activities he loved.

It was a venue for experiences, providing Paul the chance to express his individuality, through playing table-tennis, and to receive feedback and validation from others, in the manner detailed by Erikson (1995). As Martin related:

“…*I think he values the friendship*…”

Martin: interview at the Centre, 3rd May 2018.

Connie concurred:

“…*it’s like people...you’re not made to feel embarrassed or anything like that…he just enjoys going up”.*

Connie: interview at home, 14th March 2018.

Within this local place, amongst others who could offer the sort of validation to which Erikson refers, Paul was able to participate in physical activity. Social contact in the context of local sport had always meant a great deal to him. The extent to which it still did is demonstrated by this example:

‘*Paul and I played table-tennis for approximately forty minutes… Paul smiled… chasing shots that were at the very extent of his reach… ’*

Paul: participant observation at his Centre, 23rd April 2018.

This in turn linked to the life affirming idea of freedom seeking, as identified above. Paul was not especially close to anyone within the group, but he appreciated the opportunity the Centre provided to retain the social interaction he had always valued. For example, Connie reflected:

"Paul's fine…if he were asked something by anybody…he'll come up with some quip…"

Connie: interview at home, 14th March, 2018.

In the context of Paul's contemporary world, often characterised by feelings of lost social skills, the Centre offered opportunity for meaning about what he was doing, and through participation to continue to evolve his sense of himself (Stevens, *et al.,* 2017). Social citizenship happens in ordinary places (Bartlett, 2016), and the Centre allowed Paul to continue to express his individuality in the manner he enjoyed, in the heart of his community (Cohen-Gewerc and Stebbins, 2013).

Having discussed how having fun at the Centre continued to play a role in shaping Paul's identity, and how this was manifested, I now turn to his second higher-order theme, 'It's important to do your best'.

5.3.4 'It's important to do your best'

This is underpinned by three first-order themes:

1. I like to do well when I play

2. I had a clear role in the teams I played in
3. I have always liked to feel fit

Paul's life story, and the significance place holds for his sense of identity are features that reoccur within this higher-order theme.

5.3.4.1 I like to do well when I play

Reflecting upon his personal history, Paul always liked to do well when he played sport. For example, on one occasion whilst playing table-tennis together I commented to Paul, and he replied:

C.R: *"You are a good player Paul".*

Paul: *"You never lose it!"* (Paul smiled broadly)

Paul: go-along interview at his Centre, 23rd April 2018.

Winning was important, but it was playing well that mattered more. When we played Paul was never interested in keeping score, but he was determined to do well. For example, during one game together:

'…Paul concentrated very hard…I attempted to engage Paul in conversation…This was not successful…Paul's approach…was consistently determined. Everything I hit at him he more or less returned. At points it was a metronomic pattern'.

Paul: participant observation at his Centre, 8th January 2018.

His desire to do well was mirrored in the games of dominoes that Paul also engaged in regularly at the Centre. For example, Connie recounted:

"…that's what we do, we take dominoes and play a game… there again, he likes to win, you know!"

Connie: interview at home on 14th March 2018.

As scholarship suggests (Perras *et al*., 2015; Lindelof *et al.,* 2017) Paul's identity intersected with his physical activity identity through engagement in sporting endeavour. He was aware of his reduced ability to undertake activities, as often occurs for people living with dementia (Alzheimer's Disease International, 2014). As a result, and in the same way as for others living with dementia (Bosco *et al.,* 2019b), he experienced a consequent loss of agency in his daily life. However, physical activity offered opportunity to fulfil sporting potential (Dröes, *et al.,* 2017), and through strengthening his physical activity identity Paul could challenge how far dementia defined his identity, and reframe his sense of self to demonstrate personal power, as described by Kissow, 2015. Dementia meant this was no longer so easy in other arenas, for example social situations where conversation was required. In addition Paul used table-tennis to moderate his sense of 'biographical discontinuity', as described by Williams, 1994, for example, by endeavouring to play well he was replicating the approach he had always taken to sport.

5.3.4.2 I had a clear role in the teams I played in

Paul's lifelong competitive spirit linked to how he viewed previous sporting roles, for example as a defender. The motivation for doing well in this context came not from narcissism, but because by doing so he helped the team. As Paul said,

"*I was a centre half you know. My job was to save the team*."

Paul: go-along interview at his Centre, 23rd April 2018.

As Weiss (2001) argues, having a clear role within social contexts helps individuals confirm identities, and this was what Paul drew upon now too. Paul was reflective on the part he performed within sports teams, distinguishing between being a player, and having specific responsibilities within the team. For example, as an opening batsman Paul felt he had responsibility to protect the interest of his team by remaining at the wicket.

Paul: *"…that's what I played like…"*
C.R.: *"…so that you didn't get out?"*
Paul: *"…that's right."*

Paul: interview at his Centre, 8th January 2018.

By perceiving himself as a player with a role Paul felt he was a group member, and that his behaviour had meaning, in the manner suggested by Wearing (2011), and Stevens, *et al.,* (2017). Now, when Paul played table-tennis, an individual sport, the collegiate nature of the team was mirrored by being a member of the regular gathering (Sabat, 2018). Paul was utilising a socializing situation (Williams, 1994) to claim his place in the community (Phinney, *et al.,* 2016; Spracklen, 2013). For example:

‘Paul enjoys what he does in the group...he smiled throughout our game of table-tennis.’

Paul: participant observation at his Centre, 8th January 2018.

This was the function leisure afforded him in relation to this aspect of his identity (Spracklen, 2013), i.e. Paul could feel he was a ‘team player’ again. As his place in the world, and his ability to influence it, were corroded by dementia the individual and collective identities he took from being both a player and team-member helped him strengthen his sense he could participate in life, as a social citizen (Bartlett and O’Connor, 2010).

5.3.4.3 I have always liked to feel fit

This aspiration to claim a place in the world was reflected in what Paul believed about feeling physically fit. Being fit was always important to his sense of self. For example, Connie related that Paul has,

“…never been in a hospital in his life.”

Connie: interview at home, 14th March 2018.

Being fit also included the sense Paul had of his own build, perceiving his stature suited athletic endeavour. Here matters regarding the gendered elements of identify were evident. For example, Paul continued to construct his masculinity through exercise (Kivel and Johnson 2009), with physical fitness accorded significant motivation for such involvement (Science Media Centre, 2018). As Paul related about engaging in physical activity:

“(You)…can’t beat it.”

Paul: interview at home, 11th November 2017.

And on a later occasion, after playing table-tennis,

“…*I could run a marathon!”*

Paul: interview at his Centre, 8th January 2018.

As reported by other people living with dementia (Genoe and Dupuis, 2011), perhaps underlying this notion of physical fitness was the belief that by retaining physical well-being Paul could shore up precious cognitive capability. As studies involving people living with dementia have related is the case (Brown, 2017; Wright, 2018) Paul was navigating himself experientially through his physical actions, and this was via engagement in regular activity of a substantial physical nature (Stebbins, 1992). Being fit, therefore, enabled him to confirm self-authenticity, a sense of self-development, and accomplishment, in the manner described by Cohen-Gewerc and Stebbins, 2013.

Having discussed how Paul always believed it is important to do your best, and how he used physical activity to demonstrate this, I turn now to the third higher-order theme underpinning his sense of identity.

5.3.5 ‘It’s not the same as it was’

This was founded upon two first-order themes:

1. When you get to an age you’ve got to cut back.
2. I am sorry about what’s gone.

5.3.5.1 When you get to an age you’ve got to cut back

Paul expressed his view that he had reduced the physical activity he undertook, because he had grown older.

“…you get to an age where…you’ve got to cut back. That’s what happened to me...”

Paul: interview at his Centre, 8th January 2018.

There was no spoken recognition by Paul that the symptoms of dementia had caused him to adapt thus. As I will illustrate later, Paul did not have to acknowledge to himself the impact dementia had upon his life, because Connie was so skilled in supporting his agency. However, by continuing to engage in physical activity, albeit by choosing to cut back to a weekly game of table-tennis, Paul felt he was maintaining a feeling about who he was. In this way he was sustaining continuity in his sense of self, in the manner set out by Lindelof *et al.,* (2017).

5.3.5.2 I am sorry about what's gone

Earlier I argued that Paul valued the sense of freedom he had drawn from life-long engagement in physical activity; enabling personal meaning to be made, and sense of identity shaped. However, now things were different, despite making adjustments to how he approached physical activity he felt older. This involved feelings of loss, for example of his playing ability. Paul said,

"*You get to a certain age, and…that's it, it's finished*".

Paul: interview at his Centre, 8th January 2018.

Paul tended to link loss with ageing rather than dementia. However, one contrasting comment stands out,

"(I am)… an idiot!"

Paul: interview at home, 11th November 2017.

Paul said this in jest, but when seeking a memory in response to a question from Connie about employment earlier in his life. It showed how he felt about his sense of personal loss. It was linked to his dementia because Paul was frustrated he could not retrieve that memory. This was potent because it highlighted what people living with dementia face, feelings of powerlessness in the face of symptoms (Brown, 2017) and this had consequent restriction on Paul's sense of freedom. Paul used physical activity to maintain his sense of identity, but engaging in leisure can also serve to remind individuals living with dementia of losses, and reduced ability to perform valued roles (Genoe, 2010;

Genoe and Dupuis, 2011). Engagement in physical activity could compensate, but Paul still felt a sense of loss about abilities that had declined. For example, my reflection upon attempts to engage Paul in conversation during our game of table-tennis:

‘Paul did not want to engage in conversation. I think this is because of his memory he feels he has nothing to offer in response… Paul smiled… he understood but did not…want to come back (on my question)…’

Paul: participant observation at his Centre, 8th January 2018.

5.3.6 ‘We’ll always be a team’

Analysis of this higher order theme was based upon two first-order themes:

1. We’ve had a good life together, much of that revolved around Paul’s love of sport.
2. Paul’s in his capsule, he’s fine.

5.3.6.1 We’ve had a good life together, much of that revolved around Paul’s love of sport.

The relationship between Paul and Connie and their life together informed his contemporary sense of self. Paul’s relationship with his daughter, Susan, contributed also. However, dementia can strain such relationships, because symptoms might change behaviour, and thus ways those close to people living with the syndrome anticipate the person will behave (Baikie, 2002; Zweig and Galvin, 2014). Thus, Connie reflected that Paul was sometimes unthoughtful in a way he never was previously. However, the reflections the couple engaged in, recollecting good times - with Paul playing sport and Connie supporting, helped mitigate this. As Connie told me,

“We used to enjoy going to Biltham, … we’d take a picnic…if they were playing cricket…it would be a family day out…Susan was interested…they used to knock a tennis ball…around afterwards… it became a family thing.”

Connie: interview at home, 14th March, 2018.

Through such occasions came relatedness, as described by Brown (2017), affording a ‘couple identity’ (Hernandez *et al.,* 2019) based upon shared sporting times. As Connie said,

“…when we were married…(I was) a sporting widow (Connie laughs)...*there again, you knew what the deal was”.*

Connie: interview at home, 14th March 2018.

This shared identity included the enjoyment Paul and his daughter had together in familial sporting moments. As Connie said,

“(They both)…would always go in the gym and go on the running road, or on the rowing machine…They are both so competitive.”

Connie: interview at home, 14th March 2018.

These shared identities were physical activity identities, of the sort described by Son, Kerstetter, and Mowen (2009). Contemporaneously Connie used their shared identity to negotiate constraints caused by dementia to Paul's ability to maintain his identity through physical activity. For example, the erosion of confidence Paul experienced within social situations. Martin witnessed this, what it meant for Paul, but also the significance for Paul of Connie's response,

"…just being…being with Connie…and talking to her, talking to people, looking happy…"

Martin: interview at the Centre, 3rd May 2018.

5.3.6.2 Paul's in his capsule, he's fine

In subtle and person-centred ways Connie connected Paul to opportunities that allowed him to maintain a sense of self, in the way described by Bosco *et al.,* (2019b). As Connie said,

"… (Paul is) in his capsule, in his little world, he's fine".

Connie: interview at home, 14th March 2018.

Indeed, I witnessed how Connie connected Paul to self-affirming opportunities as part of the research process. For example, when as a group of three we studied photographs from earlier times of Paul playing sport, and Connie guided him through them at a pace and in a manner which enabled him to draw deeply upon his memories. This aligns with arguments Dupuis *et al.,* (2012) made about the value of visual aids when undertaking research alongside people living with dementia.

How Connie connected Paul to opportunities enabling allowing him to maintain his identity in daily life involved her doing as Laver *et al.* (2017), and NICE (2018) state, and countering aspects of adversity. Connie supported Paul in this way by enabling him to lead a fulfilling life through physical activity. For example, when discussing how the couple approached their regular attendance at the Centre, and what was on offer there, Connie related:

"…well I have to be the one to say, shall we do this? …But he wouldn't take the lead. He's lost confidence I suppose."

Connie: interview at home, 14th March 2018.

With Connie's support Paul could express himself in ways to continue to evolve his sense of identity through ongoing involvement. This sense of being-in-the-world is an important component of identity for people living with dementia (Dupuis *et al.,* 2012). Being-in-the-world links back to the positive consequences of embodiment (Merleau-Ponty, 1962), for example Paul using his body to maintain connection with the social world.

5.3.7 How I conceptualised Paul's core identity*: "I am Free*"

Paul felt loss. However, through what he did, as scholars investigating similar contexts have discovered (Genoe, 2010; Genoe and Dupuis 2011), Paul remained able to consider the future. Whilst at risk of the adverse effects of the symptoms of dementia, engagement in physical activity at the Centre was the means Paul used to keep corridors to essential aspects of his sense of self clear and accessible.

The overriding feature in Paul’s life was a love of engaging in physical activity, and freedom pervaded much of the analysis of the data. It captured the essence of Paul’s identity, because throughout his life, through physical activity, Paul consistently sought the freedom he valued. Primarily this involved being able to have fun, but also the opportunity to apply himself to give his best and improve. These notions are integral to two of the four higher-order themes identified for Paul by my analysis, ‘I like to have fun’, and ‘It’s important to do your best’.

Paul understood that as he aged, life changed. The data indicated that he particularly recognised a deterioration in his physical abilities. The symptoms of dementia played a part too, but he was shielded from these by Connie. Changes to Paul’s physical and intellectual abilities impinged upon his sense of freedom, i.e. ‘it’s not the same as it was’. For Paul freedom to play was enabled, in large part, throughout his adult life by Connie. Her energy, empathy and interest meant Paul could attain what he sought from sport whilst also building his sense of a successful, happy domestic life.

I turn now to my analysis of the data as they related to Leonard.

5.4 Leonard

Early Family Life

Leonard was born in 1958, and was fifty-nine when his involvement with the research began. Leonard lived in or close to a large city in the south-west of England all of his life, Rockton. His early years were difficult primarily due to the behaviour of his father, which was neglectful and sometimes violent. Leonard became estranged from him as he grew up, but remained in touch with his mother. Leonard has two siblings with whom he is also in contact. He was bullied at school, being perceived by his peers as a ‘weakling’. Leonard is dyslexic, and was diagnosed in adulthood. He feels strongly that this was overlooked by teachers when it should have been identified, and that his educational achievement was impeded as a result.

Leisure and Physical Activity

Leonard did not like sport at school, because he found it boring and pointless. This was despite being a good middle distance runner, and strong swimmer. In adulthood, Leonard enjoyed riding his bicycle recreationally and motor-cycling. The latter was accomplished alongside a group of friends who met regularly. Motorcycling is the only sporting activity Leonard has ever been interested in as a spectator, occasionally attending professional events.

Adulthood and Employment

Leonard is married to Caroline, the couple have two adult sons. Sadly their daughter died when she was twenty-three years old, three years before the start the research.

Leonard was employed throughout his adult life. He worked as a French polisher for most of that time, and has symptoms of hearing loss which were caused through exposure to loud machinery in that role. When his employer closed down Leonard worked as a school caretaker until he had to retire because of ill health (caused by dementia) when he was fifty-six years old.

Dementia and Contemporary Life

Leonard has Posterior Cortical Atrophy, his symptoms resulting in compromised visual ability and spatial judgement, as well as impacting upon his short-term memory. He has little difficulty with speech, although occasionally feels muddled, and lacks the ability to find words as swiftly as he would like. Leonard and Caroline had attended the same group at Arby as Paul and Connie for over a year at the time data collection commenced. They became aware of the group from a directory of local services following Leonard's diagnosis. The couple extended participation across the week, beyond the activities of the group, to include games of badminton on other days, and attendance at social events. The Centre Workers who hosted the group, Martin and Jane, who also knew Paul and Connie, were participants in the research, because of their regular interaction with Leonard.

5.4.1 Leonard's thematic overview

The thematic map in Figure 5 illustrates my analysis of Leonard's data. This incorporates core identity theme (brown box, in centre), his three higher order themes (blue, larger circles), and twelve first-order themes (orange, smaller circles). The commentary which follows addresses each higher-order theme in turn.

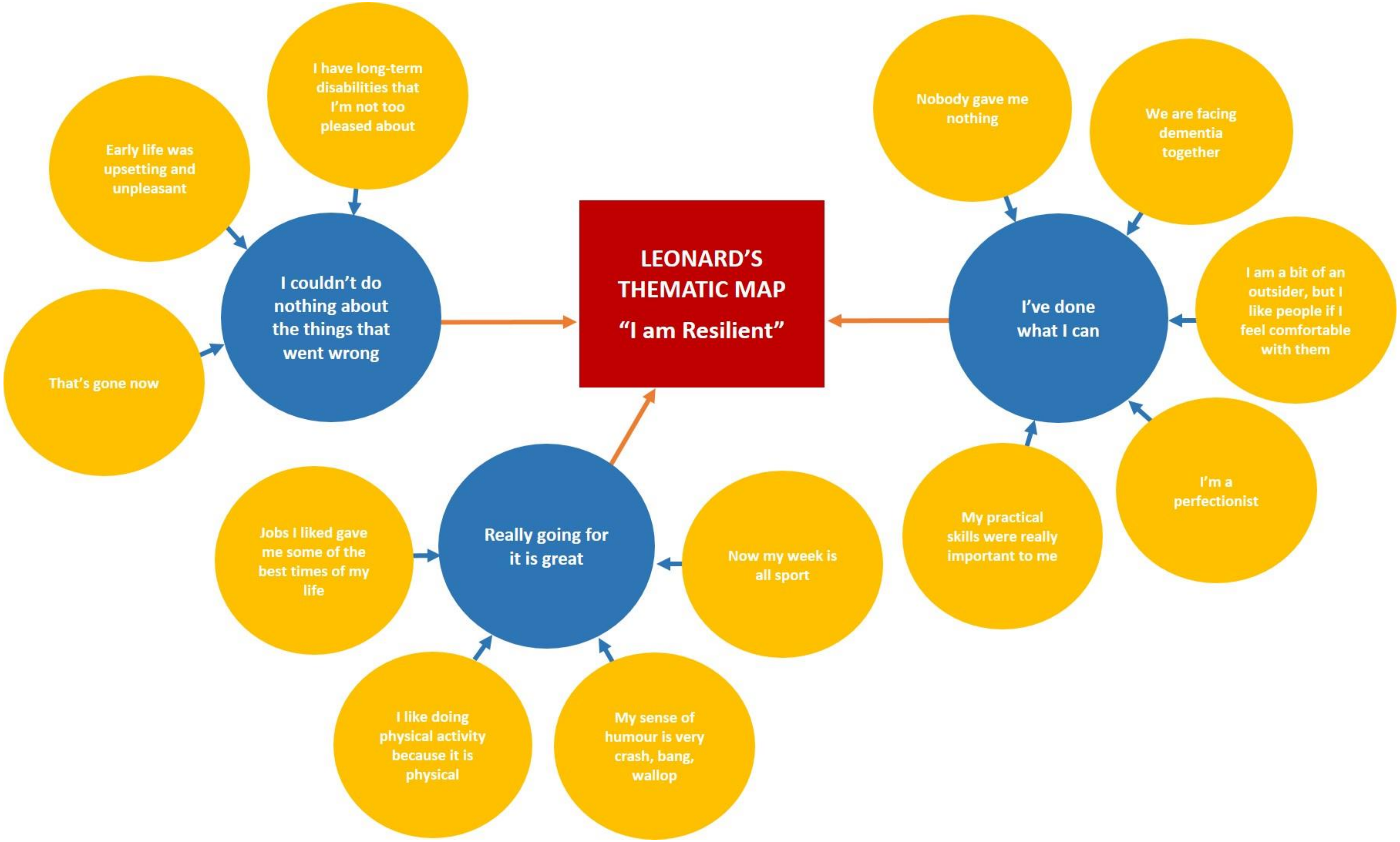

Figure 5: Schematic representation (thematic map) of core, higher order and first order themes for Leonard in the maintenance and development of his identity.

5.4.2 ‘I couldn’t do nothing about the things that went wrong’

This is the first of the three higher-order themes relating to how Leonard’s identity was influenced by his engagement with his Centre. It is underpinned by three first-order themes:

1. Early life was upsetting and unpleasant
2. I have long-term disabilities that I’m not too pleased about
3. That’s gone now

5.4.2.1 Early life was upsetting and unpleasant

Leonard reflected verbally, and through body language and tone of voice, that his early years were negative times. He particularly resented his father’s behaviour towards him, partly because he gained his practical skills, which he valued highly, from his father. As he related,

“My Dad was a bit of a handy man…so basically I was interested in working with tools and things like that ...but then once he was on the drink again it was all like up in the air”.

Leonard: interview at home, 19th December 2017.

Leonard was bullied at school, and was often ignored by his teachers. This hurt and Leonard continued to feel emotional pain. He acquired a strong dislike of physical activity during these years. As Spracklen (2013) suggests about such situations, Leonard’s experiences and socialisation, made a significant contribution to how he perceived physical activity and his approach to it. I will discuss this further below.

5.4.2.2 I have long-term disabilities that I'm not too pleased about

Leonard's awareness of his long-term disabilities, partial deafness and dyslexia, were a core part of his identity. This was because they predated the dementia. It was also because of his feelings about them – he wanted to hide both, because he felt stigmatised (Goffman, 1963) by having to wear the hearing aids and being unable to read. At the same time, in common with many other younger people living with dementia (Alzheimer's Society, 2017), Leonard felt stigmatised by his symptoms. Just as he felt his early socialisation was beyond his control he expressed feelings of helplessness in relation to these disabilities. Leonard also feared the loss of personal agency that dementia threatened, in the manner outlined by Bosco *et al.,* (2019b). For example, he and Caroline related how he felt when the symptoms of dementia began to impact upon his life:

Leonard*: "I went and got the keys cut, and when I got back…I couldn't…do anything, I couldn't sort the keys out, I couldn't do nothing."*
Caroline*: "He was very distressed…"*

Leonard and Caroline: interview at home, 19th December 2017.

This was significant because feeling he was in control mattered to Leonard, as I will show later in the discussion of the second higher-order theme, 'I've done what I can'.

In common with what others living with dementia have reported (Lishman, Cheston, and Smithson, 2016; Vince, Clarke, and Wolverson, 2017), the implications of dementia for his sense of identity were matters Leonard found threatening. He was aware of the progressive nature of the syndrome, and this induced feelings of helplessness, much as Brown (2017) argues happens. As Caroline related:

"…*he was just stunned… it took him a long time for it to sink in...he was looking at other people…and thinking, that's going to be me…he did worry*…"

Caroline: interview at home, 14th March 2018.

5.4.2.3 That's gone now

Thus, Leonard felt that much of what had gone wrong in his life had been beyond his control. Related to this were his feelings of loss. In particular the upset Leonard felt from a forfeiture of skills, employment and past-times, caused by the symptoms of dementia. Feeling such losses is a feature many people living with dementia experience (Alzheimer's Disease International, 2014). Leonard, for example, was disappointed and frustrated about losing his final job as a school caretaker.

"I did all the grounds works and painting and decorating…for…just over ten years. I'd still be there now if it weren't for er, yeah…"

Leonard: interview at home, 19th December 2017.

He felt this keenly because earlier he'd lost his most prized employment, as a French Polisher, because the profession ceased to exist. He'd held high status, Caroline describing him as,

"…the 'go to' man. He was the one."

Caroline: interview at home, 14th March 2018.

Leonard reflected,

"I just loved the job".

Leonard: interview at home, 19th December 2017.

Sadly the sense of loss Leonard's diagnosis brought was compounded as it coincided with the death of his daughter. More recently Leonard lost relationships established at the Centre through dementia, people either dying or becoming too unwell to continue playing. For example,

C.R: *"…you used to play against another chap didn't you?"*
Leonard: *"Yes, Malcolm. And he's gone downhill quite a bit."*

Leonard: interview at his Centre, 22nd January 2018.

This higher-order theme encapsulated how Leonard felt much of what had gone wrong in his life had been beyond his control. As a result he felt a sense of loss. However, his life experiences had helped form his expectations of it. This understanding is carried into the remaining two higher-order themes as I will show.

5.4.3 ‘I’ve done what I can’

The second higher-order theme is linked to the previous discussion about Leonard’s identity, in particular Leonard’s reaction to his feelings of loss and helplessness, and to the following section, which addresses his response. This higher-order theme was underpinned by five first-order themes

1. No-body gave me nothing
2. My practical skills were really important to me
3. I’m a perfectionist
4. I am a bit of an outsider, but I like people if I feel comfortable with them
5. We are facing dementia together

5.4.3.1 No-body gave me nothing

Leonard felt through his efforts he had been able to achieve what he had in life, in particular developing his practical skills and abilities. He believed he had been impeded in enhancing these, and thus the quality of his life, by others who should have been helping him, notably his father, his earliest employers, and his teachers. For example he related,

“When I started school…I didn’t have any help from anybody. I couldn’t read, couldn’t write and nobody done nothing about it.”

Leonard: interview at home, 19th December, 2017.

This accorded with feelings of loss and helplessness, but also included the germination of a sense of resistance that became a strong part of Leonard's identity, as he attuned himself to push back in ways he felt he could. His contemporary engagement in physical activity offered opportunity to do this with dementia, as has been noted in studies investigating similar contexts (Genoe, 2010). For Leonard, this provided chances to make choices in what he did and how he did it.

5.4.3.2 My practical skills were really important to me

Leonard's practical skills and ability contributed significantly to who he felt he was. Whilst some were imparted by his father, Leonard also felt he had built them himself. For example,

"*I started…to learn reading and writing a bit on me own…no one had helped me...I had a book…which I'd started reading. Which was a great effort to do because I had no idea about reading and writing…* (Leonard laughs)".

Leonard: interview at home, 19th December 2017.

This sense of making progress himself, in the face of inertia from others, continued as he found employment. He said:

"I went in as a labourer and worked my way up to a French polisher. Working with machinery and I just loved the job (he smiles broadly)."

Leonard: interview at home, 19th December 2017.

Leonard’s practical skills became important to him because he could project himself positively into the world using them, and he was valued by others because of what he offered. For example, Caroline said:

“(You) used to go to people’s houses and do all their plumbing, didn’t you? God knows how many bathrooms you’ve put in for people!”

Caroline and Leonard: interview at home, 19th December 2017.

Meanwhile the job as a French Polisher gave Leonard a sense of meaning. He appreciated the collegiality of this employment, it was something he had experienced infrequently. He felt it enabled him to develop his sense of identity through doing things he loved. For example:

“Smith’s taught me a lot, cos obviously working with furniture and making furniture up and stuff like that.”

Leonard: interview at home, 19th December 2017.

These practical skills and the ability to use them as he wished afforded Leonard a sense of agency and empowerment. As with others living with dementia (Alzheimer’s Disease International, 2014), when dementia impeded his ability to undertake them Leonard felt this keenly. However, the opportunity to engage in physical activity mirrored the agency he had once felt. In this way, as the scholarship of Torkildsen, 1999, and, Spracklen, 2013 indicated, he could choose to take part once more in things that were of interest to him.

5.4.3.3 I'm a perfectionist

Leonard held little affection for physical activity prior to diagnosis, not perceiving himself as ‘sporty’. However, being able to do things well was something that had been important for a long time. As a French Polisher and latterly as a caretaker he had achieved this. He related what was important to him:

“…it’s working with your hands isn’t it, and using your brain, and, making something that’s… (long pause)… (Leonard laughs)…*being able to make something that somebody else couldn’t do”.*

Leonard: interview at home, 19th December 2017.

This sense of perfectionism, being good at something and being valued for that, was a strand of Leonard’s identity that dementia had deprived him of. However, acquaintment with physical activity offered a substitute. As Leonard strove to cope with losses, through his chosen activities he could maintain a sense of wanting to do his best, and show this to others (Genoe and Dupuis, 2011; Spracklen, 2013). The games of badminton were substantial, and fulfilling, and he could acquire and enact skills. This was ‘serious leisure’ (Stebbins, 1992), providing Leonard with feelings of self-development, self-expression, and accomplishment (Cohen-Gewerc and Stebbins, 2013). As he said as we concluded a game of badminton:

“I like it. I feel like I’ve done something”.

Leonard: go-along interview at his Centre, 3rd May 2018.

5.4.3.4 I am a bit of an outsider, but I like people if I feel comfortable with them

Leonard was not naturally sociable, he had always taken time to get to know and trust people. This was true of his experience at the Centre. However, now he was using that place and the people who attended to bolster his sense of who he was. Leonard appreciated the fact he was engaging alongside others with dementia.

“That’s been brilliant…a big help because you can talk with all the other people with their problems…cos’ we’ve all got the same problem.”

Leonard: interview at home, 19th December 2017.

For Leonard this public space provided him opportunity to come together with others to build identity through shared interest, in the manner outlined by Young, 1990. Through social engagement and physical activity Leonard felt meaning which informed his sense of self (Jenkins, 1996). This also resonated with the sense of a shared identity, described in the work of Sabat (2018), garnered through interaction with others. As the scholarship of Wearing (2011) suggested, Leonard contextualised himself within a social group. In this way he had a sense of ‘we’ and ‘us’, as outlined in the work of Stevens, *et al.,* 2017. This had become a collective identity, built through having characteristics in common whilst engaging in sport, in a manner suggested by Jones (2017). For example:

"…it's all people in the same situation…getting on with the people like that…it's fine because everybody speaks…everybody gets on well…there's no problem".

Leonard: interview at his Centre, 2nd July 2018.

Thus, reflecting on the work of Stevens, *et al.,* (2017), what went on within the group was linked to his developing sense of self. As Spracklen (2013) suggests of such situations, through being sociable he achieved a sense belonging in this sporting context. Reflecting on similarity and also differences with Phinney, *et al's.,* 2016 study, rather than 'keeping the focus off dementia', Leonard had embraced comradeship and had instead created 'a place of belonging'. Leonard was demonstrating resistance by bonding with others, and in doing so combatting feelings of stigmatisation (Corrigan *et al.,* 2013; Ditchman *et al.*, 2013; Jones *et al.,* 2013). Reflecting on what Cohen-Gewerc and Stebbins (2013) suggested, the place, and the people with whom he engaged in physical activity provided that 'safety net' of community, alongside opportunities to strive for a sense of freedom. By doing what he could in this way Leonard had strengthened his sense of social identity (Williams, 1994). Dementia having impaired this by reducing his ability to engage in the world through his practical skills and abilities. For example:

C.R.: *"What makes you come back and do this again? What makes you return to do this?"*
Leonard: *"…the physical side of it and the people that are here."*

Leonard: interview at his Centre, 22nd January 2018.

Martin confirmed that Leonard enjoyed being alongside others in the group, as he was able to engage in physical activity at the same time. Martin reflected that he observed Leonard:

"…totally enjoying himself, and…he certainly likes his badminton…"

Martin: interview at the Centre, 3rd May 2018.

In the following section I will show how part of this feeling of inclusiveness, within that physical space, also offered Leonard opportunity to demonstrate his masculinity, in particular hegemonic masculinity. However, before that it is essential to reflect upon the significance his relationship with Caroline had for his identity.

5.4.3.5 We are facing dementia together

Leonard and Caroline related they were facing dementia as a couple, and the Centre became the focal location for this. This was part of their philosophy of life following Leonard's diagnosis, to face dementia together and to utilise physical health to do so. As Caroline said,

"…we don't know what's happening tomorrow, so let's enjoy today."

Caroline: interview at home, 14th March 2018.

Leonard was delighted to attend the Centre now, but earlier Caroline had to encourage him. For example, on their initial visit she recounted their conversation, what Leonard said first, and then her response:

“I’m not going in there now, cos there’s singing, I’m not going in, no, no, no. Let’s go, let’s go, let’s go. And I’m saying, well hang on, when the singing stops let’s see what else is on offer.”

Caroline: interview at home, 14th March 2018.

Caroline’s insistence enabled Leonard to engage with what became one of the most fulfilling aspects of his life. This aligns with the role we know family carers can play (Laver *et al.,* 2017; NICE, 2018). Caroline was able to temper the constraints to engagement (Son, Kerstetter, and Mowen 2009) that Leonard perceived. This was mutually beneficial because, whilst they had a ‘couple identity’, the Centre also offered both the chance to express their individuality, in the manner outlined in Hernandez *et al.,* (2019). As Caroline said,

“Leonard likes playing badminton. I don’t mind having a game, but I prefer to network with other carers.”

Caroline and Leonard: interview at their Centre, 3rd May 2018.

In the next section I address aspects of Leonard’s response to living with dementia. Often this involved Caroline and himself working in concert, at other points this was through his effort alone. It is to these matters, and how they influenced Leonard’s sense of identity, that I now turn.

5.4.4 ‘Really going for it is great’

This final higher-order theme relates to how Leonard’s identity was influenced by his engagement with his Centre. It is underpinned by four first-order themes:

1. Jobs I liked gave me some of the best times of my life
2. I like doing physical activity because it is physical
3. My sense of humour is very crash, bang, wallop
4. Now my week is all sport

5.4.4.1 Jobs I liked gave me some of the best times of my life

It wasn’t only the opportunity to use and improve his skills that Leonard valued about his time in employment. It was also the positive social experiences, the good times with others, he appreciated. For example, when working as a French polisher.

“I had loads of friends…it was…the best job I ever had, I got on with everybody...”

Leonard interview at home, 19th December 2017.

Employment such as this provided the ‘opportunity structures’, as described by Lundberg *et al.,* (2011), that shaped Leonard’s identity, through meeting his needs for agency, and communion, whilst doing the things he enjoyed. For example,

"…we used to go out shop fitting…about four or five of us. There'd be polishers…joiners…it was good… Working with the guys...there was always a good laugh, and a joke and everyone got on well. Everybody liked their job."

Leonard: interview at home, 19th December 2017.

5.4.4.2 I like doing physical activity because it is physical

However, it was physical activity which acted as the opportunity structure now. For example, Leonard reflected upon what he enjoyed about physical activity:

"…being there and doing it…Brilliant, great…love it."

Leonard: interview at his Centre, 22nd January 2018.

When I asked for the reason he kept coming back, Leonard replied,

"…we are here for the sport".

Leonard: interview at his Centre, 22nd January 2018.

It was the vigorous nature of his engagement though that was powerful, and aligned with Leonard's sense of himself. As he said,

"…you're achieving something aren't you…actually doing something physically."

Leonard: interview at his Centre, 22nd January 2018.

This was linked to physical fitness, as part of what Dröes *et al*., (2017) would describe as social health, and it provided the accompanying opportunity to repulse dementia. Leonard articulated a feeling of achievement through engaging in this way. For example saying, at the end of a game of badminton,

"It takes your breath away. It's brilliant…"

Leonard: go-along interview at his Centre, 3rd May 2018.

Such opportunities to assert himself physically enabled Leonard to resist the societal oppression wrought by dementia, within the 'ordinary place' of his Centre (Genoe, 2010; Bartlett, 2016; Birt *et al*., 2017). The vigorous nature of Leonard's engagement was also associated with his desire to demonstrate his relative youthfulness and masculinity. Through use of his body (Merleau-Ponty, 1962) Leonard reflected how he felt about aspects of himself, as a young man, who remained physically fit. Thus, he used what Brown (2017), and Wright (2018) categorise as experiential and embodied self to support this identity. Demonstrations of masculinity are intended to be manifestations of personal power, often when men feel they lack such agency because of prejudice (Connell and Messerschmidt, 2005). Leonard felt he could exercise power, and show this through how he engaged in physical activity. Leonard framed this in terms of getting rid of feelings of aggression. For example,

"I'm not so keen on table-tennis. Cos, you can't really whack it can you? (Leonard laughs heartily)…*I think it's a bit of getting rid of aggression."*

Leonard: interview at his Centre, 2nd July 2018.

5.4.4.3 My sense of humour is very crash, bang, wallop

Leonard's sense of humour was physical too. Caroline described it as "sadistic" and "warped". Engaging in physical activity offered Leonard the chance to continue to identify himself through his humour. For example,

"I like doing the bodyline…aiming the shuttlecock right at the person and hitting it as hard as I can…I don't know, it is just funny, and…no one can get hurt…"

Leonard: go-along interview at his Centre, 22nd January 2018.

This was Leonard feeling he could be himself through physicality, in the manner outlined by Tregaskis (2003). His humour had meaning beyond the joke element, however. For instance, it enabled him to relate to his two adult sons, through pranks and horseplay:

"…whenever they go in the swimming pool, all they want to do is drown me (Leonard laughs). *So it's a bit of a fight, and one is trying to drown the other…it gets a bit aggressive."*

Leonard: interview at his Centre, 2nd July 2018.

5.4.4.4 Now my week is all sport

The fluid and adaptable nature of identity, characterised within the work of Snyder and Spreitzer (1979), and of Brown (2017), enabled Leonard and Caroline to transform how they approached life, in particular through the introduction of engagement in activity at their Centre.

Participation was simple and clear, in contrast to the complexity of modern society (Weiss, 2001). Similarly to people living with dementia engaging in leisure more generally (Dupuis *et al.,* 2012), Leonard found he could develop his identity through what he did. As suggested by Cohen-Gewerc and Stebbins, 2013, such activity can provide personal agency. Leonard found this because he could choose what to do. The multiple opportunities for activity and their availability enabled his new direction, and in this way his connection with this place of leisure could be strong (Cohen-Gewerc and Stebbins, 2013, p.8). As Leonard said:

"…it's the variety, there's lots of things to do."

Leonard: go-along interview at his Centre, 22nd January 2018.

Additionally, the empathetic facilitation of Martin allowed Leonard to craft a routine laden with sporting opportunity. As he said:

"He's helpful…he's always around…and he's always helpful".

Leonard: interview at his Centre, 2nd July 2018.

Peers and coaches are important in enabling new identities to emerge through physical activity (Snyder and Spreitzer, 1979). However, Leonard was also drawing upon what Lundberg, *et al.,* (2011) had identified as inspiration for identity negotiation from his peers. For example:

“It’s about playing together, to achieve something…not necessarily…beating the person. Winning isn’t necessary. It’s about having a good game...enjoying playing together.”

Leonard: go-along interview at his Centre, 3rd May 2018.

Leonard and Caroline had used engagement at the Centre to reshape how they lived their lives. For example, they would play badminton and swim on days outside of the weekly schedule of the group, and visit to have a meal or engage in other social activities. As Leonard related:

“We come up here once and we was watching the rugby on the telly.”

Leonard: interview at his Centre, 2nd July 2018.

What Leonard engaged within was communicative leisure, characterised by meaningfulness and self-affirmation (Spracklen, 2013). It was not surprising therefore that he was so keen to continue to attend.

5.4.5 How I conceptualised Leonard’s core identity*: “I am resilient*”

Resilience provided the core element of Leonard’s identity. For example, the higher-order theme ‘I couldn’t do nothing about the things that went wrong’, aligns with resilience because, despite his desire to struggle, there was little he felt he could often personally do to make things better. This included, for example, his long-term disabilities, the adverse behaviour from his father towards him, and the arbitrary closing of his employment.

‘I’ve done what I can’, communicates how Leonard felt he endeavoured throughout his life to influence for the better those aspects he perceived as negative. For example, as a young adult educating himself in the academic and practical skills he needed to be successful in employment. He tried to address deficits that he felt strongly should have been attended to by others, such as his schoolteachers.

‘Really going for it is great’, suggested a key way Leonard engaged with the world to resist its unappealing aspects was to utilise his physical being as vigorously as possible. This was evidenced by how Leonard engaged in physical activity, how he realigned his routine to maximise opportunities to behave physically, and how he employed his sense of humour energetically and boisterously.

Leonard used his physicality to resist dementia, employing strengths based responses through physical activity. This has congruence with what has been written concerning the rehabilitation for people living with dementia (Swaffer, 2016). Rehabilitation framed as recovery through physical activity (Huang and Brittain, 2006), by offering ways from negative self-identification by providing potential for positive subjectivity, aligns with this. This is particularly powerful because resistance to stereotypes is freedom (Guthrie and Castelnuovo, 2001). Thus, elements akin to accounts of other primary participants were present for Leonard. The sense of collective identity he had formed through engagement alongside others, for example, highlighting the significance of his sociability within the setting of his Centre.

I turn now to my analysis of the data as they related to Jacqui.

5.5 Jacqui

Early Family Life

Jacqui was born in 1954 in Warkham, an industrial town in the West Midlands of England. She was sixty-three years old at the time the research commenced. Jacqui spent her childhood and most of her adult life living in Warkham. She experienced a difficult upbringing, lacking parental affection. Jacqui has one sibling, a younger sister, who she felt was afforded the love she never was. Both parents, her father in particular, had expectations of her which Jacqui believed she could not reach, for example in relation to academic attainment.

Leisure and Physical Activity

At school Jacqui was a keen runner, good enough for selection for competition at county level. However, she was discouraged from continuing to participate by her parents, primarily her father, who required her to prioritise paid employment as soon as she was old enough. In her late thirties Jacqui took up running again, for recreation and pleasure. Physical activity has always been important to her, but not so much organised sport. For example, latterly it helped to determine her choice of employment with the post-office. Here Jacqui valued the regular physical exercise of moving letters and small packages, throughout every day, across a large warehouse.

Adulthood and Employment

Jacqui had a difficult relationship with her husband, which contributed to divorce and estrangement from her three adult children and grand-children approximately four years before the research began. Prior to this Jacqui had worked alongside her husband for many years, helping manage his small business. She had entrepreneurial flair, for example building up a rented accommodation portfolio, which helped supplement their family finances. Upon the divorce, however, she lost this employment and income. Jacqui relinquished the final job she held, with the post-office, having to retire on grounds of ill-health caused by dementia, three years prior to engagement with my study.

Dementia and Contemporary Life

Jacqui was diagnosed with dementia with Lewy bodies. As a result she had difficulty with posture and physical dexterity, alongside compromised ability to read and write. Jacqui also had minor hallucinations which impacted upon her ability to orientate herself to her surroundings, and caused short term memory loss.

During data collection Jacqui engaged with the Centre closest to her home, on at least three days every week. She had attended there from time to time at different points during her life. She engaged with a range of publically available activities, for example going to the gym and using the swimming pool on her own. Additionally, Jacqui chose to attend exercise and physical activity sessions at the Centre for adults identifying with a range of physical and cognitive illnesses (not necessarily for people living with dementia exclusively therefore). Jacqui also took part in the weekly walk that was organised by her Centre.

These were open to anyone using the Centre and were typically two to three miles long. Patrick, the Centre Worker who facilitated the walk and several of the other activities Jacqui engaged with, was included as a research participant.

During the research Jacqui was living alone in a village, Moshton, five miles from her Centre. No public transport was available and she had to drive herself there. Since her divorce Jacqui had become a Jehovah's Witness. Company afforded through this was the only significant social contact she had with others, apart from through attendance at the Centre.

5.5.1 Jacqui's thematic overview

The thematic map in Figure 6 illustrates my analysis of Jacqui's data. This incorporates her core identity theme (turquoise box, in centre), her three higher order themes (blue, larger circles), and the eleven first-order themes (orange, smaller circles) which inform the analysis. The commentary which follows addresses each higher-order theme in turn.

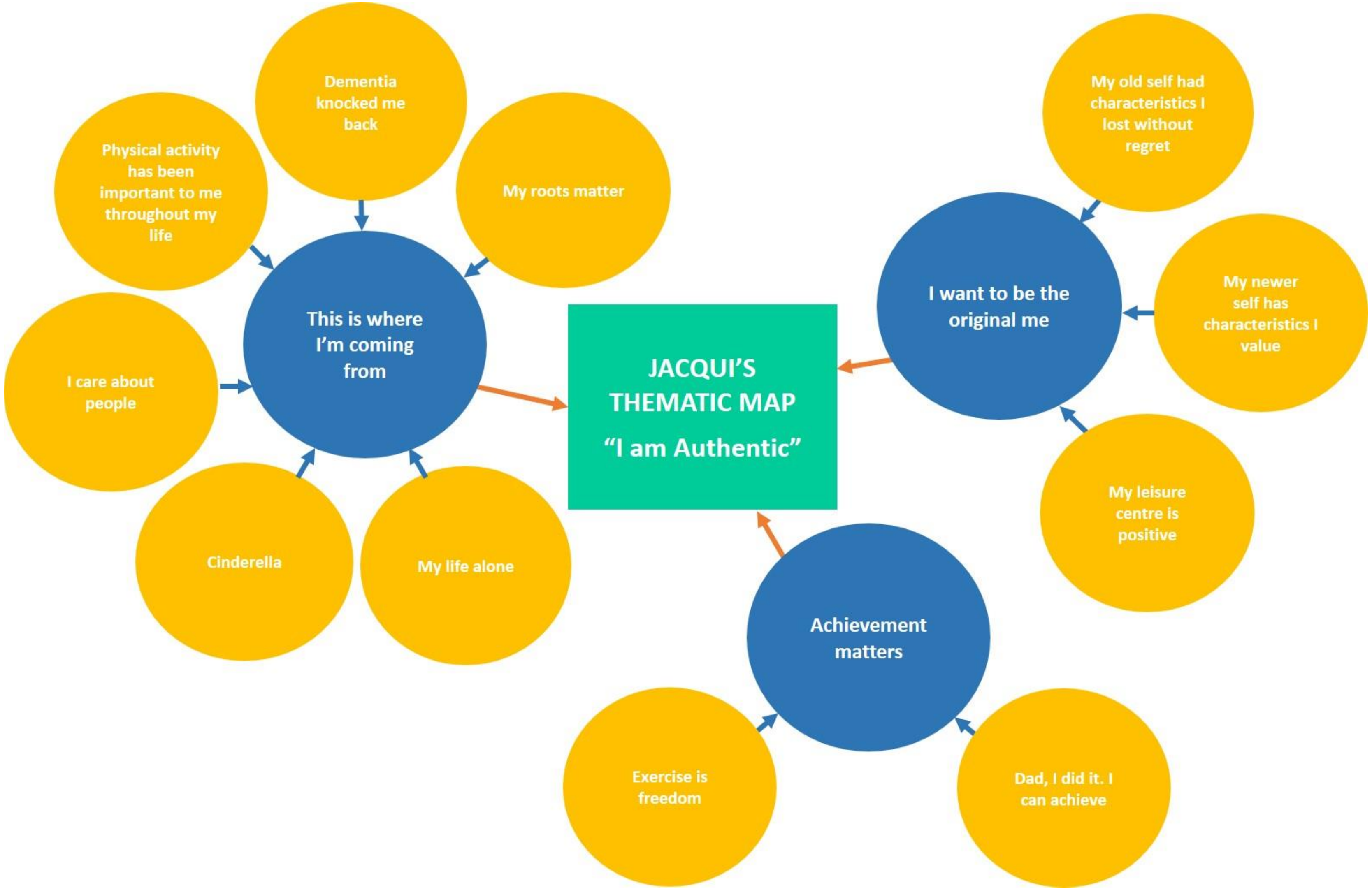

Figure 6: Schematic representation (thematic map) of core, higher order and first order themes for Jacqui in the maintenance and development of her identity.

5.5.2 ‘This is where I’m coming from’

This is the first of the three higher-order themes relating to how Jacqui’s identity was influenced by her engagement with the Centre. It is underpinned by six first-order themes:

1. My roots matter to me
2. I was Cinderella
3. Physical activity has been important to me throughout my life
4. I care about people and want the best for them
5. The dementia has knocked me back
6. My life alone

5.5.2.1 My roots matter to me

In the manner suggested by Spracklen (2013), Jacqui’s contemporary leisure choices, and what they meant to her, were influenced by the experience of her formative years and up-bringing. This involved understanding how being from Warkham influenced her sense of identity. It also concerned the impact the values and behaviour of her parents and grandparents had upon her.

Jacqui lived in or close to Warkham most of her life. Reflecting upon what this meant to her she said:

“It’s just born and bred, it’s just how you feel”.

Jacqui: interview at her Centre, 4th October 2018.

Thus being in and around the town from her earliest years held personal value for Jacqui. Some of her early memories were positive, for example those with her grandparents. Jacqui's paternal grandfather had been employed by the railway, an industry important to Warkham. Her memories of her contact with him in that context were joyful:

"…he worked on the railways, and he took me under his wing. He took me on the train, he took me to the trains."

Jacqui: interview at her Centre, 7th December 2017.

She spoke in similar terms when reflecting upon experiences alongside her maternal grandmother. As Warkham grew, different forms of employment had developed and Jacqui's grandmother had been employed as a house-keeper for a wealthy town-resident. Jacqui felt that this had left an impression on her, that in later years she had benefited from. For example, she related:

Jacqui: *"…she did the…really old fashioned cooking… and she used to sit us all on the table …with the Pear's soap and scrub our necks…"*
C.R.: *"And you're smiling now…"*

Jacqui: interview at her Centre, 7th December 2017.

5.5.2.2 I was Cinderella

The recollections, set out above, from early times in Warkham were positive and affirming. However, those involving her parents were the opposite. Jacqui explained:

“My parents were very Victorianised, and I wasn’t allowed to do anything because they would not spend on it. I had a younger sister…she was the apple of their eye and I was pushed out…”

Jacqui: interview at her Centre, 7th December 2017.

There were expectations too, for example:

“I was expected to get myself up for school… I had to clear out the ashes, re-lay the fire, fetch the coal in…I wasn’t encouraged to have friends…I was expected to do a lot of chores...”

Jacqui: interview at her Centre, 7th December 2017.

Jacqui referred to herself from that time as Cinderella. Later, whilst struggling to come to terms with dementia, the malignant social positioning she experienced from work colleagues at the post office, of the sort described by Sabat (2001), and Patterson *et al.,* (2018), was reminiscent of this. Thus, Jacqui’s conceptualisation of herself as Cinderella endured. As she said:

“…the others were feeling I was letting them down...swinging the lead…I really had…over worked…my mind was exploding and I didn’t understand…why.”

Jacqui: interview at her Centre, 7th December 2017.

A sense of being an outsider pertained, for example:

"I've always been different and that's why people disliked me, didn't understand me, because I wasn't a run of the mill."

Jacqui: interview at her Centre, 4th October 2018.

As I will demonstrate, feeling a weight of expectation she couldn't fulfil, interpreting this as unfair, and striving to show she could achieve, were powerful features of her identity, born from these formative features of her life. Thus, as Williams (1994) would argue, Jacqui's pre-diagnosis socialisation was powerful in influencing how she used physical activity to express who she was.

5.5.2.3 Physical activity has been important to me throughout my life

Physical activity had played a consistent part in Jacqui's life. This was despite her father ending the opportunity to be a runner. Jacqui explained:

"When I was young I was picked for the town sports, which I wasn't allowed to do by my Dad...I was always good at running…I got picked to be in a Warkham team, which would have gone national."

Jacqui: interview at her Centre, 7th December 2017.

In middle-age Jacqui would return to running for pleasure. As she related:

"I've always been an active person."

Jacqui: go-along interview at her Centre, 13th June 2018.

She valued the physical side of her employment, and illustrated this with an example, taken from when working with the post-office:

"They called me Road Runner… (Jacqui laughs)…*Because I was always in there, doing something, putting the hours in, rushing round."*

Jacqui: interview at her Centre, 5th February 2018.

Jacqui incorporated physical activity into her life. She was keen to argue, however, that she had done so without conforming to what she perceived as stereotypical behaviour based upon gender. For example she said:

"I'm a tom-boy…not into dolls. We'd go off on bike rides…climb trees, wear trousers, mix with the lads…"

Jacqui: interview at her Centre, 7th December 2017.

Jacqui appeared to equate this interpretation of gender to a proactive approach to physical activity, as she continued:

"*I've always felt that I have a need to be doing something but I don't know what. But it isn't sort of feministic, not powder and paint and fashion*."

Jacqui: interview at her Centre, 7th December 2017.

5.5.2.4 I care about people and want the best for them

Jacqui related a sensitive and compassionate side to her identity, which she felt was longstanding. For example:

"…I've always had that kind of inclination…I see people I like to help them."

Jacqui: interview at her Centre, 7th December 2017.

This continued and was contained in the empathy she held for other participants at the Centre:

"You can get together and talk through your problems …we've got all sorts of activities and abilities here."

Jacqui: go-along interview at her Centre, 13th June 2018.

Patrick confirmed this aspect of Jacqui's identity, relating:

"…she's a lovely lady…very caring."

Patrick: interview at the Centre, 10th April 2018.

5.5.2.5 The dementia has knocked me back

Reflecting on more recent times, however, Jacqui described how dementia had shaped her feelings about herself in negative ways. For example, the earlier example from her place of work when being presumed lazy. This offended Jacqui's perception of herself as a hardworking contributor. She said:

"I can organise things, or I did do. I was very much the organiser and left to do that... the last job…the post office…they didn't want to lose me…"

Jacqui: interview at her Centre, 5th February 2018.

A sense of feeling authentic and its importance to her thus forms a key part of my analysis. Dementia brings increasing harm to those living with the syndrome (Alzheimer's Disease International, 2014). Thus, as her circumstances changed as a result of her illness, the symptoms of dementia brought on an 'identity crisis', of the sort described by Lundberg *et al.,* 2011. This meant Jacqui had to reconsider who she was. As she related:

"(It)… isn't pleasant thinking that's as good as it gets…That ever after isn't an ever after. You think it's coming crashing ever closer...I don't know whether next year I won't be able to do it".

Jacqui: interview at her Centre, 4th October 2018.

5.5.2.6 My life alone

Jacqui lived alone, she had no family carer and no contact with family. This made her anxious about the types of practical barriers highlighted by Son, Kerstetter and Mowen (2009), in particular, being prohibited from attendance at the Centre through lacking help with transport. Jacqui's anxiety was intense because she used the Centre to construct a significant part of her contemporary identity.

However, through seeking out company locally, via social engagement at her Centre, Jacqui was creating a neighbourhood identity, in the manner expressed by Odzakovic *et al.,* (2019). As these scholars also argue is often the case, as a person living alone with dementia Jacqui was taking steps to proactively shape her identity. This included reframing her situation. For example, she also expressed how living alone had advantages:

“It’s not pleasant that, but I don’t have to answer to anyone so it doesn’t matter.”

Jacqui: go-along interview at her Centre, 13th June 2018.

This aligned with aspects of her identity found within the next higher-order theme, in particular those relating to an agentic self. Indeed, the social isolation caused by her estrangement from family had recently encouraged Jacqui to incorporate a spiritual belief into her life. She had found this of particular value because she had met a new group of people, through attendance at meetings of this evangelist Christian denominational group. Jacqui related this was important to her, because she believed she had been able to replace what she called her “real family” in this manner. She said of those she had met:

“They’ve given me everything. They’ve fed me, they’ve clothed me, they’ve housed me. They’ve transported me. And who would do that for a no-body?”

Jacqui: interview at her Centre, 7th December 2017.

That question is telling because it reflects the impact the formative experiences had had upon Jacqui’s conception of herself. Thus, the literal place and the experiences Jacqui had in her early life were part of the context in which she engaged with the Centre. In turn that context had influence upon her contemporary identity in the manner I have detailed.

In conclusion, I aligned this first-order theme, along with the five preceding it, within the higher-order theme of ‘this is where I’m coming from’. These first-order themes were characterised either by long-established character traits held by Jacqui, or aspects of her life she felt she was now struggling to influence. The remaining two higher-order themes differed in the sense they were founded upon the sense Jacqui had for her own agency. It is to the first of these I now turn.

5.5.3 ‘I want to be the original me’

This higher-order theme, relating to how Jacqui’s identity was influenced by her engagement with her Centre, was underpinned by three first-order themes:

1. My old self had characteristics I lost without regret
2. My newer self has characteristics I value
3. My leisure centre is positive

Taken together they pointed towards an aspirational identity that Jacqui sought, something she understood as ‘the original me’.

5.5.3.1 My old self had characteristics I lost without regret

Jacqui aspired to be what she called:

“…the original me”.

Jacqui: interview at her Centre, 4th October 2018.

This was not her perception of how she saw herself now. Jacqui was critical of her contemporary self, relating she was:

"…somebody that is fat and idle…"

Jacqui: interview at her Centre, 4th October 2018.

The dementia made the prominence of what she referred to as her 'old self' more likely, and Jacqui resented this. For example, when discussing a regularly attended exercise class, she said of herself in comparison to those who attended alongside her:

"…because of my symptoms I'm worse off after three years, whereas the others are better."

Jacqui: go-along interview at her Centre, 13th June 2018.

5.5.3.2 My newer self has characteristics I value

Jacqui perceived her original self as having facets of identity she valued. For example,

"…the original me…it didn't matter how many knocks I had, I got up".

Jacqui: interview at her Centre, 4th October 2018.

This was her 'Road Runner' persona - characterised by energy, agency and resilience, rather than her account of the passive, put upon 'Cinderella'. Of course 'Cinderella' had preceded 'Road Runner' in Jacqui's life history, so in fact was the original me! However, Jacqui did not conceptualise it so. She was using ‘the original me’ as an aspirational identity. This formed part of her adjustment to living with dementia. This can be a difficult process (Lishman*, et al.,* 2016; Vince, Clarke, and Wolverson, 2017), and Jacqui found this, particularly as she recovered from her tumultuous family difficulties. Engaging in physical activity at the Centre, and in doing so discarding an ‘old self’, valuing ‘a newer self’, and striving to be ‘the original me’, were part of her readjustment. This sort of adjustment is fundamental to being able to live well with dementia (Bunn *et al*., 2012; Cheston 2013; Brooker *et al.*, 2017).

Road Runner was her physical activity identity. She felt it enabled her to do those things that such a positive conceptualisation could (Son, Kerstetter, and Mowen 2009). For example, it had strong association with how she motivated herself to engage in physical activity. As Jacqui said:

“I <u>need</u> to push myself to exercise”.

Jacqui: interview at her Centre, 5th February 2018.

She had used vigorous physical activity in happier times in her life and this had afforded her feeling of strong personal identity. For example, she recounted neighbours asking:

“…who’s that woman that runs everywhere?” (Jacqui laughs) *“…whoever is she?”…I would always go at a pace.”*

Jacqui: interview at her Centre, 7th December 2017.

Now, through physical activity, Jacqui was endeavouring to move from an impaired and negative sense of self, towards one that was oriented to the future and its opportunities. This could be something characterised by personal growth, self-fulfilment and positive contact with others, of the sort identified in the scholarship of Stebbins (1992), Oliver, Hudson and Thomas*,* 2016, and Dröes *et al*., (2017). Physical activity had the potential of offer such personal outcomes (Kissow, 2015). However, as Jacqui related:

"…it was something I definitely needed but it's got to come from me…"

Jacqui: interview at her Centre, 5th February 2018.

Jacqui offered a complex, contradictory narrative of her identity. For example, she also suggested that characteristics of the 'original me' were passive, but she still valued these:

"I…hide behind a crowd. I don't want to push forward…"

Jacqui: interview at her Centre, 5th February 2018.

And,

"I would never…lead the walk, no. I have done that. Now I like to hide in obscurity."

Jacqui: go-along interview at her Centre, 13th June 2018.

These traits did not cohere with her agentic aspirational identity. Thus, it is challenging to steer a clear course through this first-order theme. However, primarily, by appealing to a newer sense of herself, Jacqui is seeking an agentic identity, building ultimately into the higher order theme, ‘I want to be the original me’. Her engagement in activity at the Centre played a key role in her trying to realise this original self, as I will now show.

5.5.3.3 My leisure centre is positive

Jacqui perceived the Centre as something positive in her life, and a place she used to reframe her identity towards ‘the original me.’ Authenticity formed a core theme of her identity, and ‘original’ could be viewed as a synonym for ‘authentic’, as Jacqui framed her identity within the context of engagement with her Centre.

It was a familiar ‘geographic space’ (Cohen-Gewerc and Stebbins, 2013), where Jacqui pursued activities offering feelings of freedom, and authenticity. Jacqui preferred to orientate around familiar spaces, because of the symptoms of dementia. Thus, there were linkages between her identity and that physical activity space, in the manner described by Wise (2015). This resonated with aspects of the sensuous geography (Rodaway, 2002), and familiarity with terrain (Hockey and Collinson, 2007) discussed in Chapter 3. Links between the physical activity space and identity were important because Jacqui had always associated physical activity with her personal sense of freedom. Here, for example, she is discussing what cycling meant to her:

“It was just freedom to escape from restriction. Freedom to escape from life, at whatever age, for whatever reason.”

Jacqui: interview at her Centre, 7th December 2017.

Engaging in physical activity offers potential to strengthen feelings of personal identity (Perras *et al.,* 2015). Thus, Jacqui used what was offered at the Centre to strengthen her sense of original self. As she said:

“You’re not just a number that’s passed through they haven’t even noticed.”

Jacqui: interview at her Centre, 4th October 2018.

It was her relationships with the people at the Centre, as well as familiarity with the place, that enabled her to aspire to be her original self, in the manner outlined by Markovitch *et al.,* (2017). Jacqui attended regularly and built relationships with others there that served to shape her identity through the feedback they offered socially, in the manner Erikson, (1995), and Lundberg *et al.,* (2011) had suggested would be the case. As Jacqui said:

“…it’s important that there are others…I’m aware of them and I know of them and it’s nice…”

Jacqui: interview at her Centre, 4th October 2018.

She chose which sessions to attend, which activities to participate in, and thus whom she engaged with. This was agentic and part of claiming her status as a citizen through leisure in a public space. This aligned with literature inherent to my study, in particular, Spracklen, (2013), Bartlett, (2016), and Birt *et al*., (2017). Generally Jacqui chose to participate in activity classes for older people or for people with disabilities. She valued this, saying:

"…it's not nice for them that they've got problems, but it's nice that you're there to commiserate…"

Jacqui: interview at her Centre, 4th October 2018.

Choosing to be alongside people in this way provided Jacqui with a sense of belonging and purpose, of the sort detailed by Wearing (2011), Anderson and Whitfield (2013), Stevens, *et al.,* (2017), Jones (2017), and Sabat (2018). Jacqui corroborated this reflecting:

"…it's nice that there's the facility for us all to be in our various ways".

Jacqui: interview at her Centre, 4th October 2018.

This also helped Jacqui feel better about who she was, offering a means to reject the oppressive attitudes she had encountered in her life, most recently relating to the dementia. However, only rarely did Jacqui seek to establish long-term relationships. She preferred instead to engage more lightly, for example relating:

"I don't know them beyond the walk."

Jacqui: go-along interview at her Centre, 13th June 2018.

The regular walks were a good example of how Jacqui used her embodiment to support her identity, in the style described by Merleau-Ponty (1962) and Wright (2018). There was no need to talk if she did not want to, and because Jacqui chose not to establish long lasting relationships she could engage in a manner she felt most comfortable with. This aligned with traits she associated with her old self, illustrating once more the complex nature of her identity. However, in the manner described Spracklen (2013), Jacqui used engagement at the Centre to create her sense of belonging, and she achieved this through keeping the focus off dementia (Phinney, *et al.*, 2016). This was even though she felt kinship alongside attendees who had other health difficulties.

In addition, Jacqui felt the Centre to be a positive place in large part because of the contribution of Patrick. The way in which he facilitated activities and his presence helped Jacqui to reframe her sense of self. For example, she said:

"…whether he's walking or within a class, or in the gym, he's obviously watching you and understanding the differences, and…he adjusts the exercises …and he talks us out of our problems…he just calms us."

Jacqui: interview at her Centre, 4th October 2018.

Lindelof *et al.,* (2017) indicated that good facilitation could enhance motivation to engage in activity, and Patrick's approach helped encourage Jacqui to participate in physical activity. Additionally, Rojek (2005) suggested that leisure could link participants to a sense of community. Jacqui related that she felt engaged with the community of the Centre, and this was associated with how

Patrick went about his role. Furthermore, the nature of the facilitation had rehabilitative components of the sort detailed by Swaffer (2016). For example, Patrick enabled attendees to play roles in supporting and leading activities. Thus, Jacqui moved from feeling negative about herself to a more positive self-image, in the manner advocated by Huang and Brittain (2006). As Patrick said:

“Jacqui…supports everything…anything that I tried to start Jacqui would support and promote for me…first person (in), last person to go. Always will help me…”

Patrick: interview at the Centre, 10th April 2018.

Being able to find this agency in a physical activity context meant Jacqui felt free to seek what she wanted, her original self. This provided the combination of a sense of her individuality, alongside feeling she was part of a community providing purpose and meaning, such as that outlined by Cohen-Gewerc and Stebbins, (2013). As I discussed earlier, Jacqui aspired to feelings of authenticity which she linked to positive attributes about herself. Her contribution to facilitation of activities helped to demonstrate that to her and others, in the manner detailed by Weiss (2001).

The approach Patrick employed had another important benefit. Without familial contact Jacqui lacked opportunity to establish the couple identity I described earlier (Hernandez *et al.,* 2019). Potentially, therefore, she was denied the connectivity such relationships could afford to emotional and practical resources (Bosco *et al.,* 2019b). By organising the offering of the Centre as he did Patrick provided activities aligned with Jacqui’s priorities (Brooker and Latham, 2016). There was relatedness between them, as described in Brown (2017), on this occasion in a professional rather than a familial sense, that enabled participation in the life of the community (Menec *et al.,* 2011; Glicksman, Ring and Kleban, 2016). Patrick was thus a ‘significant other’ for Jacqui, in the manner described by Williams (1994), who was able to use the situation of the setting and his own professional empathy to contribute towards Jacqui’s socialisation as the ‘original me’.

5.5.4 ‘Achievement matters’

This is the final higher-order theme relating to how Jacqui’s identity was influenced by her engagement with the activity of Centres. It is underpinned by two first-order themes:

1. Exercise is freedom
2. Dad I did it, I can achieve

5.5.4.1 Exercise is freedom

Jacqui valued physical activity because it offered positive outcomes. She used exercise to achieve improvements in her life, for example employing it to escape the oppression she felt at the hands of her father’s influence and husband’s behaviour. In recent times she utilised physical activity to ameliorate the negative impact of dementia, by:

“…keeping a par with it.”

Jacqui: interview at her Centre, 4th October 2018.

Jacqui believed that through engaging in physical activity she was recognized as someone with purpose in her life, according with an essential tenet of social citizenship (Bartlett and O'Connor, 2007 and 2010). This also links to the concept of freedom, a core element of my discussion. As Torkildsen (1999) suggested, such opportunity afforded the freedom to choose and this could feel empowering. Jacqui perceived this, saying:

"…it is a freedom. It is actually something I can do, I have done…I know it achieves something".

Jacqui interview at her Centre, 4th October 2018.

Jacqui utilised physical activity to demonstrate who she was, in the manner suggested by Spracklen, (2013). This offered opportunity to use the freedom she believed physical activity offered to continue to perceive herself as someone with a positive future. Leisure generally can offer this for people living with dementia (Dupuis *et al.,* 2012). Jacqui utilised this through physical activity. She valued engagement in physical activity very much therefore:

"…because life's there".

Jacqui: interview at her Centre, 5th February 2018.

The authenticity Jacqui sought could be demonstrated through achievement. This was a long-standing identity trait. For example, Jacqui was proud of how she had established the property portfolio of her family business:

"I didn't do it for a brag, I did it because you can. The world's there. You can get it."

Jacqui: interview at her Centre, 7th December 2017.

A sense of achievement can be realised by people living with dementia through leisure activity (Genoe, 2010). This was what Jacqui felt now, via engagement in physical activity. She linked this to her feeling of agency, relating:

"…everybody should want to be active because the more…you're not reliant on somebody else. The more you can still continue to do for yourself or somebody else."

Jacqui: interview at her Centre, 4th October 2018.

5.5.4.2 Dad I did it, I can achieve

Much of the desire to achieve and thus show her true self came from the influence of her father. It was a reaction to how he had behaved towards her. As she said forcefully when reflecting upon her achievements in life:

"Dad, I did it."

Jacqui: interview at her Centre, 7th December 2017.

The powerful impact of his legacy fundamentally influenced how she approached life, and what she expected of herself. Jacqui believed hard work and achievement mattered, and the responsibility for them lay with the person themselves. As she said:

"…you've got out, you've come here, you've done some kind of exercise...there is something infinitely better than having just stayed at home and sat."

Jacqui: interview at her Centre, 4th October 2018.

In line with the findings of both, Genoe (2010), and Cohen-Gewerc and Stebbins (2013), the public and transparent nature of her physical activity offered opportunity to demonstrate this achievement and authenticity. Jacqui had used her body in physical activity to realise her sense of an empowered self, at key moments, all her life. For example, as a young runner, and later as 'Road Runner'. This was 'embodied identity mobility', an important way in which voices marginalised within society can be given voice (Mayoh, Jones and Prince, 2018).

5.5.5 How I conceptualised Jacqui's core identity*: "I am authentic*"

Authenticity encapsulated much of Jacqui's enduring framework for her identity. I believe this was also demonstrated within the email correspondence from Jacqui to me that I set out in Chapter 4 (see page 138). That reflected the value Jacqui placed upon authenticity. This was a contemporary example, highlighting the importance she accorded with what she felt was empathy.

Authenticity has been a motivating priority for her life, emanating from the difficulties she experienced in early times, and reflected in how she responded by showing what she considered to be her true self through her actions. Later, Jacqui strove to be someone with an energetic and proactive identity, encapsulating this as ‘the original me’. There is uncertainty about chronology, and also a blending of the attributes Jacqui perceived as attractive. Thus, more passive characteristics, mainly associated with earlier times in her life, were cited as positive at the time of the research. This was despite the strong ambition she had for herself to rediscover and maintain that newer, more proactive, self-identity. However, authenticity was her priority, and it overlaid other features that came through strongly, such as resilience, freedom, and sociability. Jacqui used physical activity to achieve, to propel her sense of self towards the desired identity as ‘original me’, and in this way to demonstrate her authenticity.

5.6 Conclusion to the Findings: Participant stories chapter

In this chapter I have introduced the four people living with dementia who were the primary research participants in my study. I have set out how each used engagement at their Centre, and physical activity to maintain and develop their identity. There are similarities and differences between each participant story. These involve over-arching themes of loss and continuity, and four core identity themes of authenticity, freedom, resilience and sociability. The following chapter will explore insights that can be garnered from across the four accounts, to contribute understanding about how engagement with Centres can enable people living with dementia to maintain and develop their identity.

Chapter 6: Cross Cutting Themes

6.1. Introduction

Loss and continuity were over-arching themes derived from my analysis. In the previous chapter I set out how every primary participant had experienced loss as a result of dementia. For example, loss of status and role, that frequently related to employment and social standing. There was also loss in terms of ability, expressed as no longer feeling able to engage well when in company. I detailed how these losses had influenced the identity of primary participants.

However, I also argued that each had striven to sustain continuity in their lives, in particular through engagement with what went on within their Centre. I suggested that by endeavouring to realise and sustain feelings about themselves linked to sociability (Ivan), freedom (Paul), resilience (Leonard) and authenticity (Jacqui), continuity could be attained. These were the core identity themes derived from my analysis, although categories were not exclusive to each primary participant but were also evident in others experiences too. Loss (Brown, 2017) and continuity (Lindelof *et al.,* 2017) have been previously noted to inform the experience of living with dementia. However, a dynamic, progressive sense of continuity, where individuals living with dementia harness feelings about their future and aspirations, is less often reported.

This chapter progresses my discussion with twin aims. Firstly, to explore how the over-arching and core identity themes might extend beyond the context of the primary participant I have attributed them to, and thus play a wider role in influencing identity for people living with dementia. Secondly, based upon this, to understand more about how Centres might help people living with dementia continue to shape their identity in dynamic and progressive ways, and to retain a feeling of still being ‘me’.

I employ theory drawn from two studies in my literature review, the opportunity structure model, as developed by Lundberg *et al.,* (2011) and from the scholarship of Williams (1994). Both were conceptualised in the context of physical activity by athletes with disabilities. Although my research did not have a specific focus upon athletes with disabilities in the traditional sense, there is resonance in that theoretical insight helps illustrate how, by engaging in activity at Centres, people living with dementia have the opportunity to continue to construct their identity. Lundberg’s work explains how Centres can operate in ways to enable the shaping of identity. Williams’ study enables me to highlight the influence people living with dementia bring to identity construction, and the nature and significance of social interaction within this. Whilst the study was published some time ago it was also valuable because Williams was endeavouring to strengthen understanding about identity formation where explanations were theoretically inadequate. I was wrestling with similar issues, my research having found there remains no theory of identity construction for people living with dementia engaging in physical activity.

I also utilise the phenomenological philosophy underpinning my study to articulate how people living with dementia relate their sense of identity to their lives, and how people use their bodies to realise meaning about their sense of self. Additionally, I continue to draw upon the concept of social citizenship, for example regarding how relational citizenship has been applied to the context of living with dementia (Kontos, 2017), and also understanding the ‘active citizenship’ of people living with dementia (Birt *et al.,* 2017, p.203). Both accorded with my findings, for example recognition of the significance of social interactions, and how people bodily use activity offered by Centres to continue to progress their lives in agentic ways as they adjust to living with dementia. I also return to theoretical understandings about place articulated by Lengen and Kisteman, (2012), which enable me to consider the influence of place on the identity of people living with dementia.

6.2. Loss, Continuity and Identity

The sense of loss held by primary participants relates to many features inherent to their identity, for example of loss of abilities, employment and relationships. Loss is common in the experience of people living with dementia, as symptoms of related illnesses and their impact, serve to disrupt narratives of life, and denies individuals a sense of future (Sharp, 2019). As I explain below my findings showed that loss was inter-twined with continuity in how primary participants perceived ongoing understanding of their identity.

6.2.1 Loss, dementia and identity

Although focused upon individuals generally, research by Seto and Schlegel (2018) was instructive in enabling me to understand loss in relation to the identity of people living with dementia. These scholars argue individuals hold a sense of their identity, and this comprehension changes over the life course. They suggest that identity tends to be increasingly characterised by feelings of authenticity. Seto and Schlegel advanced two theories to illustrate this. The first was where individuals combined knowledge of personal history with aspirations for their future, with the goal of a sense of coherence and meaning about their identity. The second was where individuals, irrespective of age, perceived their identity had transformed significantly over the previous ten years, but anticipated minimal change in the years ahead.

Advancing the work of Seto and Schlegel is important for understanding loss for people living with dementia in relation to their identity, because both theoretical trajectories suggest individuals reach a point where understanding about who they are is enhanced, and sometimes even settled. Thus, the first holds that identity will feel more authentic over time as individuals combine their life story to date with their aspirational future, whilst the second includes comforting certainty about the stability of one’s contemporary identity. In contrast with both, people living with dementia are likely to experience sharp feelings of loss in relation to their identity, because dementia brings with it loss of certainty about and confidence in one’s future. Behaviour of individuals or groups which, even unintentionally, stigmatises and/ or discriminates against people living with dementia (Kitwood, 1997; Patterson *et al.,* 2018; Bartlett and Brannelly, 2019a) will exacerbate this.

Erosion of feelings of an authentic self is particularly corrosive considering the value society places upon the virtuosity of authenticity, with ‘finding your true self’ being popularly aspirational (Seto and Schlegel, 2018). Authenticity, a core theme of my analysis, has been understood in the context of living with dementia as meaning being true to oneself (Hughes, 2019). In the previous chapter I showed how this loss is likely to be powerfully felt, and resisted by individuals living with dementia.

6.2.2 Loss, dementia and older age

There is correlation between dementia and ageing (Odzakovic *et al.,* 2019). Within the daily context of their lives people living with dementia are likely to experience feelings of loss related to both dementia and older age. This is complex because these are issues that are intertwined but also separate, and studies show how losses relating to physical health can involve both older age and dementia (Chern and Golub 2019). For example, those resulting in sensory loss.

Loss of physical health is a preconception facing older people (Wheaton, 2019). Therefore, because dementia is a state of ill-health, and despite the growing narrative that it is possible to live well with dementia (Brooker and Latham, 2016), the medicalised paradigm presenting ageing as inevitable decline (Wheaton, 2019) is a further marker of loss for people living with dementia to bear. There are losses too inherent in how older people, and people living with dementia are perceived within society. These are damaging to the identity held by people with dementia, because of societal conceptions of older people being a burden (Tulle, 2015), working in tandem with perceptions of people living with dementia in older age as entirely passive, and without purpose (Latimer, 2018). My research indicates this should be challenged, and I explain how later in relation to societal notions of the vulnerability of people living with dementia inevitably implying weakness.

Primary participants felt loss in relation to their age. This had resonance with phenomenological understandings of the temporal nature of life, described in Chapter 3. In particular, where feelings of angst promoted self-understanding about being-in-the-world (Heidegger, 1962). For example, Paul said, when considering his earlier experiences as a sport's player:

"…it's all gone now hasn't it."

Paul: interview at home, 11th November 2017.

Paul was the oldest primary participant. However, the younger participants felt loss relating to age and identity too. For example, as Jacqui said of relinquishing her employment due to dementia:

"I couldn't do it now…there was a total and utter void for about a month after I left work".

Jacqui: interview at her Centre, 7th December 2017.

Therefore loss was keenly felt by primary participants, in part because they recognised a risk they could no longer be true to their understanding of their identity. How feelings about loss of identity might extend to other people living with dementia more is complex. My research demonstrated that angst was important in generating a sense of loss, and I have utilised theory to help conjecture how this could apply to others living with dementia.

6.2.3 Loss and 'identity crisis'

The concept of the identity crisis, developed by Erikson (1995), and incorporated into the work on identity within physical activity contexts by Lundberg *et al.,* (2011), is helpful to my discussion explaining what loss means in relation to identity formation. An identity crisis is a situation or time when a person explores a different way of perceiving themselves due to adversity within their life. For example, Lundberg *et al.,* (2011) suggested this could be through negative labelling and stereotyping experienced by athletes because of their disability. This resonates with Heideggerian ideas about angst discussed in Chapter 3. I believe that people living with dementia in my research experienced identity crises prompted by losses felt brought on by the syndrome. For primary participants these related to those which eroded their sense of identity.

How Lundberg *et al.,* (2011) interpret identity crisis is helpful in understanding what loss means in these circumstances. This is because the study reframes the concept to suggest it can also be about discovery of new knowledge about oneself, or rediscovering knowledge. This is achieved through what has been termed an opportunity structure (Swann and Bosson, 2008). Understanding this assists my analysis because it shows how loss can link to continuity, and how continuity can be something progressive and positive in relation to identity.

6.3 Opportunity Structures and their role in the continuity of identity

Continuity ran parallel to loss within the accounts of the primary participants and from my observations, appearing to offer something dynamic and positive in contrast. Opportunity structures are helpful in comprehending this as they understand that individuals subconsciously set out to maintain their identity (Swann, 1987). Motivations include the desire to retain autonomy and competence, feelings of being a whole-person psychologically, and of belonging and connectedness with others (Swann and Bosson, 2008). Opportunity structures can meet these needs by providing feedback upon one's identity through engagement with vocations, hobbies, leisure activities, or from individuals (Swann and Bosson, 2008).

This concept resonated with my analysis for two reasons. Firstly, the self-perception of people living with dementia can be strongly influenced by the feedback received from others, especially relating to how much agency others perceive the person retains (Sharp, 2019). Inherent was my understanding that the influence of societal features, including how people living with dementia felt they are perceived by others (Bartlett and O'Connor, 2007 and 2010; Birt *et al.,* 2017) can be significant in whether people living with dementia can look ahead positively to their future.

Secondly, the scholarship of Lundberg *et al.,* (2011) progressed understanding of opportunity structures to offer comprehension of identity formation within the milieu of adapted activities for disabled people. Although not absolutely aligned with my research, it had similarity, and the concept thus offered potential to enable me to understand more about what I was interested in. For example, Lundberg *et al.,* (2011) argued that for disabled athletes experiencing identity crisis triggered a personal reformulation of their future. For primary participants in my research this involved utilising aspects of their core identity in new ways. For example, Ivan expressing his sociability without speech. Additionally, Lundberg *et al*. identified characteristics of opportunity structures which had similarities with the themes of my research. Their work acknowledged autonomy, competence, and wholeness, whereas my analysis identified authenticity, and resilience. Their scholarship suggested opportunity structures offered potential for athletes to realise belonging and connectedness, whilst my analysis had highlighted how primary participants valued sociability. In the discussion that follows I will also show how my findings indicated freedom intersected with opportunity structures. Prior to this, however, I will address the three ways in which understanding of the opportunity structure enabled me to explain how Centres offered people living with dementia the prospect of shaping their identity.

I include here the Schematic Representation of my Findings (Figure 7). This shows how opportunity structures can play a role in the ongoing construction of identity of people living with dementia. This is by acting in combination with the life story and personal attributes of individuals as they engage at Centres, and the interaction those individuals have with others in Centre settings. My research also showed how, in these ways, identity can be shaped so that the physical activity identities of individuals living with dementia can extend beyond the Centre location, and into daily life. I will explain this, with reference to this schematic representation as my discussion continues.

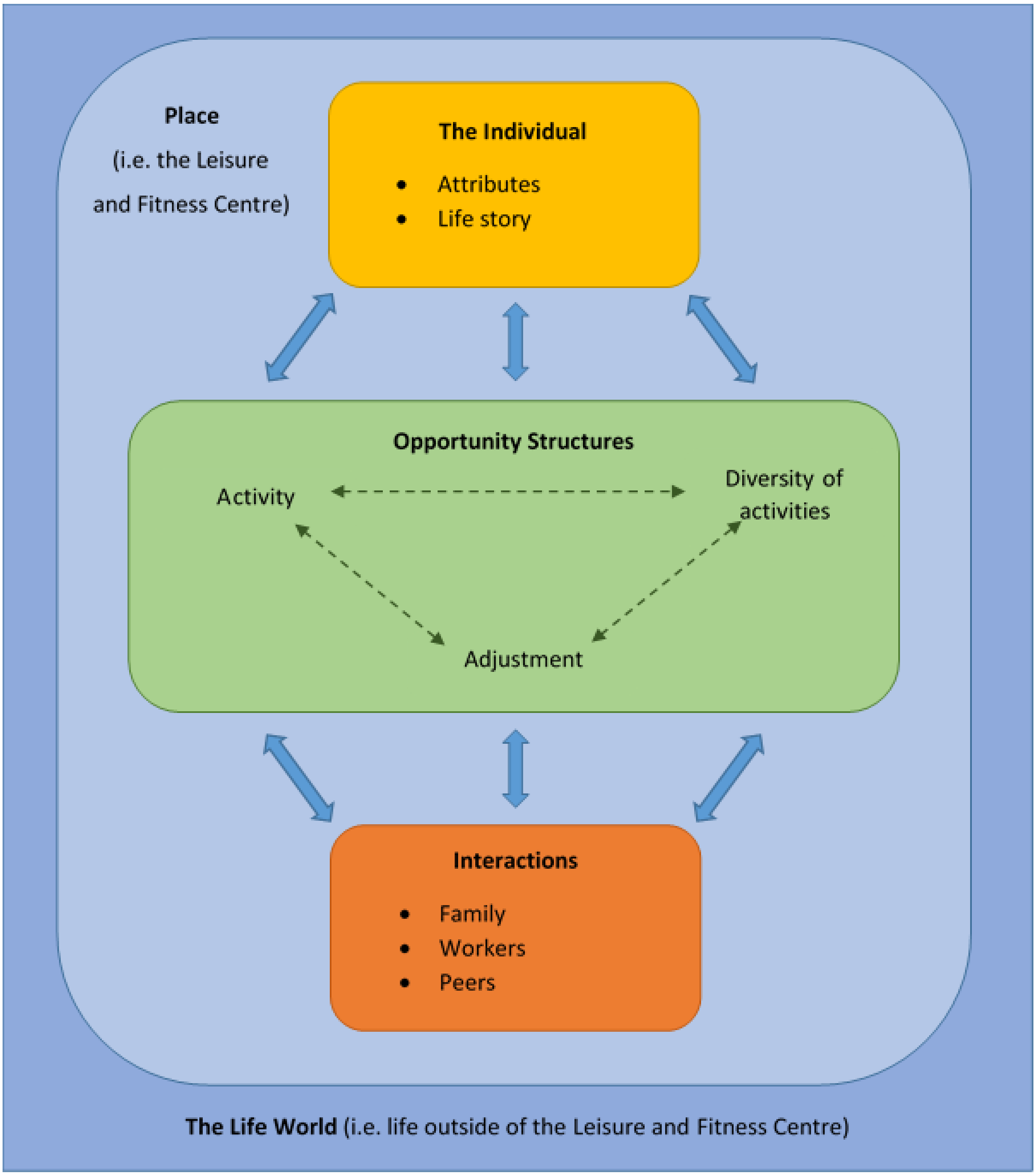

Figure 7: Schematic Representation of My Findings

6.3.1. Physical Activity as an opportunity structure

Lundberg *et al.,* (2011) concluded that adaptive sports and recreation activities were opportunity structures that facilitated identity negotiation. It was the adapted activities which enabled this, either through how participants felt about their engagement with them, or from feedback received from others. In their study these activities had been adapted to meet the participation requirements of disabled athletes. This differs from my research as the sports activities were not adapted, and primary participants were living with dementia rather than a physical disability. However, there is helpful insight to be gained.

For example, Lundberg *et al.,* (2011) argued that activities could provide a context through which a stigmatized identity could be redefined. Their participants related that by participating in adapted activities they could feel 'normal'. This was not a term used by primary participants in my research. However, what was said, and what I observed, indicated that engaging in physical activities were frequently motivated, by what might be described as normal concerns. For example, Jacqui told me part of her motivation was related to keeping in trim:

'I don't like being heavy weight…I'm a lot fatter than I was when I was working'.

Jacqui: interview at her Centre, 5th February 2018.

Another example is from what I observed of Leonard playing badminton alongside a volunteer, who had become his friend at the Centre. I noted:

‘Leonard and Ken get on well. They are comfortable in each other’s company. They chatted at points about things they had been doing in recent days whilst they played.’

Leonard: participant observation at his Centre, 2nd July 2018.

Thus, the activities primary participants engaged in acted as opportunity structures. Jacqui’s comments reflect her desire to feel agentic and authentic. This was also true of Leonard’s engagement in badminton, and suggested too that sociability could be realised in that way.

Lundberg’s research participants reported that through physical movement they had experienced a sense of freedom (Lundberg *et al.,* 2011, p.221). Freedom was a core theme of my analysis, and engaging in specific activities had offered primary participants both freedom from undesired aspects of life, and also freedom to participate in activity that were attractive. For example, freedom was realised through resisting societal stereotypes (Guthrie and Castelnuovo, 2001) as Leonard’s game with Ken illustrated. Societal expectations for people living with dementia are often low and negative (Noone and Jenkins, 2018). In my experience public perceptions of people living with dementia do not include that they play badminton in leisure centres, certainly not whilst casually discussing day to day matters irrelevant to formal arrangements for their health or care.

An example, provided by Jacqui, illustrates how her chosen activity provided freedom. She said:

“I just go with the flow.”

Jacqui: go-along interview at her Centre, 13th June 2018.

Feeling you are able to engage in the activity of your choice is important in enabling individuals to continue to redefine their identity (Lundberg *et al.,* 2016).

Thus, through providing specific physical activities, Centres are well placed to enable people living with dementia opportunity to shape their identity. There is no guarantee of this of course. Indeed a very prescriptive approach may limit freedom of choice (Williams, 1994). For example, Jacqui said she liked approaches to leisure free of restriction:

“I could do something without somebody saying “you can’t”.”

Jacqui: interview at her Centre, 7th December 2017.

Therefore, to maximise opportunity individuals should be enabled to determine how they wish engage in leisure (Torkildsen, 1999; Williams 1994). Freedom of choice in activity is essential to realising freedom for people with dementia in the leisure context (Noone and Jenkins, 2018, p.885).

6.3.2 Opportunity structures that help people adjust to living with dementia

Feelings of loss, including relating to identity, can impede the ability of people living with dementia to adjust to their circumstances (Sharp, 2019). In addition, people living with dementia may recognise the progressive nature of the syndrome, but be uncertain about how and when this will disrupt their future (Birt *et al.,* 2017).

Despite this, it is possible for people living with dementia to adjust, and feel able to approach their future with a sense of ongoing purpose (Sharp, 2019). To do so certain factors must be in place (Cheston, 2013). For example, it is important for individuals to retain a sense of their strengths, to continue to hold personal beliefs, have social contact, and a feeling of equality when with others (Williams, 1994; Birt, *et al.,* 2017). This aligns with the 'continuity theory of aging' (Lindelof *et al.,* 2017), identified within my review of the literature, where continuity of identity is linked to physical activity. For example, individuals endeavouring to maintain this through sustaining a routine of physical activity.

Engaging with what is offered by a Centre could contribute to people making such adjustments, if presented as opportunity structures in two particular ways. Firstly, their offering must be tailored in ways to support people to be active citizens, in the manner suggested by Birt, *et al.,* (2017), in particular to sustain participatory roles within daily life. Secondly they must organise what they do so it enables people to recognise how engagement is having an impact upon how they perceive themselves. Lundberg *et al.,* (2011) summarise this as individuals being enabled to note feedback relating to identity, and use it to shape their ongoing sense of self.

Considering the first of these ways, in the current research primary participants engaged differently with their Centres, suggesting that such opportunity structures were present. For example, Ivan chose to participate within mainstreamed activities, such as exercise classes and use of the gym. In contrast Leonard valued the opportunity to attend the group for people living with dementia, as well as participating in other activity, for example, public swimming sessions. Paul was happy to play table-tennis with peers in a public place. Jacqui chose to support the provision of activity by helping Patrick deliver exercise sessions. Such decisions and examples suggest that feeling one is an equal member of whatever forum one chooses to engage within may be even more important than the nature of the activity itself. The opportunity that Centres provide enables people living with dementia to continue to shape their identity and thereby adjust to living with the syndrome.

The second factor is recognition that feedback can help individuals reframe the sense of self, and build new physical activity identities which have a focus upon the future (Lundberg, *et al,* 2011; Son, Kerstetter, and Mowen, 2009). Again it is the manner in which the offering is made that can determine the effectiveness of this for people living with dementia. Thus, it was through the support her Centre gave Jacqui which enabled her to continue to frame herself as someone with a physical activity identity. For example, she related:

'…somebody's diarising it for you…dictating it for you…pushing you to do something.'

Jacqui: interview at her Centre, 5th February 2018.

This is the sort of freedom identified by Cohen-Gewerc and Stebbins (2013), when they highlighted that freedom emanates from feeling one has personal choice, in combination with feelings of safety and support arising from structures put in place by others.

My research also discovered that new identities can be formed in this manner, and that feedback does not have to be provided by another person. For example, Leonard used his own reflections, to adjust and develop a physical activity identity. He had been reluctant to engage with the activities of the Centre, and had not conceptualised himself as ‘sporty’. However, he had engaged, liked what he did, and, in his opinion, had done well. For example, when asked about how he felt about playing badminton said,

‘…brilliant, great… love it.’

Leonard: interview at his Centre, 22nd January 2018.

Because the offering enabled reflection upon his feelings about engagement, Leonard had been able to reshape his identity. Of course, it is possible for individuals to exercise alone, perhaps at home, and therefore it need not be necessary for a Centre to be the entity that is the opportunity structure, in the manner I have described. However, Centres tend to be places where socialisation happens, enabling opportunity structures the chance to operate in this way. The example highlighted above, involving Leonard and Ken, is indicative. The nature of the offering of Centres provides opportunity for individuals to express their reflections on feelings about engagement, in ways that could not happen in contexts where activity happens in isolation, and also highlights the importance of place.

Indeed the public nature of engagement is important in the context of this discussion about identity formation, and the example of Leonard is illustrative of that too. It enabled him to demonstrate the significance of feeling resilient, which as I showed was important in helping him adjust to living with dementia. This accords with phenomenological understandings of resoluteness, described in Chapter 3. Thus, in the manner suggested by Heideggerian philosophy (Heidegger, 1962) Leonard had been enabled to achieve a moment of vision when preconceptions he held about himself could be shaken off. This was through his resoluteness, being able to respond to uncertainty about the future (Large, 2008). For Leonard this was through the opportunity his Centre afforded him to engage in vigorous physical activity.

Resilience, demonstrated as part of resoluteness, is relevant here. It is understood as the ability to cope with major life stressors and to respond in ways that either enhance or hold stable the situation of the person (Fontes and Neri, 2015). My study found resilience is future oriented, in the sense that people look ahead and make plans to cope and respond to adversity (Conder *et al.,* 2015). Primary participants might not have deliberated on this consciously or in detail. However, they used their engagement with their Centre, and dedication to what they were doing there, to be resilient, in the manner outlined by Fontes and Neri (2015). For example, as Jacqui said about continuing to engage regularly in physical activity:

'…it's got to come from me'.

Jacqui: interview at her Centre, 5th February 2018.

Such resilience, born out of a sense of purpose, can be especially powerful and affirming because it is meaningful to the person (Fontes and Neri, 2015).

The opposite of resilience is vulnerability (Fletcher and Sarkar, 2016). People living with dementia are popularly perceived as vulnerable, but scholars argue that this need not imply weakness and so should be challenged (Bartlett and Brannelly, 2019b). The resilience primary participants showed helped counter the notion of vulnerability as weakness. For example, each adapted to engagement in physical activity within public spaces, and whilst doing so showed perseverance, and fortitude, which are key elements of resilience (Fletcher and Sarkar, 2016; Mannino, 2015).

Resilience was particularly evident on the occasion I met Ivan in the months leading up to his death, when he was becoming increasingly unwell. We had just completed an exercise session:

'Ivan's sense of determination, and desire not to be patronised came through... (as) we walked back through the car park. It was cold and showery. I had offered to bring the car round. Ivan was clearly against this. As we walked Ivan strode purposefully ahead…I think the desire to carry on is a strong element of his engagement.'

Ivan: observation at his Centre, 2nd February 2018.

On that day Ivan had shown his resilience through his determined approach to physical activity in a public setting. He was now able to carry this perseverance, and fortitude with him beyond the walls of his Centre and out into his daily life.

By acting as opportunity structures Centres can support people living with dementia adjust to their diagnosis, and in so doing promote the continued construction of identity. However, in addition, much depends on social relationships of people living with dementia within the context of engagement within Centres. Alongside the opportunity structures, connections are required to enable the different sort of structures to be sustainable. These include, for example, relationships with peers, family carers and the workers helping to facilitate activity (as I will explain further below). Activity also happens within spaces inhabited by others, and so how people living with dementia engage is public and transparent in nature. If matters progress well this is likely to be positive, as I alluded to when discussing social citizenship occurring in in ordinary places (Bartlett, 2016). However, it is also possible for things to proceed badly, for example, with participants being reminded of skills they no longer retain. Therefore, how Centres might enable adjustment and progression of identity requires more detailed exploration.

6.3.3 Diversity of activity as opportunity structures within Centres

Centres can help people express their continuity of identity through the flexible and diverse nature of activities they make available. My research showed how, potentially, people living with dementia have a wide choice in what they wish to engage in those places. This is important because physical activity can help individuals demonstrate authenticity of self, and this is valuable in enabling people to fully express themselves (Powell-Williams, 2018). It has been demonstrated that performativity, performing a role through engaging in physical activity (Spracklen, 2013), enables a person living with dementia to sustain their presence in the social world (Genoe, 2010). Centres can offer opportunity for performativity. For example, primary participants could opt to engage in numerous and diverse activity. Thus, Ivan engaging as an individual in the gym, or within exercise classes. Paul choosing to play dominoes as well as engage with the vigorous type of activity he was more used to, enabling him the freedom he sought. Jacqui electing to partake in individual gym sessions, exercise classes and the weekly group walk, offering different ways through which she expressed her authenticity.

Leonard selected the activities he engaged with because of their nature. He preferred to engage vigorously and physically, in the manner he believed allowed him to fully express himself. His engagement also offered opportunity to resist the influence of dementia upon his identity, as has been recognised in studies exploring leisure and identity for people living with dementia (Genoe, 2010). Leonard was able to make choices in what he did at the Centre, and for reasons he elected. For example:

“I’m not so keen on table-tennis. Cos, you can’t really whack it can you?

Leonard: interview at his Centre, 2nd July 2018.

Thus, Centres offer opportunity to people to express their identity by providing a venue for performativity, via the range of activities available to demonstrate this.

A note of caution is required though. Despite the diversity of activity potentially on offer, what Centres can provide will not be for everyone. This is because not everyone will want or be physically able to engage with activity at Centres. However, for some people living with dementia, Centres are well placed to enable understanding and expression of identity, and through this provide opportunity for individuals to continue to shape it. The diverse range of activities and how they are offered provides opportunities for a greater number of people than a sports club focussing on just one activity.

6.3.4 How opportunity structures aid understanding of loss and continuity in identity for people living with dementia

The examples and arguments in this section can help counter the paradigm that with dementia inevitably comes a loss of self (Noone and Jenkins, 2018). As someone adjusts to living with dementia, alongside the other transitions associated with aging, engaging in leisure activity can help strengthen and progress one’s sense of self (Genoe, 2010; Clarke and Bailey, 2016). The conceptualisation of the opportunity structure has been helpful in showing three ways in which this might be achieved through engagement with activities at Centres. Figure 7 (above) illustrates how opportunity structures align with my analysis.

The discussion is also notable because it takes the concept beyond that detailed by Lundberg *et al.,* (2011), who saw opportunity structures as being particular activities, or individuals. It might be possible for Centres themselves to act as opportunity structures, particularly because (as Figure 7 indicates) opportunity structures may blend with each other, and/ or work in tandem.

However, how they might operate to enable people living with dementia to shape their sense of self can only be explained up to a point through that theory. More is required because of the complexity of identity formation, of the lived experience of dementia, and of the nature of provision in Centres. Such understanding is provided by my reflections upon the work of Williams (1994), and arguments within and arising from that as they relate to disability sport socialisation and identity construction. That detail is also highlighted in Figure 7 (above).

6.4 Disability sport socialisation and identity construction

Williams (1994) seeks to enhance knowledge of how, through socialisation within sporting contexts, disabled people might acquire a sporting or physical activity identity. There has been no detailed study of identity construction for people living with dementia based upon physical activity or sporting contexts. Thus, his scholarship is helpful because it engages with the notion of continuity of identity formation within a context akin to my research. Williams' scholarship was similarly attempting to engage with what he concluded were deficits in understanding related to identity. It suggested that the nature of continuity of identity is dynamic, and progressive, arguing that through socialisation individuals can develop themselves beyond the narrow confines of physical activity identities, towards fuller realisation of themselves as social beings (Kissow, 2015).

Williams reflected upon the value of two sociological approaches, structural-functionalism, and interactionism. Structural-functionalism, he argued, helped understanding of how social interaction and socialisation contributed to producing a sporting identity. This was through the influence of others and the social contexts within which disabled athletes engaged in activity, which acted to shape the identity of individuals (Williams, 1994). However, interactionism afforded the opportunity to also understand identity construction, by prioritising the personal history of participants within physical activity settings. This was important, Williams argued, because structural-functionalist approaches alone overlooked how individuals have ability to shape their sense of themselves. Here identity could be constructed as individuals brought their life history, experience and attributes to interactions with others in sporting contexts. Identity formation for disabled athletes was thus not something passive, as structural functionalism implied. This was because individuals engaged elements of their identity, to form a key part of the construction process, as these were incorporated into their interactions and social discourse within sporting contexts. It is this interactionism, Williams argues, that makes continuity of identity construction dynamic.

While scholarship on disability sport and athletic identity has advanced, Williams' early acknowledgement is useful in understanding further the influence upon identity for people living with dementia through engagement with Centres. In addition, the body of work more generally helps illustrate how my over-arching and core identity themes might cut across the individual narratives of primary participants to contribute to this understanding. It was particularly helpful in illuminating the relevance of my findings to the significance of personal attributes, life story, interactions, and, of place within identity construction. I alluded to these within my discussion about opportunity structures (above). However, Williams' scholarship enabled me to investigate and make fuller sense of their relevance to my enquiry.

6.4.1 Personal attributes, life story, and interactions

6.4.1.1 Personal attributes and life story

Absent from the opportunity structure model is what individuals living with dementia themselves bring to the context of ongoing identity construction. This is remedied by the understanding offered by Williams (1994), in the ways I have argued above. This matters because every person, whether they live with dementia or not, will bring their own personal attributes and life experience to engaging in activity. Indeed Williams highlighted the phenomenon of 'biographical discontinuity' (Williams, 1994), when an individual's personal narrative of their life is unexpectedly and significantly interrupted by illness. Thus, the attributes and life stories people living with dementia bring play a part in how their identity is shaped through engagement in activity at Centres.

I described in Chapter 1 how a focus upon individuals living with dementia, rather than the nature of the illness is increasingly accepted as essential if people are to live well with dementia. This is congruent with the concept of personhood in dementia, described as, “a standing or status bestowed upon one human being by others in the context of relationship and social being. It implies recognition, respect and trust” (Kitwood, 1997, p.8). Allied to this is that the interests and experiences individuals hold must form part of their ongoing personhood (Brooker and Latham, 2016). These may vary, and possibly diminish as symptoms worsen, but acceptance that people living with dementia retain what makes them holistic individuals must endure. This resonates with social citizenship, in particular the importance of opportunity for personal growth (Bartlett and O’Connor, 2010).

The attributes, and experience of life primary participants brought to the context of engagement in activity of Centres were relevant to understanding how engagement shaped their ongoing sense of self. Thus, for Ivan sociability emerged as a core theme of the research because this was a long-standing and significant part of his identity. Engagement in activity at the Centre was an important way in which he could continue to do so. Likewise for Paul, and the sense he had of himself as free, Leonard as resilient, and Jacqui as authentic. The Centres afforded ideal venues to realise this because the focus was sport or physical activity, which, by their nature, are associated with making personal progress, and thus inclining towards and understanding of both present identity and identity looking ahead (Mayoh and Jones, 2015).

A physical activity identity as described by Son, Kerstetter and Mowen (2009), was manifested by each of the primary participants through their particular core identity theme, and by how other core identity themes inter-related with these. For example, Ivan demonstrating resilience alongside sociability, and Jacqui a sense of freedom in combination with feelings of personal authenticity. I have already drawn links to serious leisure (Stebbins, 1992), and I believe the traits reflected in that were notable in enabling people living with dementia to use their engagement to continue to shape their identity. This was because those activities had meaning for the person concerned in relation to their sense of self. Alongside this, because social citizenship happens in ordinary places (Bartlett, 2016), primary participant experiences demonstrated how the Centre allowed each to express her/ his individuality in the manner each wished.

In addition I found that physical activity identities informed more than primary participants' engagement in physical activity. For example, Jacqui's desire to feel authentic meant she also contributed to facilitation of activity. Inevitably this led to opportunities to be sociable. It also afforded multiple occasions whereby she could demonstrate resilience in the face of her symptoms, but also societal preconceptions about the capability of people living with dementia, and roles they might aspire to. As I argued in relation to relevant literature (Huang and Brittain, 2006) such activity can influence conceptions individuals have about their identity positively. Once more, therefore, continuity of identity for people living with dementia can be conceptualised in ways that are dynamic and progressive.

Leonard provides pertinent examples also. As related his physical activity identity was different to other primary participants, in that he did not consider himself sporty prior to engagement at the Centre, and indeed he resisted participation with aspects of provision there too. Soon, however, he was using engagement to demonstrate resilience. Alongside this came opportunities for sociability. For example, the times he and Ken devoted to conversation during their games of badminton (above). This extended even further, beyond the immediate context of engagement in physical activity, through opportunities Leonard took which enhanced and built upon his sense of self, especially in relation to his authenticity. In particular occasions when I saw him socialising with a wider group of other people:

'I witnessed…both Leonard and Caroline greeting other members of the public and acquaintances on shared badminton courts and having conversations together'.

Extract from research diary, 4th July 2018.

These were not people Leonard knew well, but reflecting with him afterwards I discovered that additional social opportunities, for example lunch out at a pub, had come through such examples. These were occasions Leonard and Caroline attended together, and I explore the significance of relatedness further in the following section. However, this example demonstrates how engagement at the Centre afforded him opportunity to shape his identity beyond the immediate resilience he showed in the multiple instances detailed in Chapter 5. Here Leonard could be true to how he felt about himself, authentic, but he was using his new physical activity identity, garnered through engagement at the Centre, to continue to shape his identity, for example beyond his higher-order theme, ‘I’ve done what I can’. Leonard used the social opportunities provided at the Centre, and his strengthened his sense of resilience, to re-mould his authentic self, and engage with new company outside of the context of his Centre.

6.4.1.2 Interactions

For Williams, social interaction was at the heart of how identity could be constructed for disabled athletes. He argued that personal attributes and experiences of individuals, in combination with the relationships and interactions with others, whilst engaged in contexts where sport and physical activity go on, were key to identity formation (Williams, 1994). Drawing upon earlier scholarship (Kenyon and McPherson, 1981) Williams highlighted how significant others, play a part in identity construction.

However, interaction, relatedness between individuals, is also highly important within the context of living with dementia, as the earlier quotation defining personhood showed. This relatedness is an important way for individuals living with dementia to understand their sense of self (Kitwood, 1997). In addition, as I noted earlier, social attachments are increasingly recognised as an important feature within the lived experience of dementia (White, Cotter and Leventhal, 2019). I have already suggested that by spending time with others engaged in activity of Centres, people living with dementia can develop their identity, and this can be personally transformational. As Kissow (2015) stated, being alongside others can be powerful, extending individual identity beyond the physical activity context into wider social identities. For example, Leonard said:

“I never used to talk to people straight away, people used to have to talk to me first. But I do that now.”

Leonard: interview at his Centre, 3rd May 2018.

In chapter 5 I detailed how for Ivan, Paul and Leonard a ‘couple identity’, the combined identity of two people in a relationship, where one has dementia (Hernandez *et al.,* 2019), could unite with the connectivity such affiliations offer to afford enhanced emotional and practical resources for each (Bosco *et al.,* 2019b). For example, I showed how Paul could continue to realise the freedom that was important to his identity through the actions of his wife Connie. Previously I argued Leonard had been able to combine his sense of resilience, garnered via physical activity, with new conceptions of his authentic self, gained through being sociable within his Centre. This had enabled him to extend his understanding of his physical activity identity beyond the context of the Centre, and into social opportunities in the wider community. Yet Caroline’s contribution was important too. For example, perhaps by bolstering Leonard’s confidence as he chatted with others he did not know well, but certainly in terms of the practical assistance she offered in driving the couple to their meals out.

Thus carers/ family members are significant others in terms of ongoing identity construction for individuals living with dementia in the context of engagement with Centres. However, two other groups of people are significant also in the context of this discussion, Centre Workers, and the peers with whom individuals living with dementia engage alongside. I will discuss each in turn. These relationships are so important, because, as I argued above, opportunity structures are especially effective in reinforcing identity when others show interest in how individuals feel about engaging in physical activity. Figure 7 (above) illustrates diagrammatically how this might operate.

Turning first to Centre Workers and their role. One facet of social interaction important to ongoing identity formation concerns the interplay between relatedness and freedom. I argued in the previous chapter that couple identity (Hernandez *et al.,* 2019), combined with relatedness could facilitate personal agency and therefore freedom (Brown, 2017; Bosco *et al.,* 2019b). I also suggested couple identity might be extended to include professional relationships between individuals living with dementia and workers.

It is in relation to the core identity theme of freedom that the significance of Workers is especially strong. This is because what freedom feels like for an individual is important. However, feeling free can be unsettling because it can imply isolation and being alone, through the sense of living without constraint (Cohen-Gewerc and Stebbins, 2013). Workers are in a good position to temper freedom, or enable it to be temporary. For example, by mirroring how freedom manifests itself in life, where individuals can live without restriction, but are aware this is not open-ended, and is likely to be less permissive than immediately apparent. Supporting this individuality alongside being part of a community providing direction and meaning (Cohen-Gewerc and Stebbins,

2013) occurs naturally within a Centre, between Workers and participants in activities, whether they have a dementia or not. It is a form of relatedness Centre Workers can promote. For example as Jacqui said of Patrick:

"…he's seen the progress up or down or static that we've made… he's obviously watching you and understanding the differences, and the needs…"

Jacqui interview at her Centre, 4th October 2018.

It is common for people living with dementia to experience anxiety about wanting to retain independence and not to be a burden on family or friends (Bartlett and Brannelly, 2019b). If those with whom they have interactions are aware of this and anticipate it, then their response can be important in enabling people to adjust well, and thus be able to continue to shape their identity, in ways that involve continuity rather than loss. The following is an example of Ivan's experience alongside Kyle, as he facilitated physical activity in the gym. It is notable because Ivan was then facing significant difficulty with declining physical and cognitive skills.

"Ivan…takes instructions from Kyle and goes to it …He does not physically try to prevent Kyle assisting him…but indicates through his posture and body language that he wishes to do as much for himself as possible. Kyle is always there…ready to assist but giving Ivan the space he judges he wants."

Ivan: participant observation at his Centre, 1st February 2018.

To build relationships that enable facilitation in such ways, to support the person adjust well, and be able to continue to shape their identity, requires skill. This is because the sense of freedom held by people living with dementia can be stifled if the support of others is perceived as unhelpful (Sharp, 2019). Acting authentically alongside people living dementia is vital (Hughes, 2019). Authenticity in this context should involve empathy, i.e. knowing oneself and the other person well (Stein, 2000). Through such authenticity relationships can promote personhood, but also active citizenship, enabling people to continue to shape their sense of self.

Interaction alongside the peers with whom people living with dementia engage in activity at Centres is significant in the context of the ongoing construction of identity. In this regard, Anderson and Whitfield’s (2013) findings appear to concur with Williams’ arguments about biographical discontinuity. For example, suggesting a stroke might provoke interruption in the personal life stories of individuals. However, feeling part of a social group can mitigate this through providing individuals with a sense of purpose (Anderson and Whitfield, 2013). Indeed, what individuals alone can contribute to identity formation as they enter older age may be limited, and partnerships with others, it has been suggested, are important to the construction of future self (Dionigi and Son, 2017).

Peers can contribute by supporting resilience, in particular through ‘team resilience’. This has been advanced by scholars as protective from negative effects of stressors people may encounter together whilst engaging in physical activity (Morgan *et al.,* 2013). In Chapter 5 I explained that Paul drew comfort from being with others in a way that perhaps mirrored his experience of contributing to sports teams through his life. Jacqui, Leonard and Ivan all reflected also on the value they drew from engagement alongside others, albeit in ways unique to themselves. Regular attachments and interactions which build relationships are affirming (Clarke and Bailey, 2016). Those constructed and maintained, with and between people living with dementia as they engage in activity at Centres, have potential to realise team resilience. Relationships based upon knowing others well can support continuity of identity.

The nature of the interaction with fellow participants in activity is also important. For example, a sense of friendship through play has the capacity to build mutually beneficial relationships that afford space to determine identities (Foley, 2017), and promote a sense of well-being for those involved (Dröes *et al.,* 2017). This is what Leonard said lay behind his enjoyment of playing badminton with his peers:

“It’s about playing together… about having a good game...enjoying playing together.”

Leonard go-along interview at his Centre, 3rd May 2018.

This example demonstrates how sociability can motivate engagement in physical activity (Recours, Souville, and Griffet, 2004). The ongoing connection to the contemporary spirit of the times is what many people with dementia desire (Bartlett and Brannelly, 2019a), and through such social interaction comes feelings of authenticity. This might be about people feeling being able to be true to themselves (Hughes, 2019). Partnerships with other people are likely to inform this when they involve making connections to social commitments, communicating honestly and valuing perspectives of others (Hughes, 2019).

The example provided by Leonard (above) reinforces that it is important to recognise that pleasure accompanying physical activity (Higgs and Gilleard, 2015) is often accomplished alongside others. It shows how the offering of Centres can provide the chance for people living with dementia to realise continuity in the sense of themselves by persisting in living through what could alternatively be termed wholly traumatic events (Clarke and Wolverson, 2016). The power and significance of this for people living with dementia is illustrated by two statements made by participants, included in Chapter 5, reflecting upon feelings about diagnosis. Caroline said of Leonard:

"…*he was just stunned… he did worry*…"

Caroline interview at home, 14th March 2018.

Whilst Ivan said:

"You just think, oh no, not me…"

Ivan interview at home, 12th December 2017.

Interaction with significant others is important in ongoing identity construction therefore. Its importance is enhanced because the creation of social environments, enabling people living with dementia to preserve their sense of purpose, contributes to retention of identity (Clarke and Wolverson, 2016). Thus, it is to a discussion of place that I now turn.

6.5 Place

Individuals understand themselves through people and places (Williams, 1994), and how people behave when together greatly influences the lived experience of those with dementia (Pulsford, Duxbury, and Carter, 2016). My research was located within the physical places of Centres, and place thus formed an important part in my study. However, understanding how the identity of people living with dementia was influenced by place is challenging. In particular, because understanding what place entails is difficult due to the diversity of meaning afforded to the concept. Considering how cross-cutting, over-arching and core identity themes may have played a role here too adds additional complexity. Identity formation within places is about more than the influence of others (Williams, 1994). Thus, I return to the conceptualisations of place, articulated by Lengen and Kisteman (2012), outlined in Chapter 1, to enable my discussion to consider the influence of place on the identity of people living with dementia.

6.5.1 Physical locations

Phenomenological philosophy suggests that understanding of physical spaces must include how it is perceived by people within it (van Manen, 1997), and the physical nature of the spaces were significant in my study. For example, in the expressive approach Leonard was able to take to his engagement:

‘Leonard smiled or laughed throughout the games. We both played hard and there was lots of heavy breathing and sweat on both sides’.

Leonard: go-along interview at his Centre, 22nd January 2018.

The spaces where my research was located, being designed to enable physical activity of all sorts, provided such opportunities for primary participants to use their bodies to express meaning about their identity. Corporeality and embodiment are significant here, because how one uses one’s body to engage in physical activity is an expression of meaning (Merleau-Ponty, 1962), and because physical activity is frequently reciprocal in nature and therefore sociable (Kontos *et al.,* 2017). Thus, Ivan could engage vigorously and purposefully in the gym to demonstrate his resilience, whilst utilising paraverbal communication with fellow gym users to manifest his sociability, and seek confirmation of his authenticity as an individual exercising within the physical space of his Centre. For example:

‘…one other gym user greeted Ivan warmly as they passed with a big smile. Ivan nodded to her in recognition.’

Ivan, observation at his Centre, 16th December 2017.

The location of the Centres was also significant in relation to ongoing identity construction. Because they tend to be located within conurbations, and neighbourhoods (as supported by my own questionnaire findings, see Appendix 3), their offering can be organised to enable participants with dementia to “claim their place in the community” (Phinney, *et al.,* 2016, p.389). Their locations can enable people living with dementia to continue to express their individuality alongside others, within their neighbourhood. This must be cherished (Bartlett and Brannelly, 2019) because it enables social citizenship to happen in ordinary places (Bartlett, 2016). Examples, in my research included Paul's huge attachment to geographic space and home, helping him to sustain feelings of authenticity. Also for Jacqui when she related about her affinity with her town, relating:

"It's just born and bred, it's just how you feel".

Jacqui: interview at her Centre, 4th October 2018.

6.5.2 Concentrations of social relations and social practices

In section 6.4.1.2 (above) I articulated how social interaction was important in enabling continuity in the construction of identity for people living with dementia, and the potential nature of this continuity. Places can act as a forum for this to happen by enabling social relations and practices between individuals. In particular because, when places where people meet give rise to mutual support and enjoyment then identity can continue to be shaped and maintained for individuals engaging in activity there (Williams, *et al.,* 2018). Jacqui indicated this by expressing what she valued whilst engaging in activity sessions held in the sports hall at her Centre:

"Y*ou can get together and talk through your problems... It is relaxed. You can come and go. You don't feel threatened…you get hugs."*

Jacqui: go-along interview at her Centre, 13th June 2018.

This is pertinent, considering what (Odzakovic *et al.,* 2019) argued about people with dementia who live alone being failed in relation to being supported to participate in the life of their communities. The social relations and practices described by Jacqui afforded her connectivity, of the sort outlined by Glicksman, Ring and Kleban (2016), so she could enjoy participation in her local community, in the manner set out by Menec *et al.,* (2011). At the same time, this acted as an opportunity structure based upon activity (see above), so the place provided opportunity for individuals to gather, and offer feedback to Jacqui. This enabled her to continue to conceptualise her authentic self, including aspects of freedom, here through her sociability. This was encapsulated by Jacqui when she said:

"…it's nice that there's the facility for us all to be in our various ways".

Jacqui: interview at her Centre, 4th October 2018.

Additionally, the places within Centres can afford identity construction through social relations and practices for individuals who are physically unwell. Thus, whilst it is true that we are always bodily in the world, it is often only through the enabling activity of others that genuine self-realisation for people living with dementia occurs (Bryden, 2016). This is important because some people living with dementia are significantly impeded through ill health from coordinating movements, and this can be immensely distressing for them (Bartlett and Brannelly, 2019). As Ivan demonstrated, corporeal and embodied ways of showing authenticity of identity are possible, but others (in particular Centre

Workers) are likely to have to attend to the needs, abilities and preferences of people living with dementia (Oliver, 2016) in such situations to support manifestation of their identity.

6.5.3 Zones of experience and meaning

Zones of experience refers to the meanings people living with dementia, participating within Centres, are able to draw from engagement within those places about their identity. As such they can offer "places of belonging" (Phinney, *et al.,* 2016, p.387), where people forge a sense of themselves. Places can also offer opportunity for people to feel they are their authentic selves, in the manner described by Tregaskis, 2003.

For example, as Paul and I played table-tennis I noted:

'Everything I hit at him he more or less returned... Paul is clearly a good player'.

Paul: participant observation at his Centre, 8th January 2018.

For Paul there was no need for conversation, he could continue to show who he was through action. Embodied actions such as these are significant within the manifestation of identity by people living with dementia (Wright, 2018), and can act as a manner through which people continue to maintain their identity, and illustrate it to those around them (Birt *et al.,* 2017). As Cohen-Gewerc and Stebbins (2013) suggest physical space can be utilised by individuals in this way to provide opportunity to be who they genuinely want to be. In this example the space within which activity took place acted as a zone of experience and meaning (Lengen and Kisteman, 2012), because it offered Paul a rehabilitated sense of himself as a sports player, within a place where he could continue to apply his skills and abilities. In turn these reflected an opportunity to continue to consider himself as authentic and resilient. This was also a demonstration of active citizenship of the sort identified by Birt *et al.,* (2017).

Spaces acting as zones of experience and meaning might also link to feelings for individuals of well-being. It is argued that this is via what has been referred to as 'spatial dwelling-mobility' (Mayoh and Jones, 2015, p.243). This is where well-being is fostered for individuals through engagement within familiar and comforting environments, alongside opportunities for experiences presented via sporting activity. Feelings of well-being, fostered in this way, can be meaningful to the individual's sense of identity. For example, Paul had always enjoyed playing sport, and continued to do so, illustrated here by what I saw of him playing table-tennis:

'Paul smiled for most of the time…He appeared to be enjoying himself a great deal'.

Paul: reflection upon observation and go-along interview, 8th January 2018, from researcher's field notes

The body can express distinctiveness (Kontos, *et al.,* 2017), and here Paul was using his body to reflect what participating within his Centre meant in relation to his sense of self.

Individuals can verify the authenticity of their identity, literally ‘feeing real’, through play (Carter, 2016). Other primary participants felt more confident to articulate verbally the meaning they gained for their sense of identity through engagement within their Centre. For example, Leonard’s view on what it felt like to be on court playing badminton,

“…brilliant, great…love it” (Leonard laughs).

Leonard: interview at his Centre, 22nd January 2018.

6.6 Conclusion

What people living with dementia do within the spaces provided by Centres, and the relationships they have with others there, informs the extent to which engagement shapes their identity. Chapter 5 demonstrated how powerful this was for four people. This chapter has shown that, whilst not generalisable, findings extend beyond their experience. The offerings made by Centres can provide people living with dementia opportunities to be, to engage with the world as themselves, and to progress and evolve their sense of identity. People living with dementia feel loss, including to their sense of identity. However, like most other people, they also desire to continue with their lives. This was shown in my research where primary participants’ feelings about authenticity, resilience, freedom and sociability helped determine how they continued to shape their identity.

That discussion was complex, and my understanding was enhanced by the contribution of the theoretical models of opportunity structures, and the scholarship of Williams (1994). The former allowed me to argue that activities provided by Centres can promote continuity of identity, aid adjustment to living with dementia, and enable people to feel they are their authentic self. It might also be possible that Centres and their potential whole-offering could act as opportunity structures. This would progress the debate, because until now it has been suggested that only particular activities, or individuals act as the structures through which identity can be shaped. More research is required on this point, and I return to this in my concluding chapter. However, Figure 7 (above) illustrates how this could happen, highlighting that different opportunity structures might work together, within the setting of a Centre, to contribute to identity construction for people living with dementia.

Williams (1994) enabled me to highlight that for Centres to act as opportunity structures close attention must be paid to the individuals participating in activity within them, and their interactions. Thus, in order for Centres to play a positive role in identity formation, people living with dementia must be known, recognised and understood as whole people, with pasts, presents and futures, with skills, interests and ambitions. The chances of this occurring will be stronger if this is understood by those facilitating activity such as the instructors and coaches. How all the users of a Centre relate and interact with other participants is important too.

Centres have opportunity, through the physical spaces they provide, and their focus upon engaging people within activity, to bring people together, to foster continuity of identity. In combination with the nature and diversity of activity on offer this can be personally aspirational in nature, and can enable new or strengthened physical activity identities to extend beyond the physical setting of Centres into the daily lives of individuals. The social milieu is crucial to this identity formation, but so too is the chance for people living with dementia to continue to progress their identity in embodied ways. Use of the body is a key part of the offering of Centres, because it enables people to demonstrate who they feel they really are.

Next, I will conclude my study reflecting upon how making personal meaning from engaging with Centres can help shape identity for people living with dementia. I will describe how services can frame themselves to achieve this, to enable people with dementia to live well, and to connect with their communities. The chapter will make these arguments, whilst recognising that the context of financial austerity might threaten the provision of services to the public, and hinder the ability of Centres to realise their full potential.

Chapter 7: Conclusion

7.1 Introduction

This chapter concludes my study by summarising findings as they relate to the research question: ‘how does engagement in activity within Centres influence the identity of people living with dementia?’ It consolidates the new knowledge gained from the research about the lived experience of dementia in the context of engaging in activity within Centres, and understanding of how Centres can promote opportunity for people living with dementia to participate as fully as they wish within their lives. Additionally, the chapter identifies the strengths and limitations of my study, before making recommendations relating to research and practice.

7.2 The contribution to knowledge made by my research

7.2.1 Key factors in participation within Centres that influence the identity of people living with dementia

The main contribution to knowledge is that the identity of people living with dementia can be influenced through engagement with activity of Centres. Primary participants engaging in activity, with their personal attributes and life stories, and via social interactions with others, were enabled to shape their identity by the opportunity structures on offer.

Loss was frequently experienced by primary participants. It was diverse in nature, but felt unpleasant and negative. ‘Identity crisis’ was how this was encapsulated, and opportunity structures were the means by which feelings of loss could be reframed by primary participants. For example, by discovering new knowledge, or by utilising long-standing aspects of identity alongside physical activity to adjust to living with dementia. Enabling people living with dementia to maximise opportunity to continue to shape their identity in positive ways requires sensitivity and skill, often on the part of Centre Workers. How this might be accomplished is discussed below.

Physical activity within Centres enabled four people living with dementia to feel a sense of resilience, authenticity, and freedom in relation to their sense of self. Identity can be shaped by individuals via intense embodiment (Mayoh, Jones and Prince, 2018), and this was found to be the case, for example in relation to what Leonard and Ivan did. However, the nature of engagement did not need to be intense. Other examples, whereby people chose to engage differently, also realised ongoing construction of identity. The regular walks that Jacqui participated in being a good example of how a different sort of embodiment supported identity.

Sociability was also a feature of identity primary participants continued to hold. Interaction with others, in particular family carers, Centre Workers, and fellow participants in activity, played a role in shaping this. Social interaction contributes to how opportunity structures enable ongoing identity formulation, and openings for this are important in how Centres can enable people living with dementia to continue to shape their identity. This is also discussed further, below.

My research found that Centres offer multiple opportunities for physical activity and social interaction, often in combination, and are thus are well placed to offer people living with dementia opportunities to continue shape their identity in positive ways. Questionnaire responses showed those in leadership positions within Centres value partnerships with local services, demonstrating that my findings can be used strengthen working arrangements between services. This is so very important because the physical identities primary participants fostered through engagement were incorporated into their lives beyond Centre walls, evidencing the wider positive influence of the engagement addressed throughout my study. The most striking example being of Ivan who took the resilience that was part of his physical activity identity out and into his wider lifeworld (daily life).

7.2.2 The lived experience of dementia in the context of activity within Centre settings

I demonstrated in my review of the literature that knowledge about the experience of engagement by people living with dementia in Centres is minimal. My consultation with Centres, through use of my questionnaire, was helpful in beginning to redress this. For example, responses indicating that people living with dementia engage in activity of Centres, and do so within both bespoke and mainstream provision.

However, a significant contribution to knowledge was the detailed information my research gained through its deep engagement with the experiences of people living with dementia participating regularly in those settings. This enabled understanding not only that people living with dementia attend and participate, but those whose symptoms are relatively advanced do so too, for example Ivan and Paul. Furthermore, both continued to draw meaning in relation to their identity from their experiences, and were consistently keen to return to engage. When people living with dementia are so frequently marginalised by society this knowledge is important. Ivan and Paul were supported in their engagement by family and Centre Workers, but I found that engagement is possible for individuals whose abilities are quite significantly impacted by cognitive difficulties caused by dementia.

The research also showed how a sense of purposefulness or agency was demonstrated by every primary participant. For example, Jacqui realising opportunity to do more than participate in activity, and contribute to its facilitation also. Such activity can influence conceptions individuals have about their identity positively, as scholars had previously related about alternative contexts (Huang and Brittain, 2006). I have drawn links to serious leisure (Stebbins, 1992), and the traits reflected in that, for example, whereby physical activity felt fulfilling, were notable in enabling people living with dementia to use their engagement to continue to shape their identity in this regard. This was because those activities held meaning for the person concerned in relation to their sense of self.

Finally, the experience of engagement was found to have mutual benefits for spousal family carers. Engagement with activities of Centres offered carers opportunity to utilise time in relation to their own self. This is a valuable, positive conclusion, in contrast to understandings which tend to characterise such caring relationships as corrosive and negative. Centres were able to offer couples affected by dementia time together and/ or time apart, as demonstrated by Jemma and Ivan's situation. Offering time and opportunity for couples to be together in ways they wish are mutually affirming in terms of their identity and citizenship (Keyes, Clarke, and Gibb, 2019). Adjusting to the change dementia brings is difficult for every person affected by dementia, but is essential to living a life characterised by well-being (Brooker and Latham 2016; Laver *et al.,* 2017; NICE, 2018). If this process can be facilitated for carers through engagement with Centres, then it is possible for their social heath to be enhanced (de Vugt and Verhey, 2013).

7.2.3 How Centres promote opportunity for people living with dementia to participate

Centres demonstrated many ways in which their offering could promote opportunity for people living with dementia to participate in activity, and in other aspects of their lives as they wished. However, Jacqui's experience of living alone and in a rural location was notable because of the barriers she faced to engagement. The offering of the Centre felt positive for her, and my research demonstrated numerous ways in which she was able to utilise it to progress her sense of identity in an agentic manner. Unfortunately the transport links she used to reach the Centre were fragile, thus putting these positive features at risk.

My questionnaire indicated that Centres are unlikely to be located in villages. Thus, people living with dementia, based in rural locations, are liable to struggle to engage with what Centres offer. In the context of national priorities focusing upon reducing isolation and loneliness (Department for Digital, Culture, Media and Sport, 2018) this is a conclusion relevant to high level policy and decision makers, particularly because my research showed how sociability was a core theme of identity that could be fostered through engagement.

However, I found multiple examples of how what was offered by Centres promoted opportunity for people living with dementia to participate. One was the emphasis Centres were able to place upon the provision of choice for participants living with dementia, through multiple and diverse opportunities for activity. The immediate moment is important to people living with dementia (MacPherson *et al.*, 2009; Smith, Mountain and Hawkins, 2018) and thus opportunity to engage in an activity of choice can feel especially empowering.

The ability of Centres to afford such choice is linked to the spaces they offer. Centres tend to have spaces designed for flexible use and this can enable participant choice to be realised. To be dementia friendly, participation of individuals within life of communities is a goal (Menec *et al.,* 2011). Therefore, space must be utilised not only to enable flexibility in choice of opportunity, but also to extend engagement into wider social life. For example, through provision of space that can be easily be used for social interaction. This involves having a physical environment suited to the needs of people living with dementia, and people within those spaces attuned to those needs and their aspirations (Life Changes Trust, 2019).

Centre Workers are key, therefore, to how Centres can promote opportunity for people with dementia to participate within societal life. For example, my research found that by attending to the personal preference of participants social connectivity, of the sort envisaged by Glicksman, Ring and Kleban, (2016), was enabled. In addition Centre Workers, through skilled and encouraging facilitation of activity can enable individuals living with dementia to construct self-efficacy and motivation to continue engagement, as Lindelof *et al.,* (2017) suggested. Workers can promote communicative leisure, characterised by meaningfulness and self-affirmation (Spracklen, 2013), and in so doing help shape the culture of a Centre (Harvey and Griffin, 2019). I found they are also well-placed to form regular attachments and connectivity with participants that build affirming relationships, as highlighted by Clarke and Bailey, (2016). This is especially pertinent in relation to people with dementia living alone, because they are generally poorly supported to participate in societal life (Odzakovic et *al.*, 2019).

However, this is sensitive and complex work. I witnessed instances where individuals living with dementia experienced feelings of loss provoked by engagement in leisure activity, of the sort highlighted by Genoe and Dupuis, (2011). Centre Workers are frequently and immediately involved in such situations because of their role, but as I highlight (below) reduced budgets risk reducing staffing resource for Centres. Thus, the ability of Workers to promote opportunities for people living with dementia is challenging, especially when the social and moral obligation Centres have towards their clientele is ambiguous. It seems likely that more conventional leisure centres, not run for profit, will be more likely to prioritise such support (GLL, 2020), than commercial ‘fitness gyms’, but this is uncertain. My questionnaire indicated that training is at a basic awareness level for Centre Workers. This suggests that presently support for Centre Workers is lacking.

Other features are important in Centres promoting the engagement of people living with dementia within wider society. For example, maintaining and progressing physical fitness that feels agentic, with opportunities not formally tied to health or social care programmes. This enables individuals to participate as citizens rather than patients, in the manner recommended by Phinney *et al.,* (2016). In the context of the negative societal perception facing people with dementia this could feel liberating for individuals. Collectively it provides another opportunity for other people, lacking the lived experience of dementia, to reflect upon how they conceptualise those who do live with the syndrome.

In turn this will help counter the narrative that vulnerability inevitably means weakness. Primary participants in my research offered numerous examples of how engaging in activity within Centres demonstrated strengths. Social citizenship incorporates change and evolves (Bartlett and Brannelly, 2019a), and my findings contribute by helping to challenge the notion of vulnerability attached to people living with dementia. Instead it recognised the abilities primary participants held and demonstrated. This conclusion is notable as resilience through engagement is of interest to policy makers seeking ways in which the well-being of older people can be enhanced (Zhang, 2018).

The contribution Centres can make is tempered, however, by the significant challenges services face in the delivery of their offering. Notably, these relate to reduced budgets for publically provided leisure services, accompanied by increasing demand upon their services (Local Government Association, 2017). This context of parsimony and consequent challenge to resource extends to that of dementia support generally, which is blighted by underinvestment (Alzheimer's Society, 2019c). Funding models for community based interventions to support people living with dementia are also inconsistent and fragmented (Morton *et al.,* 2019). The response by local authorities to financial austerity within leisure sectors has often been to institute non-paid volunteers as a substitute for services previously provided by trained and remunerated staff (Findlay-King, *et al.,* 2018).

My research showed how committed leisure professionals enabled ongoing identity maintenance for people living with dementia. The deep listening and soft-skills required in this role, valuable in reducing health inequality for members of disadvantaged communities, must be valued and nurtured (Allen-Collinson, *et al.,* 2019). Direct interventions enabling social contact (Age UK, 2018), such as those described in my study, provided to accentuate opportunity to express individuality and validation from others (Erikson, 1995) also contributed to people living with dementia sustaining their identity. It would be regressive to be tempted to rely upon provision of free, untrained lay-labour to try to sustain this. Indeed, contemporary approaches to support advocate coordination of response, not fragmentation (World Health Organisation, 2017).

However, even in the face of these challenges there remain positive signs. For example, the first ever outcome sets to evaluate physical activity interventions for people living with dementia have been published (Gonçalves, *et al.,* 2019) and there is growing awareness that the engagement by people living with dementia in sport and physical activity is important (Alzheimer's Society, 2019). There are different ways for people to come together in sport and physical activity. My research demonstrated that alongside the benefits to physical fitness that exercise is traditionally expected to foster, there are also advantages of engagement related to identity. This element of sport and physical activity must not be overlooked.

7.3 Contribution made to the disciplines of leisure and dementia studies

My study identifies the complex and multi-layered engagements some individuals have with physical activity and community fitness and Leisure centres. The research demonstrated how the people living with dementia I encountered were able to mould and develop their identity via the opportunity structures provided through participating in activity at Centres, alongside their personal attributes and life stories, and by way of social interactions with others. Noteworthy, also, was that whilst engagement in sport and physical activity tended to enable individuals to look forward and attach aspiration to their involvement, there were difficulties encountered, illustrating more nuanced aspects of participation. For example, whilst taking part in sport and physical activity within the public and communal venues provided by Centres was agentic, and contributed to identity formation which felt positive, there were inherent risks. Participants could be reminded of capabilities that had declined, for example, and reported sadness at the loss of acquaintances and friends with dementia, with whom they had previously played alongside. It was often through the skilled and empathetic facilitation of activity, and its provision, that these negative elements were ameliorated, and I expand on this below.

The constructive outcomes countered the negative, however, and this is important and encouraging in a context where life with dementia is popularly perceived as passive and negative. I have shown how engagement with the activity offered by Centres enabled people living with dementia to shape their identity and sense of future in a manner that was agentic and aspirational, and in novel ways that were inclusive of others with whom they were close, for example spousal carers. This matters because adjusting to life with dementia is challenging, and the responses of formal services and society are often found lacking. Thus, the original insight provided by my research demonstrates how Centres, situated at the heart of local communities, can contribute to more enlightened practice, and an emancipatory future for people living with dementia.

Included within my overall conclusions lie features relating to the fields of leisure and dementia studies that are noteworthy. I set these out below, alongside their rationale for inclusion. In the section that follows (7.4) I do the same in relation to the contribution my study made to theory.

7.3.1 Leisure Studies: noteworthy features

7.3.1.1 For people living with dementia participating in leisure activity can engender ‘agentic couple identity’.

This is an original concept, drawn from my findings, which can apply between people living with dementia engaged in sport and physical activity and their spousal carer. It can also be between a participant in leisure activity with dementia, and Centre Worker. The approach taken by this additional person, be they a family carer or Centre Worker, must be tailored in a certain way for this to work well, however. Thus, I found that ‘agentic couple identity’, is the combined identity of two people in a relationship, where one of the couple has dementia (Hernandez *et al.,* 2019), along with the encouragement for the participant with dementia’s engagement in tasks requiring perception and understanding, in synergy with that person’s capabilities and aspirations (Bosco *et al.,* 2019b). This agency will be nuanced by power relations and personal histories. It will also be influenced by temporal and spatial arrangements pertinent to the individuals concerned, and the locations within which their engagement takes place. More broadly, the societal perceptions of people living with dementia I alluded to earlier will also play a part, because of the public nature of the arenas within which engagement takes place.

However, this concept is important because, in the case of people living with dementia and spousal carers, it offers insight into the potential for *mutual* benefit from engagement with activities of Centres. Agentic couple identity enables both to achieve what would be useful, for example, the freedom from certain restrictive aspects of their lives, the freedom to do certain things together, all of which help sustain the relationship in a time of challenge and/or adversity. It was so because whilst the participant and their spouse had a 'couple identity', the Centre also offered both the chance to express individuality, as outlined in Hernandez *et al.* (2019). The 'burden' of caring is frequently reported as a significant (Cheng, 2017), but this finding demonstrates how the personhood and citizenship of both people living with dementia and spousal carers can be recognised and enacted, together and apart. The clearest example being that offered by Caroline when she said,

"Leonard likes playing badminton. I don't mind having a game, but I prefer to network with other carers."

Caroline and Leonard: interview at their Centre, 3rd May 2018.

This positive narrative can help to counter prevailing negative ones about the experience of life with dementia. It is particularly significant because it is the emotional support and company of peers, friends and acquaintances that especially sustains female family carers (Leggett *et al.,* 2020). That is something I found to be on offer within the context of Centres and the leisure-based offering they made.

This conclusion also shows how others, in this case those employed as Centre Workers, can form part of this agentic couple identity. Consistent with the work of Brooker and Latham (2016), for example, as shown by how the Centre Worker, Patrick, organising the offering of the Centre to provide activities aligned with Jacqui's priorities. Relatedness here is in a professional rather than a familial sense, and enabled participation in the life of the community of the Centre, which in turn forged positive connections with it, in the manner outlined by Menec *et al.,* 2011, and Glicksman, Ring and Kleban, 2016.

Whilst each of the Centre Workers in my study demonstrated elements of agentic couple identity through their practice, Jacqui's example provides particular prescience. This is because it shows how engagement with Centres can offer benefit to people with dementia who live alone, without familial support. I have related how by seeking company locally, via engagement at her Centre, Jacqui could create an identity within her own neighbourhood, as detailed by Odzakovic *et al.,* (2019). Such identities are afforded additional strength through the impetus provided by the agentic couple identity. This offers powerful insight to the value of leisure in the context where people with dementia who live alone can draw upon the support of others to achieve their desired outcomes. Further research is required into the role of Centre Workers, and their potential contribution to the provision of support for people living with dementia. In particular, how they can contribute to individual's experiences and how these are created and sustained in the spaces activity takes place.

7.3.1.2 It is the person’s choice that matters in the design and delivery of sporting and physical activity

To enable ongoing identity formation to be sustained, the personal preference of participants with dementia regarding which activities they engage with and alongside whom is of paramount importance. This insight will contribute to the design of services, because it helps to answer the question repeatedly posed, should the offering of sports and leisure services be designed specifically to accommodate people living with dementia, or, are ‘mainstream’/ generic offerings required and desired? My study showed that both must be on offer. This was demonstrated through the enactment of social identity theory (Wearing, 2011), with the self-contextualization of the participant with dementia as a group member (Stevens, *et al.,* 2017), either as a fellow fee-paying member of the facility, or as a member of a bespoke group for people with dementia.

The choice of the person also matters because it is part of their social citizenship (see below for a fuller discussion of this), in particular, offering another way in which an individual can demonstrate agency, and how they wish to belong within and to the social groupings that leisure activity is a part. Additionally, however, this conclusion has wider implications, for example, in helping understand what a ‘dementia friendly environment/ community’ should be, with Glicksman, Ring and Kleban (2016) suggesting these must enable social connectivity based on personal preference. This matters because, in times when the provision and resourcing of leisure, health and social care provision are at issue, the ability of Centres to offer individualised and generalised responses is of great merit.

7.3.1.3 Physical activity identities fostered through engagement at Centres can be utilised positively by people with dementia within their broader, daily lives

Primary participants had clear physical activity identities, of the sort described by Son, Kerstetter and Mowen (2009), which were meaningful to how each perceived their identity. They could utilise these identities beyond the Centres, and within their broader life-world, as shown via the core identity themes of resilience, sociability, freedom and authenticity. This was illustrated clearly by Ivan, using the resilience he demonstrated through physical activity in his approach to continuing to engage with activities of daily life as his health declined. Leonard also demonstrated this employing the combination of the physical activity, which he found so agentic, with the sociable context of that activity, to enable him to shape his identity in new, gregarious ways beyond the Centre. Once more this was enabling and empowering, in contrast to the traditional public perceptions of people living with dementia, described above.

The physical fitness and physicality, closely associated with the leisure contexts my study explored, were important in enabling physical activity identities to prosper. The capacity for individuals to seek out an alternative that offered this was limited. It mattered because for Ivan and Paul sport and physical activity had played an integral, lifelong role in their identity. Leonard and Jacqui lacked such a significant heritage, but both related how engaging physically, alongside others, had become increasingly important to who they were. In turn this aligned with nascent understandings of rehabilitation for people living with dementia (Swaffer, 2016), understood as recovery via physical activity (Huang and Brittain, 2006). Whilst there are risks in recovery being considered in exclusively medicalised ways, here empowerment was enhanced through the public and transparent nature of the physical activity on offer. ‘Embodied identity mobility’, as Mayoh, Jones and Prince (2018) have also recognised, forms a key way in which voices of people marginalised within society can be articulated, and in my study this was deployed by people living with dementia within the context of physical and sporting activity in the communal settings of the research.

7.3.1.4 The places where leisure was enacted mattered to the ongoing formation of identity for participants with dementia

The places of Centres enabled people living with dementia engaging in leisure to continue to shape identity in three ways.

Firstly, through the physical, and ‘geographic spaces’ (Cohen-Gewerc and Stebbins, 2013), they provided. Thus, leisure places themselves acted as physical venues and locations for experiences which helped forged identity, especially because other people tended to be close by to provide feedback and validation for participants, in the manner described by Erikson (1995). Additionally, these spaces, situated as they were within local neighbourhoods, were familiar, enabling people with dementia to utilise elements of the sensuous geography (Rodaway, 2002) to aid and support meaning in relation to their identity. Their physical presence within localities which participants with dementia knew well, and the familiarity individuals had with the layout both contributed to this. For example Jacqui relating, with regard to the former,

"It's just born and bred, it's just how you feel".

Jacqui: interview at her Centre, 4th October 2018.

And, when reflecting on the value her knowledge of the terrain of particular spaces within the Centre held,

"I have to go by the same routine…the same cubicle, the same locker…something new is strange… so it's what I know".

Jacqui: interview, at her Centre 5th February 2018.

This demonstrates the importance of both emotional and sensuous geographies within the context of leisure and the engagement of people living with dementia. Secondly, Centres provided fora for social relations and social practices. Thus people living with dementia could continue to express their individuality alongside others, whilst simultaneously enjoying the sort of connectivity, as outlined by Glicksman, Ring and Kleban (2016), essential to enabling communities to be 'dementia friendly'. Such connectivity was strengthened because individuals enjoyed engagement within their local community, in the manner described by Menec *et al.,* (2011). The leisure context has thus demonstrated why such connectivity must be given higher priority when considering meanings ascribed to 'dementia friendliness'. This is of note at a time when addressing loneliness of older people is a national policy priority (Department for Digital, Culture, Media and Sport, 2018).

Finally, places acted as zones of experience and meaning. Thus, the physical space Centres provided were employed by people living with dementia to realise who they genuinely want to be, to feel ‘real’ through play, as described by Carter (2016). This resulted in ‘spatial dwelling-mobility’ (Mayoh and Jones, 2015, p.243), whereby personal well-being was fostered by individuals through engagement within familiar and comforting environments, alongside opportunities for experiences presented via sporting activity.

7.3.2 Dementia Studies: noteworthy features

7.3.2.1 People living with dementia can foster their identity through physical activity

This was known in relation to other aspects of leisure (Genoe and Dupuis, 2011; Dupuis *et al,* 2012), for example hobbies, but was less well understood in relation to the sort of vigorous activity my study explored. While we recognise the general value of physical activity for people living with dementia, assumptions around engagement, mental, social, health, and identity benefits cannot be assumed or guaranteed. Moreover, given the spectrum of activities on offer to people living with dementia (particularly within, but also beyond Centres), and the limited number of participants that may be taking up physical activity opportunities, there remains scope to extend research, build up further narratives, and understand the complex engagements people have. Particularly, also, given variations of dementia causing illnesses and the socio-economic, spatial, individual differences across the population.

7.3.2.2 Engagement with activities on offer at Centres can support adjustment to change

We know that adjustment to change is likely to be significant for identity maintenance and development for people living with dementia (Lishman, Cheston and Smithson, 2016; Vince, Clarke, and Wolverson, 2017). Additionally, successful readjustment to life with dementia can augment the well-being of individuals (Bunn *et al.,* 2012; Cheston 2013; Brooker *et al.,* 2017).

I found that engagement with activities on offer at Centres assists adjustment for people living with dementia to the new circumstances brought about by their illness. Encouragingly this occurred by supporting the continuity of identity in ways reflective of a sense of aspiration and authenticity for individuals. In particular, participation provided people living with dementia the opportunity to express and enact their preferences for daily life, and thereby supported each person to be who they wished. For example, Ivan through continuing with his life-long love of physical activity, and choosing to engage with so much commitment. Jacqui's example, meanwhile, shows how a person with dementia, lacking such a deeply imbued sporting identity, can still utilise leisure activity offered at Centres to adjust to life with dementia. Here, employing physical activity to demonstrate to herself personal qualities she valued, because they aligned with her own sense of authenticity.

Engagement also assists with adjustment that enhances the wellbeing of individuals. For example, Paul used his familiarity with sporting endeavour within the context of the Centre to realise ‘spatial dwelling-mobility’ in the manner described by Mayoh and Jones (2015), described above. Thus, the activities he chose to participate in, alongside the familiarity with the spaces where they took place, enabled him to craft personal well-being. These features matter because adjustment to the change dementia brings to the lives of individuals is challenging, but crucial to their ability to live well. I found that Centres are well placed to offer a venue which will enable people novel opportunity to adjust, and in doing so contribute to their wellbeing. In combination, this is extremely valuable.

7.3.2.3 The social health of people living with dementia can be enhanced through engagement with activities on offer at Centres

Social health, as this relates to individuals living with dementia, involves recognition of existing skills and capabilities, ahead of abilities corroded by the impact of dementia symptoms, such as reduced physical coordination or short-term memory (Dröes *et al.,* 2017). Engagement with Centres affords opportunity to focus upon social health. The capacity of individuals living with dementia to fulfil their potential in this regard depends upon overcoming social and environmental challenges (Vernooij-Dassen and Jeon, 2016); however, I found that Centres are well placed to support this. This matters because, by focusing upon and enhancing the social health of individuals with dementia, well-being for participants can be realised. Additionally, social citizenship can be strengthened, I expand upon this further below, where I also discuss how the concept of serious leisure contributed to the ability of the offering Centres made to enhance social health.

Thus, for Ivan, engagement enabled participation within sociable activities identified as so valuable to social health by Dröes *et al.,* (2017). Paul could exhibit ongoing physical prowess through playing table tennis. This offered him the additional benefit of retaining the capacity for social engagement through play. For example, telling me as we concluded a game of table tennis,

"It's good when you're here. I like seeing you".

Paul: go-along interview at his Centre, 23rd April 2018

Social health was strengthened in a similar way for Leonard, and Jackie. This was notable because physical activity had not contributed so significantly to how they judged their own personal attributes in the past. Both lacked the more imbued physical activity identities of Ivan and Paul. However, Leonard felt a strong sense of his social health when he related what his engagement in physical activity meant:

"…you're achieving something aren't you…actually doing something physically."

Leonard: interview at his Centre, 22nd January 2018.

This was powerful, with Leonard confirming his sense of achievement at the conclusion of a game of badminton:

“It takes your breath away. It’s brilliant…”

Leonard: go-along interview at his Centre, 3rd May 2018.

Jacqui linked the chance to demonstrate her social health directly to the opportunities provided by the place of Centres when she said,

“…it’s nice that there’s the facility for us all to be in our various ways”.

Jacqui: interview at her Centre, 4th October 2018.

These findings extend knowledge about how strengthening social health can enhance the ability of people living with dementia to engage in social life, in the manner by Vernooij-Dassen and Jeon (2016). Alongside my conclusion that engagement in physical activity can sustain identity in positive ways, this consolidates the value of my findings. Engagement with activity on offer at Centres enables people living with dementia to sustain an active place in the communal world, via enriched social health.

7.4 Conclusions based on the contribution made to theory

7.4.1 A blend of phenomenological philosophy enabled better understanding of the lived experience of dementia

My enquiry sought understanding of what ‘being in the world’ meant for four people, living with dementia, as they engaged in the activity on offer at Centres. As acknowledged above, this drew me into an exploration of the complex and multi-layered engagements individuals had with Centres, and what this meant for their identity. Adding to this was dementia and its influence upon their lives and experiences. Phenomenological philosophy helped to untangle the inherent intricacy of this lifeworld. I chose to employ a range and blend of phenomenological ideas to accomplish this, all the while recognising the integral risks (Paley 2016 and 2018). In earlier sections I detailed how I addressed these. For example, drawing upon original phenomenological texts, and being clear about potential detriments. The blend, however, incorporating strands of interpretive, empathetic, and embodied philosophical approaches, enabled me to understand what being in the world meant for primary participants in a manner that adherence to a single strand would not. This matters because, if undertaken with care, avenues are offered towards deeper and richer understanding, unavailable via adherence to more delimited methodologies.

Thus, elements of my approach drew upon the philosophy of leading interpretive phenomenological thinkers, such as Heidegger, as their work explicitly sought to comprehension of ‘being in the world’. Heidegerrian phenomenological concepts enhanced understanding of physical activity within the context of life with dementia. For example, ‘Dasein’, being-in-the-world, understanding one’s place within that (Heidegger, 1962, pp.67-69; Crowell, 2006) and what this meant for people living with dementia, through their experiences of engagement with Centres. This was valuable, in particular, as within daily existence understanding of one’s being is opaque, because of an inevitable preoccupation with living life. It is only when anxiety, or angst (Heidegger, 1962, p.310) is experienced that comprehension of being-in-the-world is revealed (Large, 2008). My findings, via the accounts of participants, demonstrated how angst was felt by individuals and how engagement with activities offered by Centres provided opportunity to redirect this, with the consequent continuation of identity formation. For example Paul's searing personal judgement on his failing cognitive powers, saying,

"(I am)… an idiot!"

Paul: interview at home, 11th November 2017.

However, this was coupled with the contemporary chance he clasped to continue to forge his identity in the world through play, for example, as I observed:

'Everything I hit at him he more or less returned... Paul is clearly a good player'.

Paul: participant observation at his Centre, 8th January 2018.

Additionally, Heidegger's notion of temporality enabled valuable theoretical conclusions to be drawn. For example, providing the means for the context and significance of the progressive nature of dementia illnesses to be foregrounded. Heidegger argued that humans are not held to the present, but instead have a sense of themselves in the future. He linked this to his concept of 'authentic temporality' (Heidegger, 1962, pp.377-379), which I witnessed with Ivan, who strove to continue to engage with fitness classes in the gym, even while increasingly unwell with symptoms of dementia that would shortly end his life. In turn this enabled me to understand 'resoluteness', reacting to uncertainty about one's future and responding to it (Heidegger, p.463 & 477). I witnessed how this was used by primary participants to plot different futures, and personal understandings. For example, Leonard seized the opportunity to replenish his life with physical activity and social engagement within Centres, dementia having robbed him of the physical dexterity he cherished from his craftsmanship, and the camaraderie he valued with former work colleagues. Resoluteness was a moment of vision, to be seized and personalised (Heidegger, 1962, p.396; Large, 2008; Critchley, 2009). Heidegger argued this was the authentic present (Large, 2008), and was where and how being-in-the-world, was grasped (Critchley, 2009).

Thus, this theoretical construct was useful, providing a means to think about experiences of participants living with dementia, and how these related to their identity. In particular, in teasing out the meaning of authenticity for individuals. This can be difficult to ascertain, because of potential uncertainty related to memory and articulation of recall. However, researchers can construct better understanding via the building of rapport with participants over a period of time (Russell *et al,* 2020). Thus, being able to understand what experiences meant for primary participants was important, as was comprehension of the lifeworld beyond its spoken and verbally articulated context. It was here that the phenomenology of empathy was utiliterious. By encouraging me to show an emotional concern for the experiences of participants, whilst endeavouring to comprehend the predicament of that person (Svenaeus, 2015) it offered the means to facilitate a close connection with participant, and thus build the necessary rapport. As Jacqui related, *“Long catch up this time, and you impressed the others within the class…They were pleased with your suggested undertakings and around the togetherness we feel during these various sessions…”*

Jacqui: Email from her to C.R., 48 hours after research contact at her Centre, June 2018

Empathy also requires demonstration via physical actions (Svenaeus, 2015), and so, as the researcher I tailored my methods to enable my engagement in activity alongside participants. Meaning accrued via such use of one’s body can be comprehended via another phenomenological strand. This was where Merleau-Ponty’s concept of ‘embodied consciousness’ was helpful, recognising that we are always with our body, and simultaneously we are our body (Hockey and Collinson, 2007), additionally, we are always “bodily in the world” (Merleau-Ponty, 1962; van Manen, 1997, p. 103). This provided the final element of that blend of scholarship which, taken together, enabled me to understand what ‘being in the world’ meant for four people, living with dementia, as they engaged in the activity of Centres. The phenomenology of ‘embodied consciousness’ allowed the significance of movement, and, non-verbal and para-verbal communication, to be understood. Two examples, from my observation of Ivan’s experience, illustrate this.

‘…one other gym user greeted Ivan warmly as they passed with a big smile. Ivan nodded to her in recognition.’

Ivan: observation at his Centre, 16th December 2017.

Here Ivan could use non-verbal and para-verbal communication to help express his sense of identity within the public space of the gymnasium. The following example illustrates how he employed his body to demonstrate elements of this, in particular resilience and authenticity.

"…when undertaking the exercises Ivan's face was set in an expression of extreme concentration. He was taking what he did very seriously."

Ivan: observation at his Centre, 16th December 2017.

This enabled meaning to be made in relation to understanding Ivan's identity. I knew this because of my observations of participants and discussion with them. I also garnered this via conversations with those working alongside primary participants. For example, reflecting upon Ivan's engagement, Kyle related,

"You can see he's trying. There are days, like we all have, that we just think what's the point? But you can see he's trying… And you can also see that when he's not doing it right he gets very frustrated. Very frustrated. It's determination to do it right…definitely he wants to do it right."

Kyle: interview at the Centre, 10th April 2018

This example is also helpful because it demonstrates another attribute offered through recognition of embodied consciousness. Here Ivan's body has played an active role within the social life of the gymnasium. It is an example of 'carnal sociology' (Crossley, 1995), with movement and the rhythm of movement triggering feelings in participants which were interpreted by those participating alongside them.

Thus, it was the blend of phenomenological philosophy which enhanced my ability to understand the richness of what being in the world meant for participants, by providing the means to offer thick descriptions to extend knowledge and strengthen comprehension (Etherington, 2007). Interpretive phenomenology offered insight into the experiences of participants living with dementia, and how these related to their identity. The phenomenology of empathy provided the means through which rapport could be built so this could be understood. Finally, phenomenological philosophy, linked to use of the body, enabled understanding of identity within contexts where participants were regularly using their physical presence to express meaning.

7.4.2. Social citizenship is manifested by people living with dementia in the context of engagement in leisure and fitness Centres

Social citizenship is the place an individual holds and desires to hold within their social life, with an accompanying ability to express agency, and to feel belonging (Birt *et al.,* 2017; Kontos, 2017). It happens in ordinary places (Bartlett, 2016), and as a phenomenon is dynamic, being re-interpreted and built upon as new understandings of life are made, and new experiences reported (Bartlett and Brannelly, 2019). My study, set within the ordinary places of Centres, where participants expressed their identity through activity they had chosen, alongside others of significance to their social selves, provided grand opportunity to add novel understanding about social citizenship of people with dementia.

The first related to the social structures of society, in particular family and formal services, which are essential in enabling people living with dementia to participate and belong within their community (Birt *et al.,* 2017). Centres offered new and valuable ways to realise the enablement of social citizenship, by providing the forum within which family relationships and leisure services could coalesce, in a manner where participants with dementia engaged as citizens and not as patients. Citizenship in this ‘everyday’ sense is important and valuable because it is within the everyday life that individuals live out their lives (Nedlund, Bartlett and Clarke, 2019). Centres can act as venues where key elements of the fundamental social structures of society can come together to enable everyday citizenship. Furthermore, as I described above, the physical activity identities of participants, crafted and strengthened by engagement at the Centres, can be utilised within their wider lives. For example, Ivan manifesting resilience, Leonard sociability. The everyday citizenship, enabled by participation within Centres, can thus be taken applied within contexts extending beyond physical activity, into wider realms of ‘everyday’ life.

The second novel contribution relates to agency, and how people living with dementia can express this, and thereby social citizenship, through use of their bodies. My literature review concluded that the experiences of frailer individuals with dementia engaging in physical activity had largely been ignored. My findings showed that potential benefits extended beyond corporeal health, including for people whose dementia was more advanced. For example, even very tiny signals, micro gestures, can influence the social circumstances of which individuals with dementia are a part, and enable them to assert agency and their place as a social citizen (Nedlund, Bartlett and Clarke, 2019, p.5). Engagement at Centres affords ample opportunity for this, as action and gesture are integral to the activities on offer, which occur within social and communal settings. The example I offered (above) of Paul returning every shot with vigour and my reflections on what this meant for his place in the world as “a very good player”, being illustrative.

7.4.3. The contribution of ‘serious leisure’ to understand important elements of the lived experience of dementia

As far as I am aware, my study was the first occasion in which theoretical understandings of serious leisure have been applied to the dementia context. Serious leisure can support and strengthen considerations of the lived experience of dementia by providing new theoretical understandings. In particular, through its synergy with matters relating to the agentic nature of social citizenship, one’s place in the world, and how this is manifested. Components of serious leisure such as self-fulfilment and interest (Stebbins, 1992), self-development, self-expression, and accomplishment (Cohen-Gewerc and Stebbins, 2013) offer these, and were present in abundance in participant accounts.

The potential of serious leisure to enhance understanding of the lived experience of dementia is at an early stage but possibilities are exciting. For example, engagement in serious leisure enabled participants to work towards successful readjustment to dementia, in the manner suggested by Bunn *et al.,* (2012) and, Cheston (2013). More exciting still is that serious leisure offers a medium through which the agency and aspiration of people living with dementia can be conceptualised and comprehended. This is important in light of the aforementioned tendency for society to demean and ignore such progressive potential (Moran, 2001; Caddell and Clare, 2010). Leonard encapsulated the progressive and powerful potential of this when he related:

"…you're achieving something…actually doing something physically…being there and doing it…Brilliant, great…love it."

Leonard: interview at his Centre, 22nd January 2018.

7.5 Study Strengths and Limitations

A strength was that my study gathered rich and evocative data from a group of people whose opinions about their experiences had not previously been sought. Additionally, I was able to progress understanding using methods (for example go-along interviews and participant observation) that enhanced the ability to capture the insights of people living with dementia. This had the merits of immediacy, and directly linking to the topics of enquiry, thus aiding recall of information for participants. Also, it reduced anxiety primary participants felt about engaging in more traditional interviews. This was because go-along interviews and participant observations were collegiate in nature, and did not require a participant to sit and try to recall information in response to a set of verbal questions.

I also completed interviews using a more traditional approach. This proved very successful with Jacqui as she offered a great deal of information through conversation. It worked well too with Leonard, although he struggled at points with recall. With Ivan and Paul I utilised the assistance of Jemma and Connie respectively. Paul, particularly, was much happier with the go-along format. However, it should be noted that for Jacqui the traditional format worked well. Thus there are people living with dementia who can comfortably engage in research in such a manner. To arbitrarily exclude them from traditional interview formats would therefore be wrong. These matters need careful thought, anticipation and preparation, therefore, on the part of researchers on every occasion, to determine what best meets the needs and aspirations of each person.

A limitation was the relatively small number of participants. My findings, therefore cannot be said to be generalisable. However, I was not aiming for generalisability and would never claim this, advocating instead that it was the richness of the data I gathered, and its uniqueness that provided value. My findings are intended as useful and powerful insights, which can help inform policy and practice, and stimulate other research projects to investigate matters of ongoing importance. I make recommendations in relation to these below.

A further potential limitation was my place in the research. I went to great lengths in Chapter 3 to articulate the reasons I took note of my positionality and so I will not repeat the discussion here. However, I acknowledge that I was very much ‘in the research’ throughout, because of my previous experience, value base and the research methods I used. I also set store by building empathy, as I have previously described and explained. However, I believe that without such positionality my research would have been less discerning. What I brought to its context enabled me to focus better on matters requiring investigation, for example recognising that how primary participants felt about what they were doing was important. It also enabled me to tailor better every interview and observation to the needs of primary participants, for example, by drawing on my experience of working alongside people living with dementia over many years. Ultimately I believe the value of my position within the research was shown in the quality of my data.

7.6 Research and researchers

My final conclusions relate to the role of the researcher, and the discipline of research. Practice relating to research involving people living with dementia is advancing. For example, recognition of responsible research approaches to ensure investigations address the requirements of people living with dementia, to enhance their experience of life (Bartlett, *et al.,* 2018). Additionally, in 2019 Dementia Enquirers was launched. This project, facilitated by the DEEP network, will develop an approach to research where people living with dementia take the lead, and organise programmes of research (DEEP, 2019). The values inherent influenced my research approach. My conclusions, therefore, relate to ethical considerations, the practice of consultation, and enabling people living with dementia to contribute as fully as possible to the research process.

Firstly, there were unsatisfactory aspects within the process of gaining ethical consent from primary participants. Whilst recognising the imperativeness of gaining informed consent, this should never be at the cost of encouraging people with dementia to comply with a bureaucracy, whose administration is a higher priority than participant need. Thus, in the example I gave, I detailed how Ivan could have been enabled to give his consent verbally, recorded on film or on audio tape, rather than being obligated to sign. Ethics Committees must understand the needs of research participants living with dementia better, and tailor their practice and process to meet these.

Secondly, I endeavoured to consult with people living with dementia throughout my study. My motivation included ceding as much control as I thought I could within the context of a PhD project, to people living with dementia. This was based upon my belief in the importance and utility of understanding the voices of people likely to be most affected by research outcomes, and on my desire for co-created knowledge. This proved problematic because time and budget reduced my ability to reach beyond my local area to understand the views and seek the wisdom of people from more ethnically diverse communities in a manner that would not be tokenistic. More broadly, consideration is needed by those who govern the rules of practice for PhD research to determine how deeply people living with dementia can be involved in the organisation and delivery of such research that is investigating aspects of living with dementia. Contemporary understanding of social citizenship in the context of living with dementia means realising co-production of new knowledge is essential.

Thirdly, I noted aspects of researcher practice to be considered by others when attempting similar enquiries. In particular the value that body language and para verbal communication contributed to the quality of data. Despite feeling I had gained the trust of primary participants, I believe the nature of symptoms of dementia each was experiencing had corroded their confidence to discuss matters of relevance in detail. Jacqui was an exception, but she still showed through use of her body aspects relevant to the research that were highly illustrative. Paul showed me meaning through his body language, but also employed para verbal techniques, such as accentuating emphasis on words within short sentences, to articulate meaning in a different manner. The go-along technique was valuable in enabling me to gather such insight. This was especially because my enquiry was so closely associated with the landscape in which the participants engaged.

On reflection, however, I should have recognised how challenging it would be when engaging in public spaces in conversation with participants requiring insight on matters of a sensitive nature. I never set out to discuss such things in those situations. If they arose I swiftly tailored my response so the topic was not progressed. I might return to it a short while later if necessary, but only within the secure confines of an interview in a private room. It is never reasonable to consciously probe for detail that might obligate a participant to address matters of a sensitive nature in a public space. I can now see that great care must be taken by a researcher not to unintentionally do this.

Finally, I found the memory loss of participants living with dementia to be less of a hindrance than might have been expected. Memory loss is not an inevitable symptom of dementia (NICE, 2018), and to discount the ability of people living with dementia without giving due regards to their strengths is wrong. Whilst four people is not a representative sample, only Paul demonstrated a difficulty recalling events in a manner that in any way hindered my enquiry. Even so I did not believe that his memories should be diminished. Instead I felt it was up to me as the researcher to seek ways to illuminate his ability to reflect and offer insight. Thus, Paul's ability to reminisce by doing, to supply insight based upon recollection but powered by his involvement in physical activity, was extremely valuable. At the same time this felt constructive and affirming because Paul was, had been and always would be a sportsman.

7.7 Recommendations for practice and research

Based upon the findings of my research, and the conclusions set out in this chapter I make the following recommendations (Numbers 1-4 relate to practice and are intended for decision makers at senior levels of organisations, and government, both local and national. Numbers 5 – 7 are aimed towards researchers and those with responsibility for research practice, particularly in Universities and research organisations):

1. Identity is a fundamental part of the experience of living with dementia, and engagement in sport and physical activity influences how individuals perceive themselves. Thus, the significance of identity must be incorporated into policy and initiatives designed to promote sport and physical activity for

people living with dementia, alongside more traditional features such as enhancing physical fitness.

2. Effective transport arrangements, easily accessible to people living with dementia, are required to ensure the offering of Centres can be utilised.

3. Centres are well placed to support and enable people with dementia who are living alone to remain connected with their local community, but that is put at risk by barriers to engagement, such as those in 2 (above).

4. Centre Workers play an important part in enabling people living with dementia to engage in activity at Centres. They must be better supported in this, for example with enhanced levels of training related to dementia in the context of their role.

5. Future research to explore how opportunities to engage in physical activity and social interaction may work alongside each other to enable people living with dementia to meet their aspirations for engagement in physical activity.

6. Future research to focus upon the role Centres can play in meeting and sustaining the needs, wishes and aspirations of people living with dementia and their family carer (if they have one) both individually and together.

7. University Ethics Committees to review their policy and procedures to ensure they are compatible with enabling people living with dementia to participate fully within research.

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Conference Presentations

5th July 2017 Leisure Studies Association Annual Conference, Leeds Becket University, Leeds, United Kingdom. Russell, C. ‘Enacting leisure in the context of dementia and identity: the role and significance of community leisure centres’.

Appendices

APPENDIX 1: Route to retained articles. Search terms, and progress towards retained articles.

Topic No.	Search Terms	Exploratory Phase Search	Records identified through database searching	Retained articles
1 & 2 These were highly exploratory searches, which were useful for scoping purposes and enabled the following systematic searches.				
3	Dementia and sport and identity	11,374	30*	3
4	Dementia and Leisure Centre	15,925	30	3
5	Disability and leisure centre	125	30	2
6	Dementia and identity crisis	874	30	1
7	Dementia and identity negotiation	77	30	0
8	Dementia and identity and physical exercise	2,716	30	1
9	Dementia and exercise	130	30	1
10	Sport and identity	0 (297,401**)	0	0
11	Sport and identity formation	1	1	0
12	Sport and identity negotiation	1	30	1
13	Identity negotiation theory	4	4	1
14	Physical activity identity and formation	177	30	0
15	Physical activity and negotiation	65	30	1
16	Community and sport and identity	20	20	2
17	Community and physical activity and identity	70	30	1
18	Socialisation and sport and identity	4	5	0
Total		31,563	360	17

* Decision taken to review first 30 articles provided by Medline, in every exploratory search where there were more returns than 30.

**Too many resources to follow up, thus I explored a more nuanced area, i.e. Topic 11.

APPENDIX 2: Detail relating to retained articles, route to articles and summary of the rationale for my selections

Showing detail relating to retained articles, route to article, and summary of the rationale for my selections

Retained article 1:		
Author(s), year of publication, country of origin	**Search terms or route to article**	**Participants and setting**
Atherton *et al*. (2016) United Kingdom	dementia’ AND ‘leisure centre*’ / center*	Community-dwelling participants (with their carers where possible), who are able to walk 3 metres. Participant numbers not stated.
Type of Study	**Methodology**	**Summary reasons for selection**
Quantitative Open peer review	Randomised control trial	Rare example of article exploring engagement by people living with dementia in activities within setting similar to leisure centres. Relatively recently published.
Retained article 2:		
Author(s), year of publication, country of origin	**Search terms or route to article**	**Participants and setting**
Genoe (2010) Canada	‘dementia’ AND ‘sport’ AND ‘identity’	No primary research participants.
Type of Study	**Methodology**	**Summary reasons for selection**
Peer reviewed academic paper	Paper exploring leisure as a space for resistance and presentation of a proposed research agenda.	Authoritative discussion of published research relevant to topic area of my study.
Retained article 3:		
Author(s), year of publication, country of origin	**Search terms or route to article**	**Participants and setting**
Genoe and Dupuis (2011)	‘dementia’ AND ‘sport’ AND ‘identity’	Four people living with dementia, resident in the

Canada		community, experiencing early-stage memory loss.
Type of Study	**Methodology**	**Summary reasons for selection**
Qualitative Peer reviewed publication	Interpretive phenomenological study. Analysis using a phenomenological approach.	Many aspects relevant to my study (notably identity formation by people with dementia in leisure setting). Research methods offered insight into manner in which relevant insight might be gathered.
Retained article 4:		
Author(s), year of publication, country of origin	**Search terms or route to article**	**Participants and setting**
Dupuis *et al*. (2012) Canada	'dementia' AND 'leisure centre' N.B. this search enabled me to find Dupuis *et al.* (2012), via reading and noting relevant content within the following article: Genoe, M. R. and Dupuis, S. L. (2014) 'The role of leisure within the dementia context' *Dementia*, 13(1), pp.33–58. doi: 10.1177/1471301212447028	People with dementia, living in community and residential settings. Family members and recreation professionals. 215 participants returned questionnaires 10 people living with dementia were interviewed Groups convened to facilitate action research approach, numbers not stated.
Type of Study	**Methodology**	**Summary reasons for selection**
Mixed methods Peer reviewed publication	Participatory action research Questionnaire, interviews and observations. Group reflection and dialogue. Thematic analysis	Suggests outcomes which might inform my analysis relating to identity for people living with dementia in a leisure setting. Co-produced research. Interesting alternative discourse on leisure in dementia context, where leisure

		valued as expression of humanity, and being.
Retained article 5:		
Author(s), year of publication, country of origin	**Search terms or route to article**	**Participants and setting**
Phinney *et al*. (2016) Canada	Alison Phinney is an author the literature review process enabled me to identify as having significance to the research project. I was sign-posted to her earlier work via Genoe (2010); Genoe and Dupuis (2011); Dupuis, *et al.* (2012), above. I then found this recent article.	Fifteen people living with mild to moderate dementia, who are physically healthy. Community-based activity programme.
Type of Study	**Methodology**	**Summary reasons for selection**
Qualitative Peer reviewed publication	Subset of data from a two-year ethnographic study. Go-along interviews, and participant observation. Focus Groups. Interpretive, inductive analysis.	Rare, relatively contemporary, study exploring more vigorous physical activity, and citizenship. Helpful discussion of research methods to help me determine which options might best suit my inquiry.
Retained article 6:		
Author(s), year of publication, country of origin	**Search terms or route to article**	**Participants and setting**
Brown (2017) United Kingdom	‘dementia’ AND ‘identity crisis’ N.B. I found this article through linking my search terms from dementia to concepts I had discovered whilst undertaking my investigation, here from Lundberg *et al.* (2011), see below.	No primary research participants.
Type of Study	**Methodology**	**Summary reasons for selection**
Single blinded peer reviewed publication	Written discussion	Recently published article exploring the nature of

Original article, based upon a workshop session.		identity for people with dementia.
Retained article 7:		
Author(s), year of publication, country of origin	**Search terms or route to article**	**Participants and setting**
Lindelof *et al.* (2017) Sweden and United Kingdom	‘dementia’ AND ‘exercise’	21 people with dementia, living in nursing homes.
Type of Study	**Methodology**	**Summary reasons for selection**
Peer reviewed publication Qualitative	Qualitative interview Qualitative content analysis	Considers the nature of self, as related by people living with dementia. Ponders what people might want from their future and influence on future selves.
Retained article 8:		
Author(s), year of publication, country of origin	**Search terms or route to article**	**Participants and setting**
Wright (2018) United Kingdom	‘community’ AND ‘physical activity’ AND ‘identity’	19 people with dementia, living in their own homes and participating community-based physical activity. Additionally, 7 informal carers and staff were observed.
Type of Study	**Methodology**	**Summary reasons for selection**
Peer reviewed publication Qualitative	Ethnographic approach Observations and interviews Thematic analysis	Use of embodied skills to support identities. This was thought provoking and seemed highly relevant considering the setting of my research and the purpose of those places. Research methods offered potential insight

		into manner in which relevant insight might be gathered.
Retained article 9:		
Author(s), year of publication, country of origin	**Search terms or route to article**	**Participants and setting**
Tregaskis (2003) United Kingdom	‘disability’ AND ‘leisure centre*’ AND ‘identity’	12 staff members were interviewed, all of whom worked at the leisure centre where the research was situated.
Type of Study	**Methodology**	**Summary reasons for selection**
Qualitative Non-peer reviewed publication	Ethnographic approach Social model theory (related to the social model of disability) used to help interpret findings	Understanding into the experience of using a leisure centre from the perspective of a disabled person. Not a peer reviewed article, but valuable personal insights non-the-less relevant to my topic. Insight upon research methods that was illustrative in enabling me to consider which approaches were best suited to my inquiry.
Retained article 10:		
Author(s), year of publication, country of origin	**Search terms or route to article**	**Participants and setting**
Oliver, Hudson and Thomas (2016) United Kingdom	‘disability’ AND ‘leisure centre*’ AND ‘identity’	6 people, aged between seventy-nine and eighty-nine, participating in the initial ten weeks of an exercise referral falls prevention programme.
Type of Study	**Methodology**	**Summary reasons for selection**
Peer reviewed publication	Questionnaires administered regularly Semi-structured interviews	Insight into identity formation in older age in a setting offering vigorous physical activity.

Mixed methods	Thematic content analysis	Highlighted value of hearing the original voice of research participants.
Retained article 11:		
Author(s), year of publication, country of origin	**Search terms or route to article**	**Participants and setting**
Lundberg *et al.* (2011) United States of America	‘disability’ AND ‘leisure centre*’ AND ‘identity’	17 physically disabled adults who had engaged in adaptive sports and recreation, in community-based settings.
Type of Study	**Methodology**	**Summary reasons for selection**
Peer reviewed publication Qualitative	Interviews Analysis via qualitative data analysis and classical grounded theory. Phenomenology used to assist make sense of findings, in particular to understand the meaning of participants’ experiences.	Several theoretical concepts used which might help inform my study’s approach to the inquiry and analysis. For example, ‘identity crisis’, social construction of disability and opportunity structures. Phenomenological underpinning to the study guided my approach by illustrating ways in which this could inform research with a similar subject as my own.
Retained article 12:		
Author(s), year of publication, country of origin	**Search terms or route to article**	**Participants and setting**
Son, Kerstetter, and Mowen (2009) United States of America	‘Sport’ AND ‘Identity Negotiation’	271 people, aged fifty and older, engaging in park-based physical activity
Type of Study	**Methodology**	**Summary reasons for selection**
Peer reviewed publication Quantitative	Questionnaires	Theoretical concepts suggested which could help inform understanding of the context of my study. For example, leisure

		constraints. My knowledge, prior to my research, indicated that people living with dementia experienced numerous externally imposed constraints. Linkages to citizenship milieu. Focus of this article was physical activity of a vigorous nature, of the sort offered within leisure and fitness centres.
Retained article 13:		
Author(s), year of publication, country of origin	**Search terms or route to article**	**Participants and setting**
Anderson and Whitfield (2013) Canada	'physical activity identity' AND 'negotiation'	9 adults aged fifty-three to sixty-four who have experienced a stroke. All living in the community.
Type of Study	**Methodology**	**Summary reasons for selection**
Peer reviewed publication Qualitative	Single one hour interviews with each participant Study draws upon grounded theory Situational analysis	Addresses identity negotiation for people with swiftly emerging cognitive difficulties as its primary focus. Discusses impact on identity of social positioning, following a stroke. This of potential relevance because of congruence with onset of dementia, and its social consequences. Considers stigmatisation, which I anticipate might be relevant for people with dementia engaging in activity in public settings.
Retained article 14:		

Author(s), year of publication, country of origin	**Search terms or route to article**	**Participants and setting**
Snyder and Spreitzer (1979) United States of America	‘community’, AND ‘sport’, AND ‘identity’	No primary research participants.
Type of Study	**Methodology**	**Summary reasons for selection**
Peer reviewed publication Academic discussion paper	Discussion paper	Valuable theoretical underpinning to social identity formation in physical activity contexts. Authors argue that social interaction is key to this. I anticipated this would be relevant because Centres appear to offer multiple opportunities for social engagement, within physical activities they offer, and within social spaces. Also, exploration of what motivates adults to identify with a physical activity identity later in life considered. Fun is considered as part of this, and I believe this could easily be overlooked as an important factor within the context of my research.
Retained article 15:		
Author(s), year of publication, country of origin	**Search terms or route to article**	**Participants and setting**
Weiss (2001) Austria	‘community’, AND ‘sport’, AND ‘identity’	No primary research participants.
Type of Study	**Methodology**	**Summary reasons for selection**
Peer reviewed publication	Discussion paper	Progresses theoretical understanding of social identity and sport.

Academic discussion paper		Argues that social recognition is important to identity formation within sporting contexts. Useful too because the article highlights value participants attach to their sense of identity, and the performance of current sporting roles. Content might help me determine if people living with dementia feel more comfortable within group or individual physical activity contexts.
Retained article 16:		
Author(s), year of publication, country of origin	**Search terms or route to article**	**Participants and setting**
Kissow (2015) Denmark	‘community’, AND ‘sport’, AND ‘identity’	No primary research participants. Exploration of experiences and strategies developed by physically disabled people in physical activity settings, and inquiry into whether these extended into other aspects of life.
Type of Study	**Methodology**	**Summary reasons for selection**
Peer reviewed publication Critical literature review with systematic components	Literature review (but only qualitative studies, and qualitative components of mixed-methods research, included as data)	The context of physically disabled people offered alternative perspective to consider the review and research questions. The article investigates significance of being part of a ‘community of athletes’. Notion of community interesting with context of my research in mind, i.e.

		what will or won't people draw from feeling part of a community in relation to their identity? Also notable because of articles exploration of whether strategies extended into other aspects of life.
Retained article 17:		
Author(s), year of publication, country of origin	**Search terms or route to article**	**Participants and setting**
Williams (1994) United Kingdom	'community', AND 'sport', AND 'identity'. N.B. I was sign-posted to this article via Kissow (2015), above. In particular I was interested in the discussion on disabled people as social beings in sporting contexts, and what this meant for their identity beyond sporting venues.	Exploring the socialisation of athletes with disabilities through sport. No primary research participants.
Type of Study	**Methodology**	**Summary reasons for selection**
Peer reviewed publication Literature review and academic discussion paper	A review of the sociological literature on the subject of the socialisation of disabled athletes.	Considers how disability sport can socialize participants. Highlights the importance of personal biography in life socialisation, post impairment.

APPENDIX 3: Outcomes from consultation with leisure centres

Outcomes from consultation with leisure centres (Based upon answers to the questionnaire received in September 2017)

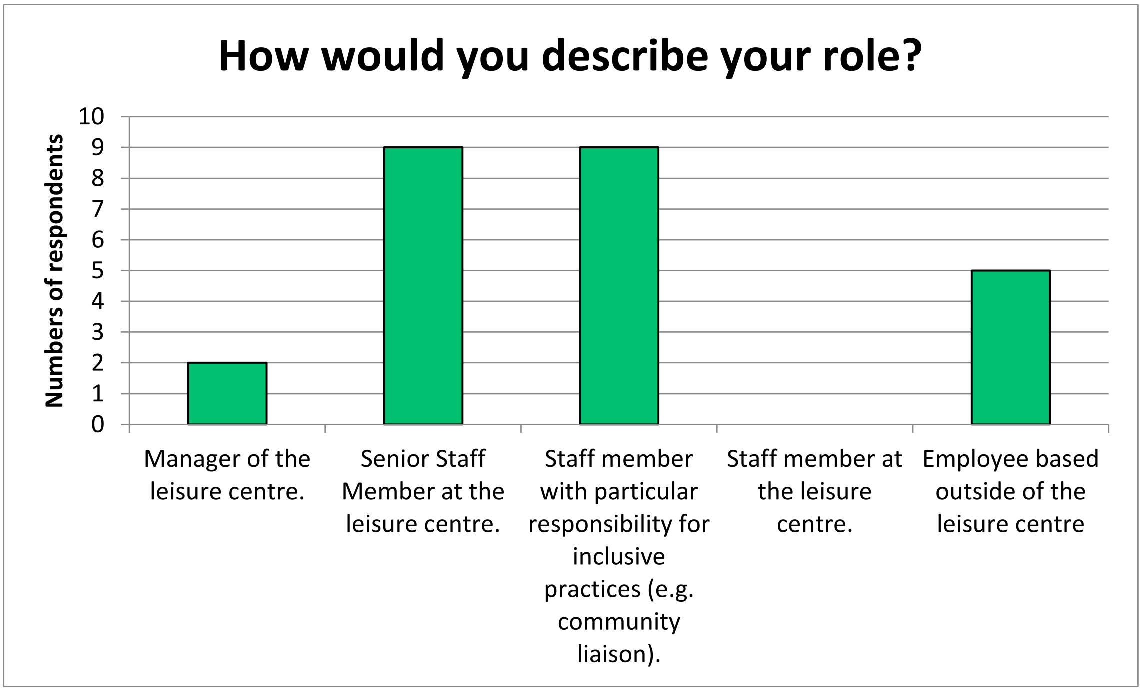
The questionnaire was completed by 26 individuals. Unless otherwise indicated, the following graphs show the responses from all 26 people. For example, if a graph says 'n=24' it indicates that two respondents chose not to answer that particular question.

Enquiry Number 1

How would you describe your role?

While only two managers responded to the questionnaire, it was reassuring to see that the majority of respondents (n=20, 77%) were a manager, senior member of staff or a staff member with particular responsibility for inclusive practices who should all have a good level of knowledge about their organisation.

Additionally, 16 respondents provided further information about their role, with six specifically mentioning that dementia was within their remit, and five others being in a health and well-being role or similar.



Enquiry Number 2

How would you describe the location of your leisure centre?

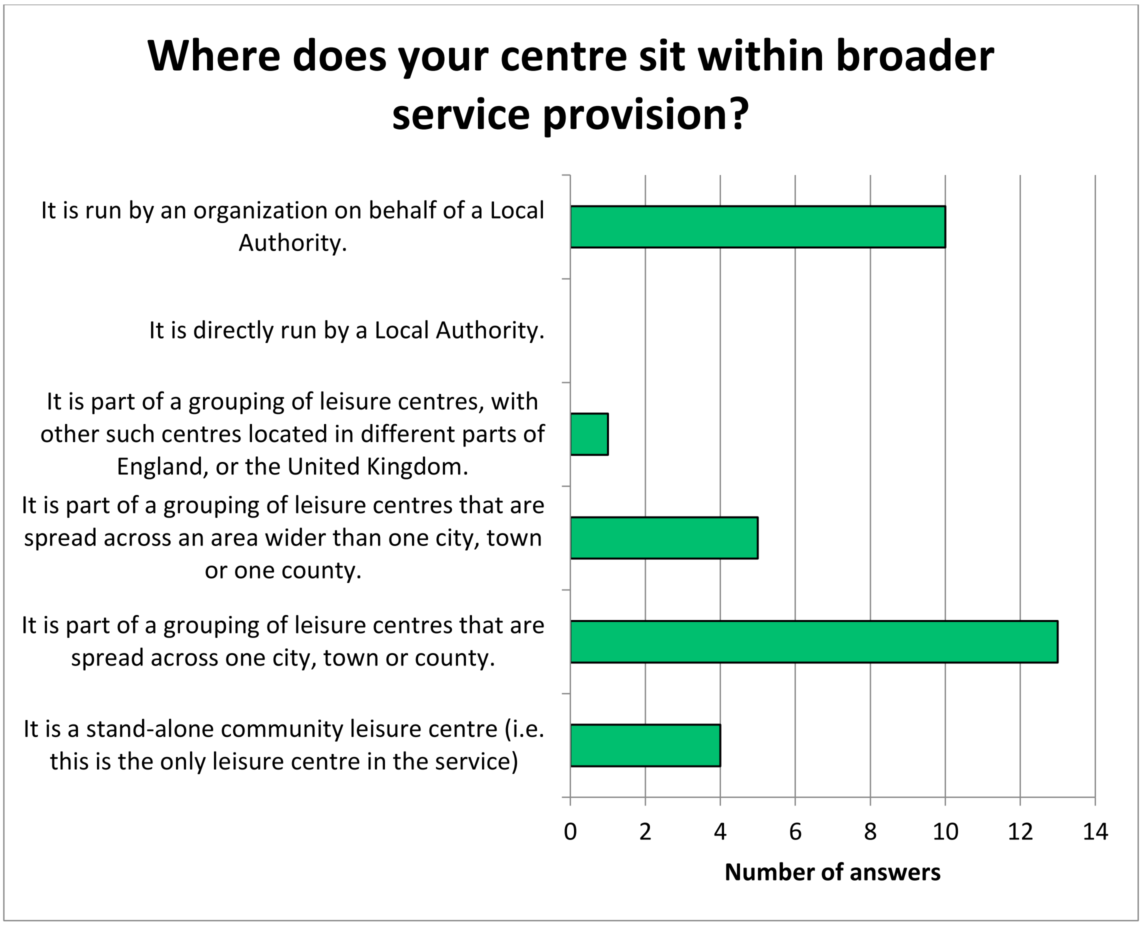
The overwhelming number of respondents (n=22, 85%) related their Centre was located in a town. This suggested that these facilities would play a role within neighbourhoods, possibly as hubs through which leisure and sporting opportunities could be offered to their local community. Additional comments seemed to support this. For example, several respondents related their centre offered provision to a local borough of a town. Numbers of city based and rural locations were tiny in comparison. There was no obvious reason for the former, but the latter suggested that people would have to travel a distance from rural settings in order to access leisure centre provision.

Enquiry Number 3

Please provide information about where your centre sits within broader service provision

For this enquiry, respondents were able to select multiple answers, hence the total number of answers shown is greater than 26.

These responses indicate that individual centres tend to be part of wider organisational entities, for example only 4 respondents related their facility stood alone. It was not surprising that respondents frequently reflected their service was part of a charitable trust, because this tended to be the membership of the organisation acting as my gatekeeper. However, it was interesting that none were run directly by Local Authorities. It seems it is no longer the case that leisure provision is directly provided by local government in the UK.

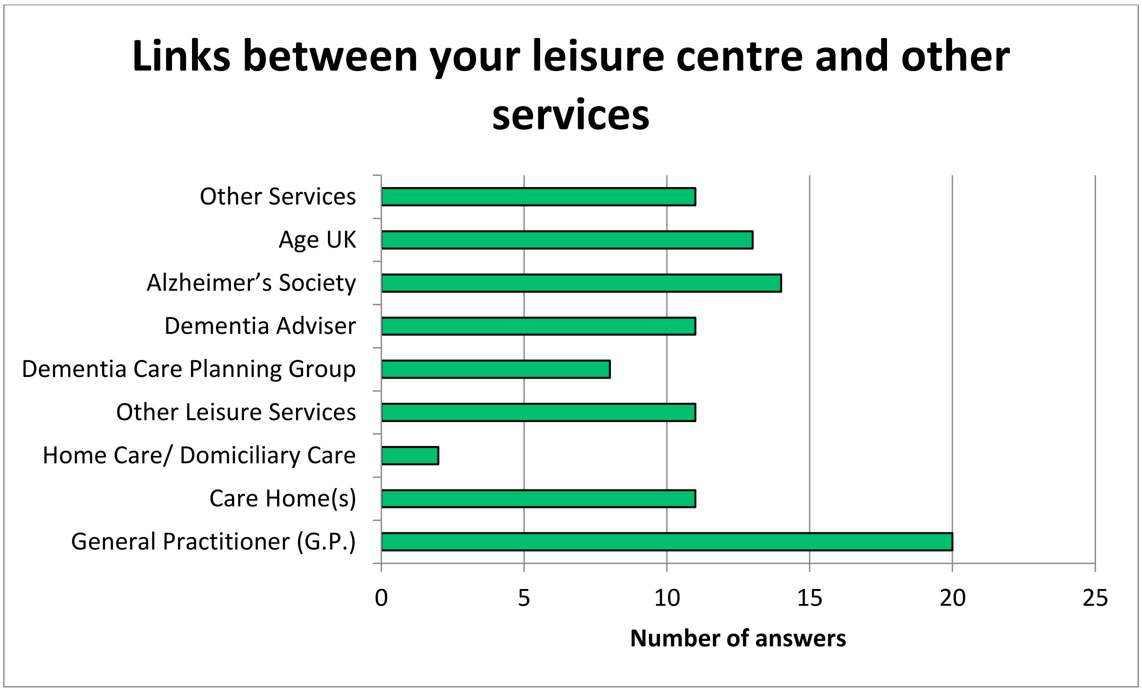


Enquiry Number 4

Links between your leisure centre and other services. Please identify which services (if any) you have arrangements with that facilitate participants in activities of your leisure centre.

For this enquiry, respondents were able to select multiple answers, hence the total number of answers shown is greater than 26.

Responses reflect the importance of partnerships between centres and the organisations, services and charities with whom they work. Whilst General Practitioners were identified most frequently, no individual comments by respondents mentioned them. Instead it appeared that local health services and charities (with a health focus) were the contacts through which centres engaged most frequently, often as part of referral schemes. Dementia and age specific charities were also reported as important, and responses to later questions help illustrate the nature of their input.

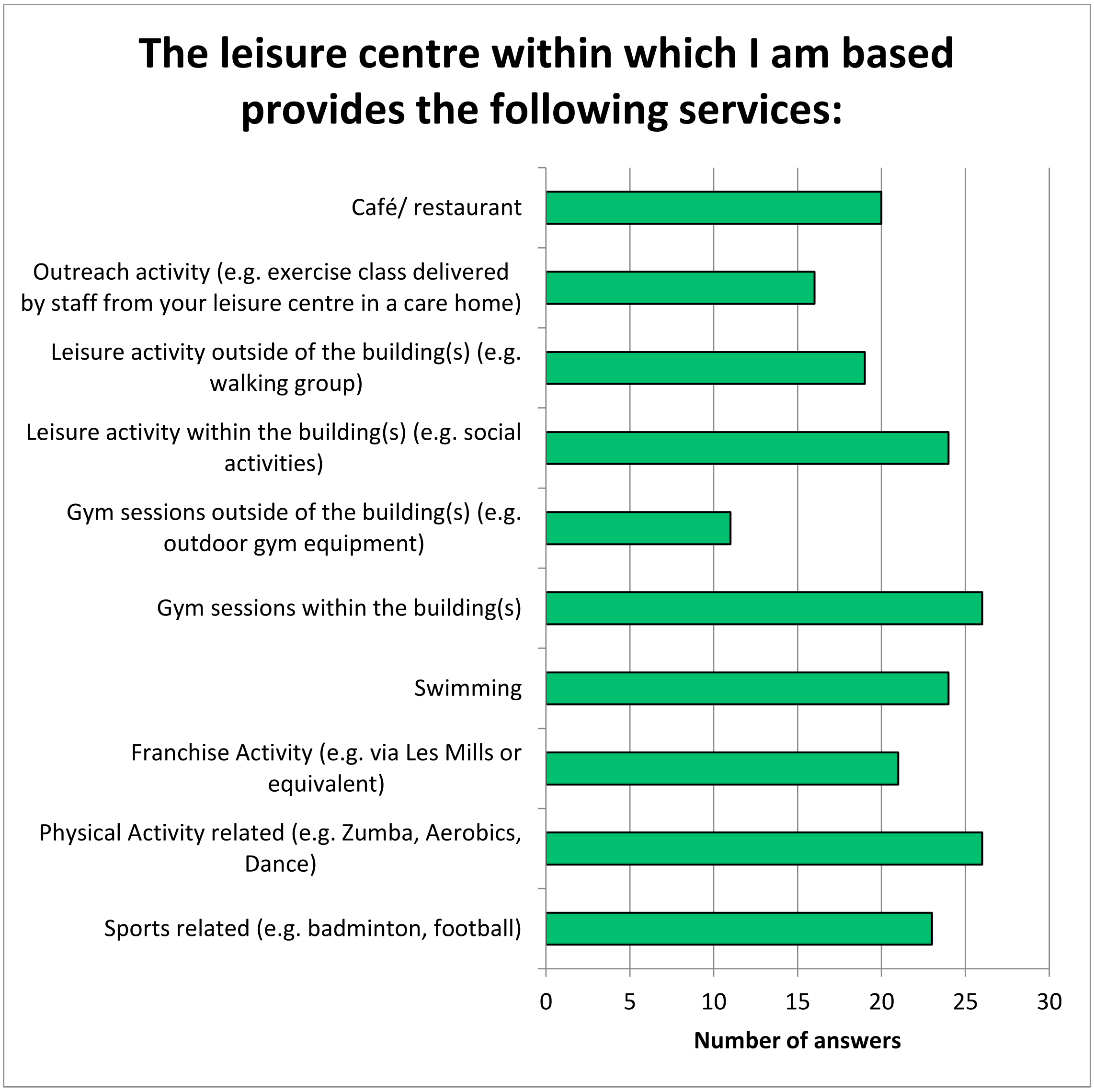


Enquiry Number 5

The services your leisure centre provides. Please provide information about the specific centre where you are based.

For this enquiry, respondents were able to select multiple answers, hence the total number of answers shown is greater than 26.

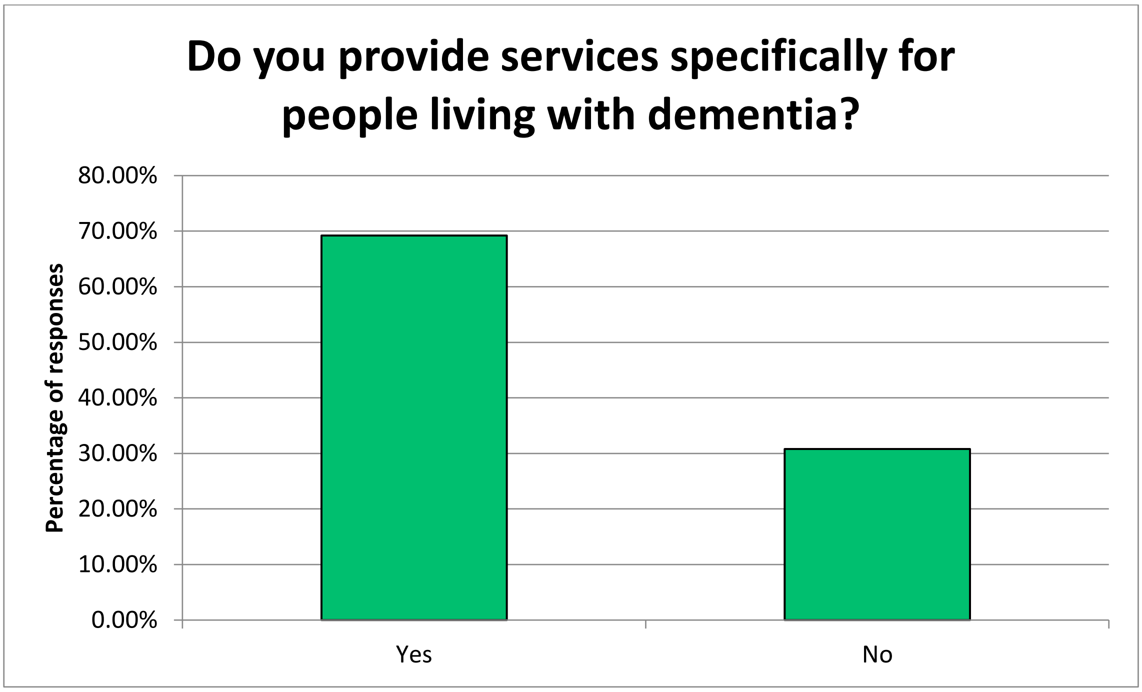
Respondent comments highlighted how their offering extended beyond the walls of the centre, for example to walks organised within the local neighbourhood (these had a focus upon physical and mental health, rather than being specifically for people living with dementia). ‘Outreach’ provision was also mentioned by 2 respondents. For example, with what were described as ‘sports development services’ being offered to ‘seniors’. There was no indication about the nature of the venues being used for such purposes, however.


The leisure centre within which I am based provides the following services:

Enquiry Number 6

Do you provide services specifically for people living with dementia?

All of the 26 respondents replied to this question. Although this group potentially had an interest in the subject matter, because they had engaged with the questionnaire, it was notable that such a large proportion of respondents did provide services specifically for people living with dementia. This indicates the phenomenon is of interest to leisure centres.

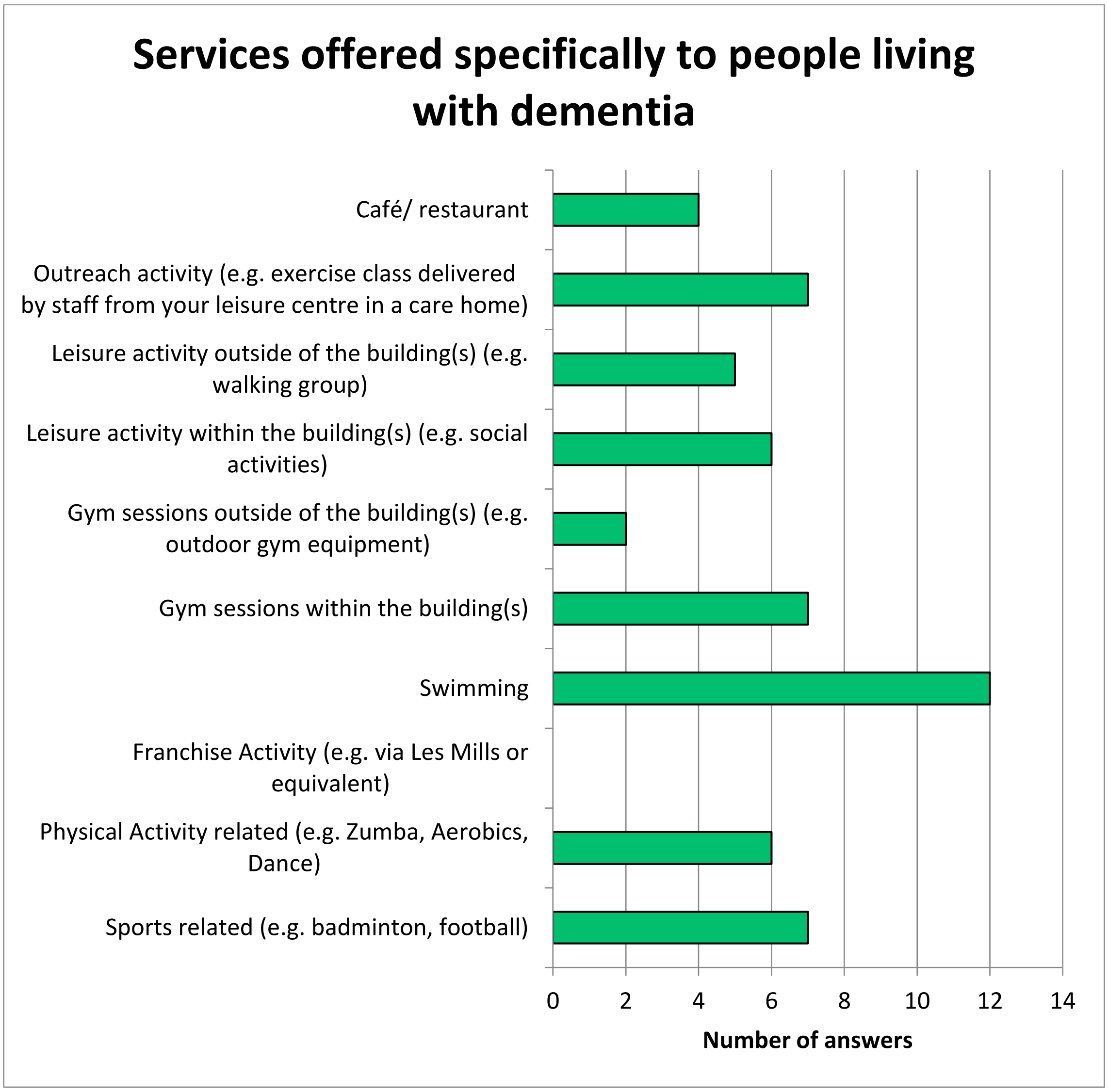


Enquiry Number 7

If your leisure centre does offer services specifically to people living with dementia, please specify which one(s).

For this enquiry, respondents were able to select multiple answers, hence the total number of answers shown is greater than 26.

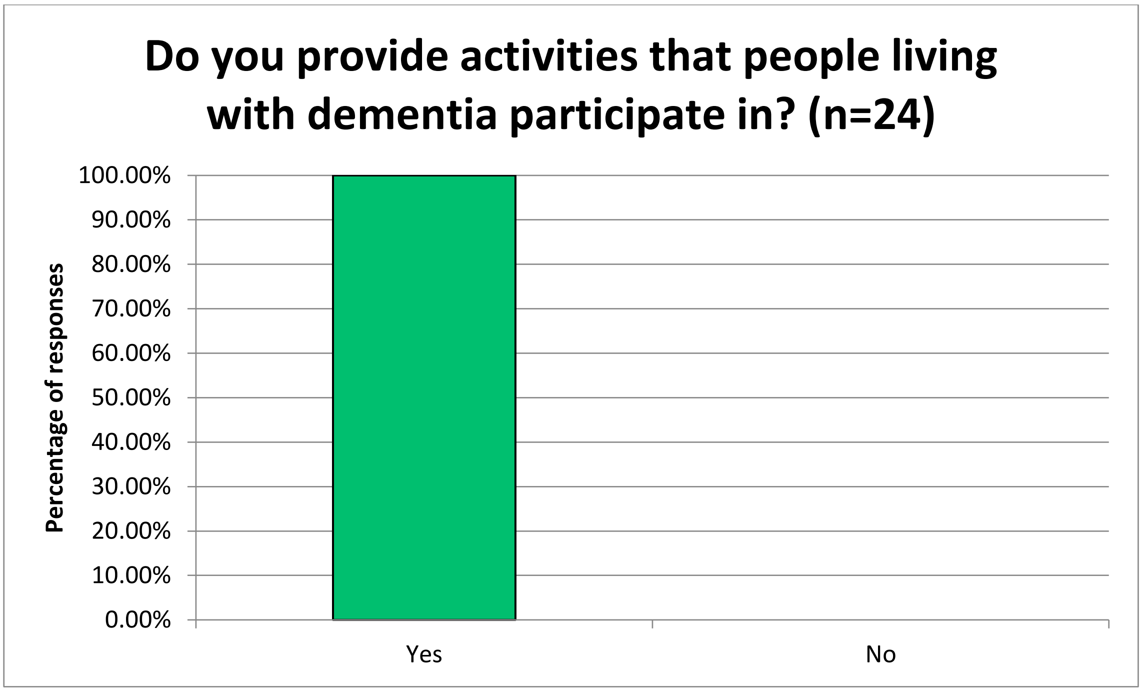
Swimming was a frequently offered option, with one respondent mentioning their provision was part of a formal initiative run by Swim England. No one offered activity under the auspices of physical activity designed and delivered by commercial franchises. Comments by two respondents highlighted how their provision included cultural, and arts and crafts components, alongside physical activity. Another respondent reported their offering also included access to ‘books on prescription’.



Enquiry Number 8

Do you provide activities that, whilst not specifically for people living with dementia, you know that people living with dementia participate within?

Responses indicated that people living with dementia participated in activity beyond that specifically provided for this group of people. Responses and comments relating to enquiry 9, below, provided more detail in relation to this.



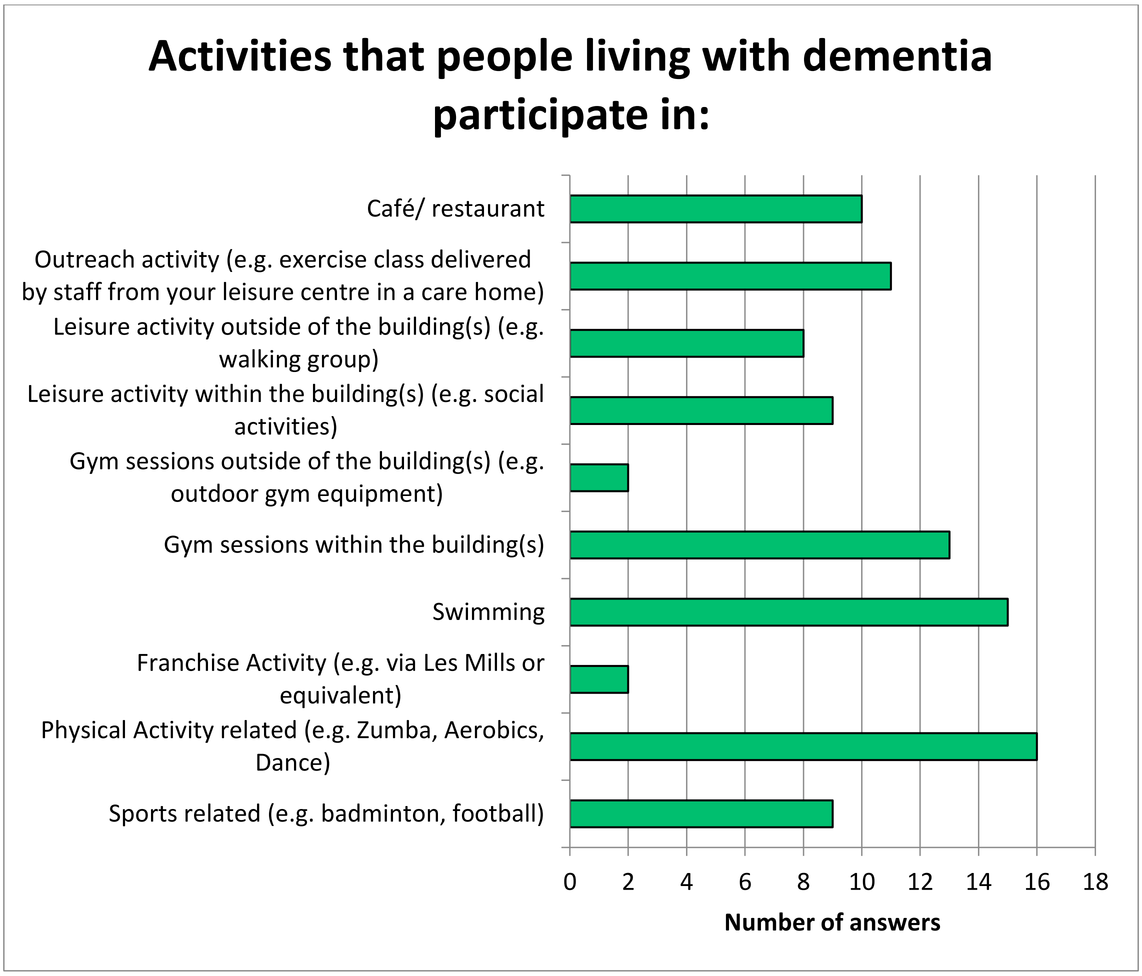
Enquiry Number 9

Which of the following activities do people living with dementia participate in?

For this enquiry, respondents were able to select multiple answers, hence the total number of answers shown is greater than 26.

The use of social spaces, i.e. café/ restaurants by people living with dementia was reported as popular. Activity that associated with mainstream, physical activity based, provision of centres was also highlighted as being utilised by people living with dementia. For example, swimming and use of the gym. Interesting to note too, though, that activity classes were popular, as were sports related activity. Physical activity designed and delivered by commercial franchises was also reported by 2 respondents to include participants living with dementia.

Comments highlighted how tea dances had been popular, even though these were not specifically designed with people living with dementia in mind. This suggests the physical space available to centres can be used flexibly for different purposes.

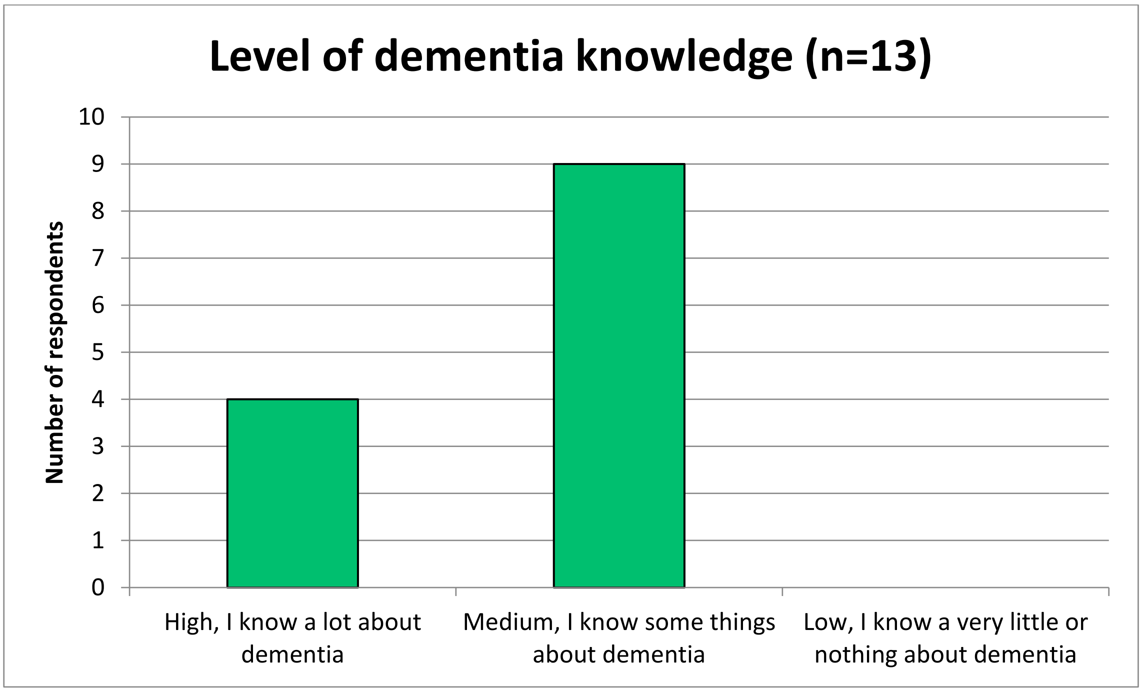


Enquiry Number 10

How would you describe your own knowledge of dementia? (Please tick the one answer which most closely matches your opinion)

For this enquiry, respondents were able to select multiple answers, hence the total number of answers shown is greater than 26.

While only 13 respondents rated their level of knowledge of dementia, a further eight provided comments. In summary this indicated that most respondents had gained their knowledge through general awareness training, or via the Dementia Friends initiative (an awareness raising programme, facilitated through the UK Alzheimer's Society). Comments also indicated that personal knowledge of family members' experiences was being used to inform understanding by several respondents.

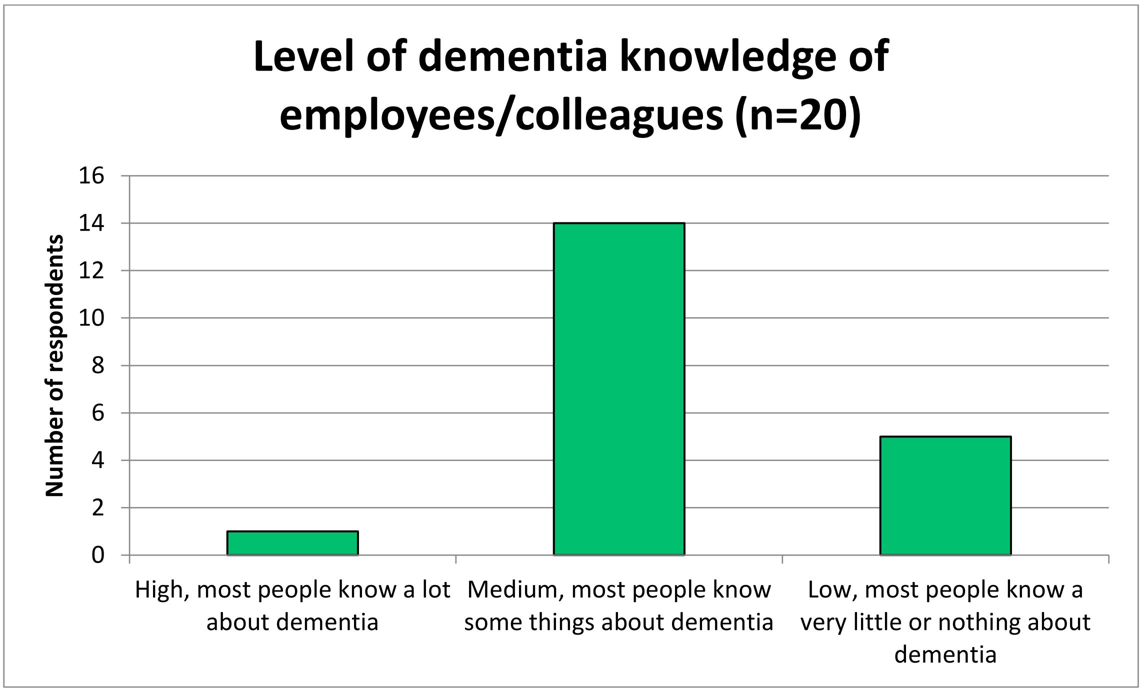


Summary of comments by respondents (n=8)

Enquiry Number 11

How would you describe the knowledge of dementia of your employees/colleagues within the leisure centre?

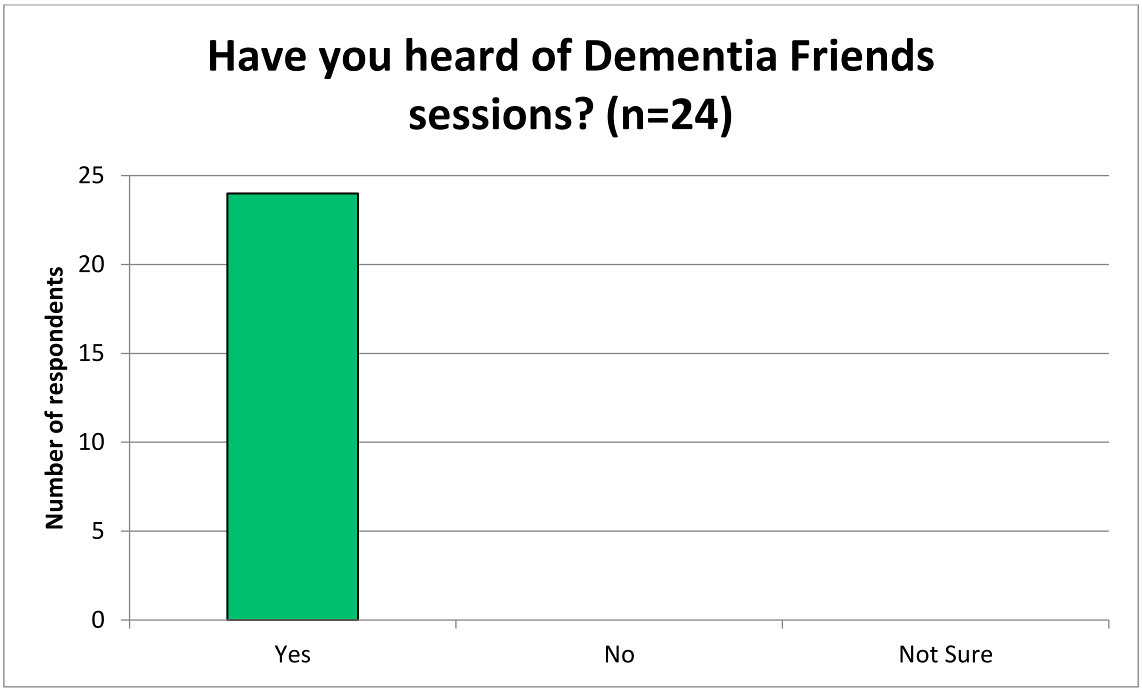
Twenty respondents rated the knowledge of dementia of their employees/colleagues with a further 4 providing additional comments. These reflected that general awareness for colleagues had been gained through similar mechanisms as described in Enquiry Number 10 (above). No mention was made of any formal training provision enabling more comprehensive knowledge of dementia to be gained.



Enquiry Number 12

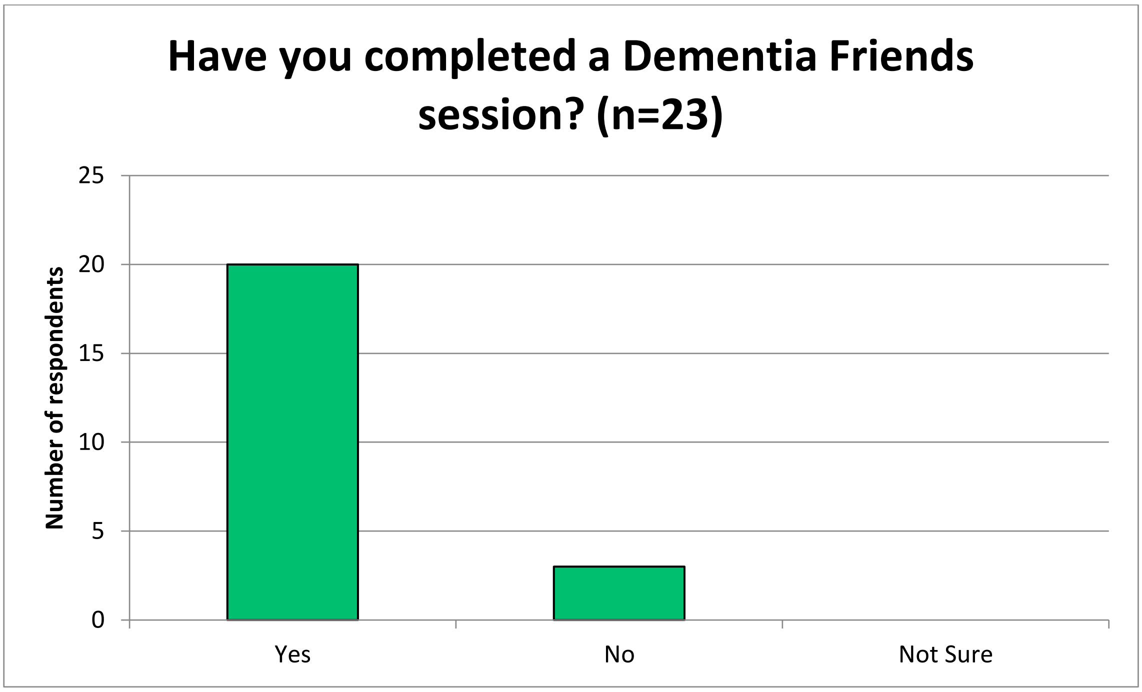
Dementia Friends sessions: Have you heard of Dementia Friends sessions?

These responses reflected that for this cohort the Dementia Friends initiative, and the awareness raising sessions available through it, were well known.



Enquiry Number 13

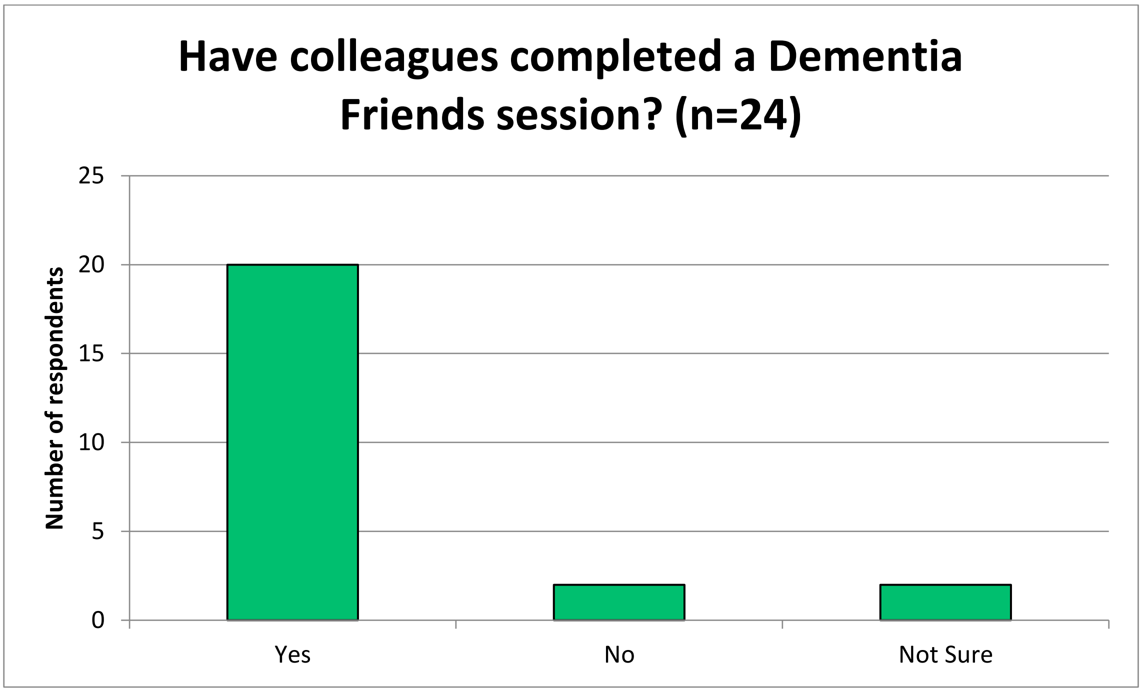
Dementia Friends sessions: Have you completed a Dementia Friends session? Please tick one answer only.



Enquiry Number 14

Dementia Friends sessions: Have any of your colleagues/fellow staff members at the leisure centre where you work completed a Dementia Friends session?

These responses reflected those detailed in the previous four Enquiry numbers, indicating the popularity of Dementia Friends sessions as a method of increasing understanding of dementia within the leisure centre workforce. One respondent commented that they planned to meet with local representatives of the Alzheimer's Society to begin to formalise arrangements for this for their centre.

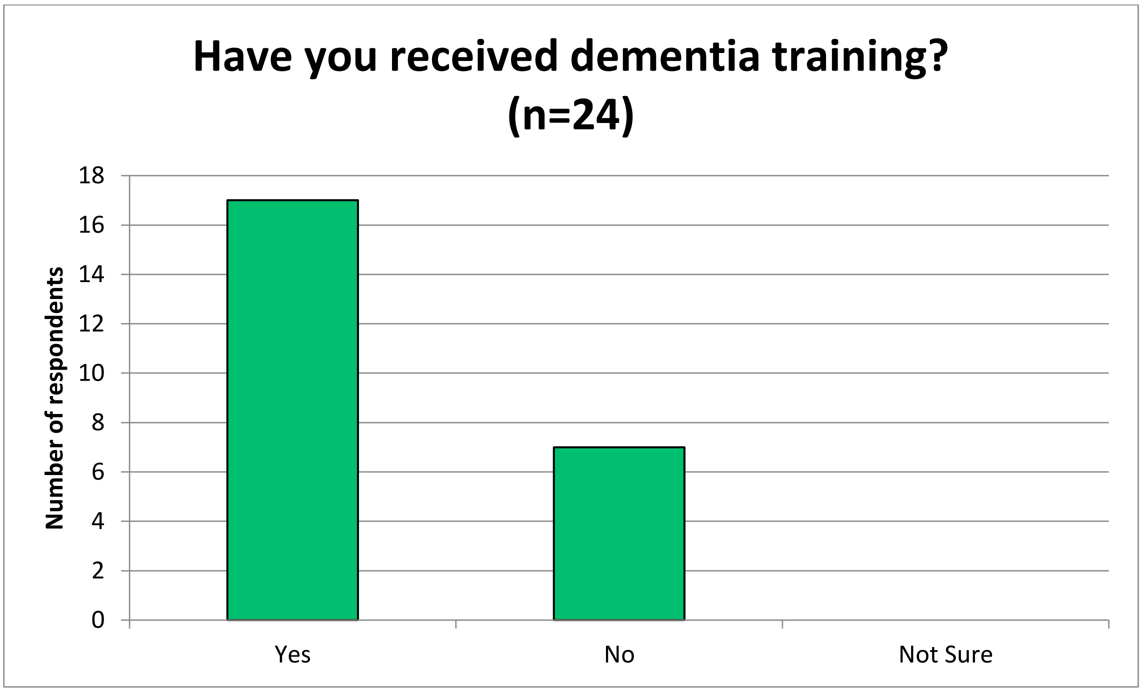


Enquiry Number 15

Your own training in relation to dementia. Have you received training in relation to dementia?

It was of note that, despite being interested enough in dementia to complete the questionnaire, seven respondents reported that they had not received any training.

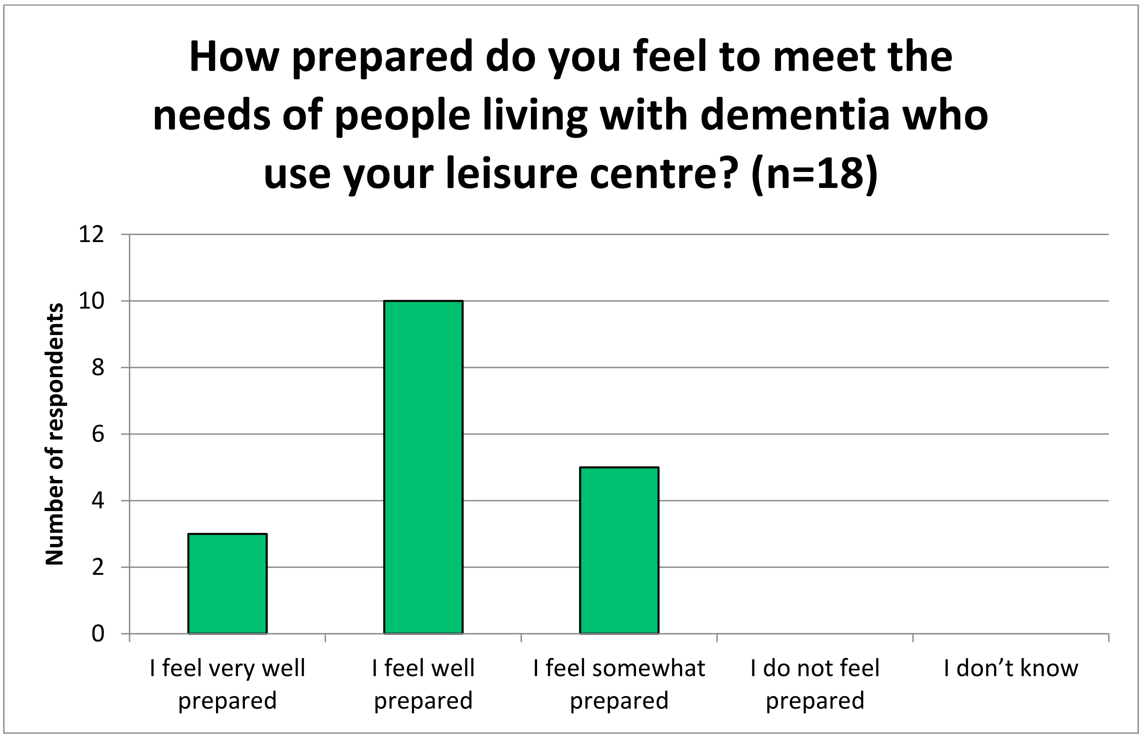
Included within comments was the reflection by one respondents that she/ he had completed the one day 'Dementia Champions' induction (this is an enhanced awareness offering, provided by the Alzheimer's Society, that enables those who complete it the ability to encourage others in their community to make positive changes in relation to dementia). That respondent commented simply that it had enabled them to act as a 'tutor' for other colleagues.



Enquiry Number 16

Reflecting upon your own level of training, based upon the training you have received, how well prepared do you feel to meet the needs of people living with dementia using your leisure centre?

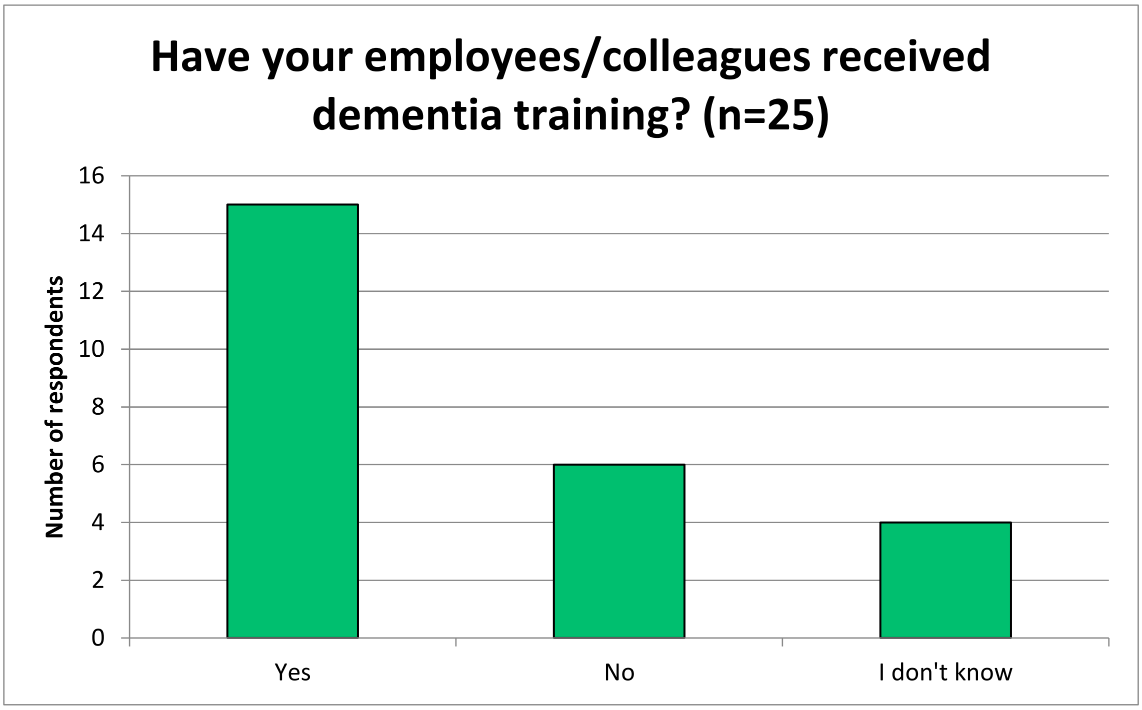
8 respondents chose not to complete this enquiry, and 5 felt ‘somewhat prepared’. This suggests there remains a need to find out more about what type of training might be required for colleagues, working within leisure centres, to feel well prepared to meet the needs of people living with dementia.



Enquiry Number 17

Training in dementia for your employees/colleagues within the leisure centre. Have any of your employees/colleagues within the leisure centre received training in relation to dementia?

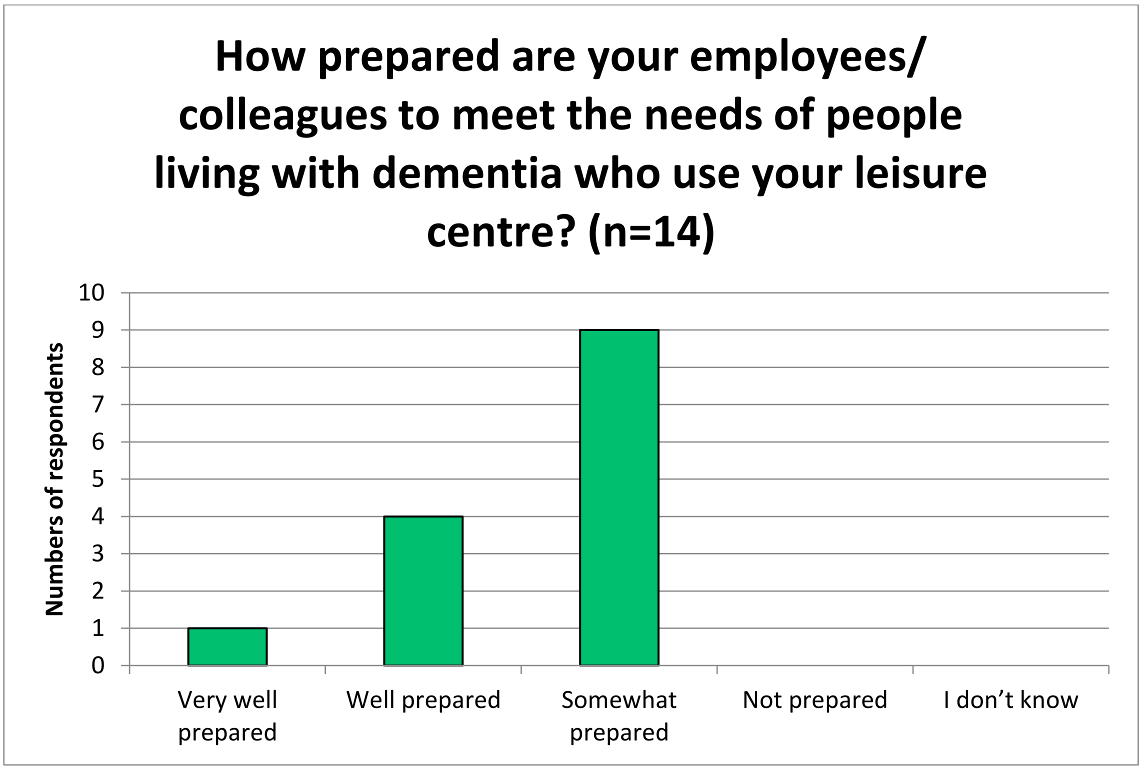
Responses and comments reflected those reported earlier, i.e. that a general awareness of dementia had been gained by colleagues through mechanisms such as the Dementia Friends Awareness sessions. One comment reflected that specific training had been provided through the Alzheimer's Society in relation to dementia friendly swimming.



Enquiry Number 18

Reflecting upon the training your employees/colleagues have received, how well prepared do you feel this has enabled them to meet the needs of people living with dementia using your leisure centre?

Responses appear congruent with those recorded for Enquiry Number 16 (above), that there is a need to find out more about the type of training that might be required for colleagues to feel well prepared to meet the needs of people living with dementia.



Enquiry Number 19

If you felt you needed guidance on enabling people living with dementia and their friends/ supporters/ family carers to use the leisure centre, where would you seek such support?

21 respondents provided information regarding where they would seek support and guidance, mentioning several different organisations and groups which fall into the following key areas:

- Charities (e.g. Alzheimer's Society, Age UK, Dementia UK) – 19 mentions
- Local Dementia Action Alliance – 8 mentions
- Other dementia health professionals (e.g. Dementia Advisor, memory service) – 4 mentions
- Other dementia organisations (e.g. local dementia groups, memory cafes) – 4 mentions
- Health partners (e.g. public health, NICE guidelines) – 3 mentions
- Sport partners (e.g. Swim England) – 1 mention
- Colleagues and other partners (e.g. local council) – 3 mentions

These responses were quite positive, indicating that most respondents are aware of multiple support options available to them, particularly those relating to dementia.

Enquiry Number 20

How helpful would you expect this support to be, i.e. guidance to enable people living with dementia and their friends/ supporters/ family carers to use the leisure centre?

19 respondents provided comments regarding how helpful they would expect this support to be.

Responses were positive, with 9 respondents indicating through their comments that they would expect assistance to be very helpful. Ways in which this had occurred included, through training which had made staff members feel more confident, and via advice offered directly to staff, people living with dementia and family members. Help with establishing groups, keeping updated with latest research, and with person-centred support for participants living with dementia was also reported to have been helpful. It was felt to be detrimental, judging comments made by one respondent, that the adviser concerned was not a physical activity expert.

Enquiry Number 21

What else would support you in your role, i.e. to enable people living with dementia and their friends/ supporters/ family carers to use the leisure centre?

Comments were provided by 20 respondents, falling under the following areas:

- Better training – 8 mentions
- Stronger partnerships with local services and charities – 3 mentions
- Better awareness of what leisure centres can potentially offer to be in the public domain – 3 mentions
- Alterations to the physical environment of the leisure centre – 3 mentions
- Examples of good practice – 2 mentions
- Increased opportunity to offer outreach, beyond the site of the leisure centre – 2 mentions
- Pump priming to initiate offering for people living with dementia – 1 mention

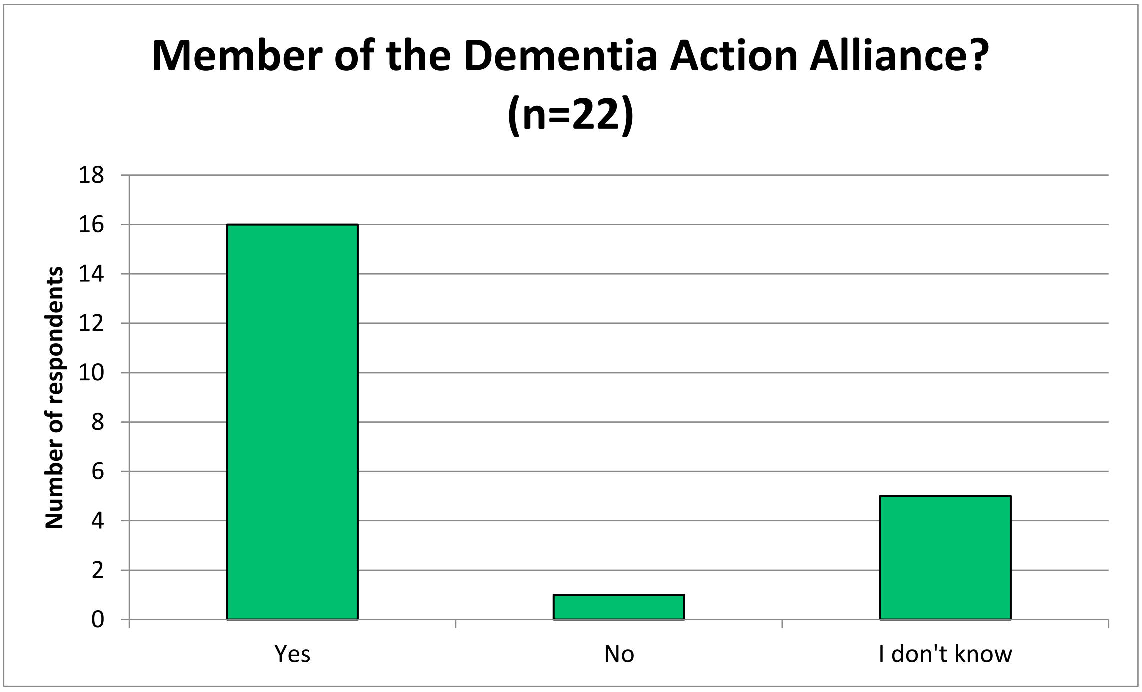
Enquiry Number 22

Is your service and/or leisure centre a member of the Dementia Action Alliance?

A Dementia Action Alliance acts as a forum to bring together organisations, charities and businesses, within a geographical location, to coordinate actions designed to improve the lives of people living with dementia.

The responses and comments already recorded above indicate that respondents valued partnerships within the context of their work, and thus it was unsurprising that 16 respondents answered affirmatively.

Comments highlighted that alliances incorporated different geographical areas. For example, one being ‘countywide’, whilst another incorporated an area covered by a District Council. No comments referred to alliance boundaries determined by nature of particular conurbation, e.g. town. This was of note reflecting on responses to Enquiry 2 (above).



Enquiry Number 23

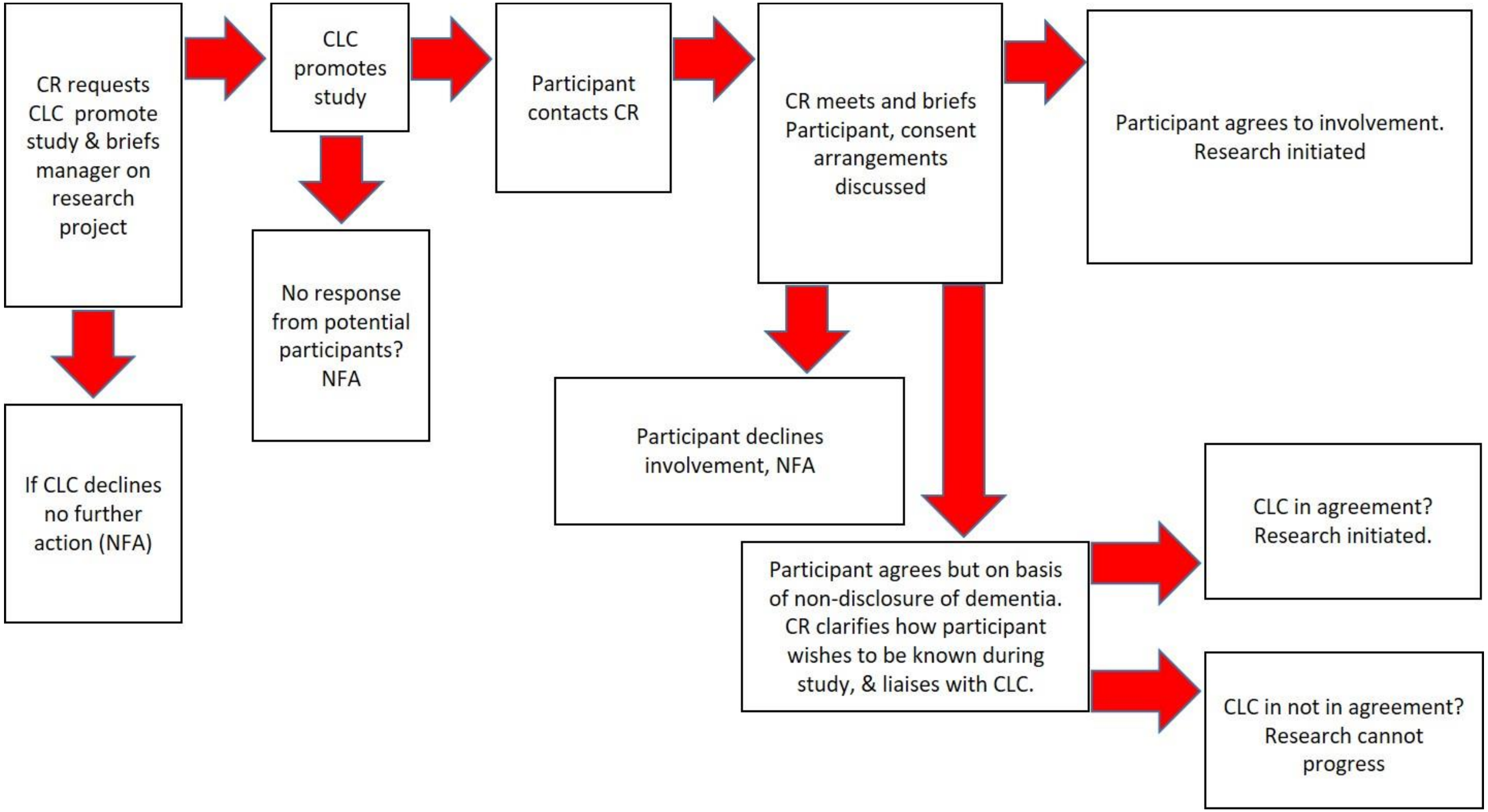
Is there any other information you wish to add in relation to any aspect of this survey?

4 respondents provided comments. Each reflected the desire to know more about dementia as it related to the offering of leisure centres, and commitment to provide services that people felt they could engage with and benefit from. Comment also reflected that their services also had competing priorities and this made developing good quality provision more challenging.

APPENDIX 4: Flow diagram of the recruitment process of participants living with dementia.

Flow diagram of the recruitment process of participants living with dementia for interviews & observations: Recruitment via a Community Leisure Centres (CLC)

a) To clarify the process for recruitment, the role of gatekeepers and matters relating to disclosure of dementia.



APPENDIX 5: Potential participant recruitment flyer.

Finding out more about sporting and leisure activity for people with dementia

Chris Russell is a researcher at the University of Worcester. He is trying to find out how important sporting and leisure activity is for people with dementia.

Chris is seeking people who can help him with the research. *Can you help?* Or, do you know someone who has dementia who might be interested in helping?

He would like to hear from you if you…

1. Have dementia, or a suspected dementia.
2. Are willing to participate in a research study, which will explore what you think about your involvement in sporting activity and its impact throughout your life.
3. Are happy to meet with him – most likely at the leisure centre you attend, and your home - on up to five occasions over a period of approximately 12 months.
4. Will consider giving Chris permission to meet with other people who are important to you in your life, for example your partner (if you have one), staff members at the leisure centre who you know.

The research has been approved, and will continue to be overseen, by the Health & Science Research Ethics Committee, at the University of Worcester.

If you would like to hear more, and possibly volunteer to help, please contact Chris on:

Telephone: (01905) Email: c.russell@worc.ac.uk

APPENDIX 6: Data Collection Events with Participants, and Detail of Data Collected.

Data Collection Events with Participants

Ivan

Interview at home, Ivan, with Jemma, 12.12.17

Observation of Ivan, in the gym, 16.12.17

Go-along interview with Ivan, in the gym, 1.2.18

Participant Observation with Ivan, in the gym, 1.2.18

Interview with Ivan, immediately post gym session, 1.2.18

Jemma, partner/ carer, interview at home, 20.3.18

Participant Observation with Ivan, exercise class, at the Centre 23.3.18

Go-Along Interview with Ivan, at the Centre, 23.3.18

Kyle, centre worker, interview, at the Centre, 10.4.18

Paul

Interview at home, Paul, with Connie present throughout, 11.11.17

Go-along interview with Paul, at the Centre, 8.1.18

Participant Observation with Paul, at the Centre, 8.1.18

Interview with Paul, at the centre, immediately post activities session ended, with Connie present throughout, 8.1.18

Connie, partner/ carer, interview at home, 14.3.18

Participant Observation with Paul, at the Centre, 23.4.18

Go-along Interview with Paul, at the Centre, 23.4.18

Interview, with Paul, immediately post activities session ended, with Connie present throughout, at the Centre, 23.4.18

Martin and Jane, centre workers, interview at the Centre, 3.5.18

Leonard

Interview at home, Leonard, with Caroline present for short and intermittent parts, 19.12.17

Go-along Interview, with Leonard, at the Centre, 22.1.18

Interview, with Leonard, immediately post activities session ended, with Caroline present throughout, at the Centre, 22.1.18

Caroline, partner/ carer, interview at home, 14.3.18

Go-along interview, with Leonard, at the Centre, 3.5.18

Martin and Jane, centre workers, interview at the Centre, 3.5.18

Interview with Leonard and Caroline over lunch, at the Centre, 3.5.18

Go-along interview, with Leonard, at the Centre, 2.7.18

Interview, with Leonard, immediately post activities session ended, with Caroline present throughout, at the Centre, 2.7.18

Jacqui

Interview, with Jacqui, at the Centre, 7.12.17

Participant Observation, with Jacqui, at the Centre, 5.2.18

Interview, with Jacqui, at the Centre, 5.2.18

Patrick, centre worker, interview at Centre, 10.4.18

Participant observation, with Jacqui, at the Centre, 13.6.18

Go-along interview, with Jacqui, at the Centre, 13.6.18

Go-along interview, with Jacqui, during organised walk from Centre, 13.6.18

Interview, with Jacqui, at the Centre, 4.10.18

Detail of Data Collected:

Participant	Time Frame for research contacts	Number and type of research contacts	Approximate interview and observation hours	Number of transcribed words from interviews
Ivan	12.12.17-10.4.18	4 interviews (inc. 2 Go-Along interviews) 3 Observations (inc. 2 Participant Observations)	Interviews: 4 hours Observations: 4 hours	2,400
Paul	11.11.17-3.5.18	5 interviews (inc. 2 Go-	Interviews: 5 hours	8,800

		Along interviews) 2 Observations (Both Participant Observations)	Observations: 4 hours	
Leonard	19.12.17-2.7.18	6 interviews (inc. 3 Go-Along interviews)	Interviews: 10.5 hours	17,500
Jacqui	7.12.17-4.10.18	5 interviews (inc. 2 Go-Along interviews) 2 Observations (Both Participant Observations)	Interviews: 8.5 hours Observations: 5 hours	18,600
Jemma	12.12.17-10.4.18	1 interview	Interviews: 2 hours	9,000
Connie	11.11.17-3.5.18	3# interviews	Interview: 4 hours	11,000
Caroline	19.12.17-2.7.18	5# interviews	Interview: 4 hours	12,000
Kyle	12.12.17-10.4.18	1 interview	Interview: 2 hours	7,600
Martin	11.11.17-2.7.18	1 interview*	Interview: 3 hours	15,700
Jane	11.11.17-2.7.18	1 interview*	Interview: 3 hours	15,700
Patrick	7.12.17-4.10.18	1 interview	Interview: 2 hours	9,000

One interview, of two hours duration, was conducted with both Connie and Caroline separately and exclusively. Additional numbers of interviews with both reflect their participation within interviews held with Paul (Connie), and Leonard (Caroline).

*One/ the same interview, conducted with both Martin and Jane due to the nature of their working relationship, i.e. they frequently facilitated activity together.

APPENDIX 7: Prompts for Enquiry Contact 1

Prompts for Enquiry Contact 1. Interview with research participants living with dementia (November/ December 2017)

Points to anticipate and note:

- Language- spoken, and body language.
- Value and relevance of experiences, especially about how experiences and people made the participant feel, and how they feel about them now?
- Employ visual clues from the setting to assist
- Potential use of participant's photographs

Areas to guide inquiry:

1. LIFE HISTORY: What can you tell me about your childhood? Where were you born, where did you grow up? What was that like?

2. LIFE HISTORY: Can you tell me about your family when you were growing up? Can you tell me about your friends when you were growing up? What was it like being with them? What did you like/ dislike about them? Can you remember anything about school? What was it like?

3. LIFE HISTORY: How would someone who knew you have described you when you were growing up?

4. LIFE HISTORY: Can you tell me about your family now? How does it feel when you are with those people? What things are important to you about those people? How would your family describe you?

5. ROLE: Tell me about different things you have done in your life? What jobs have you had? What other responsibilities have you had? What was enjoyable/ less enjoyable about those times and things?

6. ROLE/ ACTIVITY: How have you tended to spend your spare time? Has sport/ physical activity been something that has played a part in your life? Tell me about the sport/ physical activity you have engaged in. How has this made you feel?

7. VALUES/ BELIEFS: Is there anything that you feel strongly about/ what do you feel strongly about today? In times past?

8. VALUES/ BELIEFS: Is there anything that makes you feel happy/ what makes you feel you feel happy today? In times past?

9. VALUES/ BELIEFS: Is there anything that makes you feel cross or angry/ what makes you feel you feel cross/ angry today? In times past?

10. How would someone who knows you well describe you? What would they say was important to you?

APPENDIX 8: Prompts for Enquiry Contact 2

Prompts for Enquiry Contact 2

Contact 2 – *exploring with each participant their physical activity history/ sporting activity history.*

Following on from Contact 1, where the researcher explored with the participant their general life history, sense of self, sense of their own identity, this contact will aim to explore with each participant the more specific phenomenon of their physical activity history/ sporting activity history. The aim is to understand better how the participant perceives her/ his own physical activity/ sporting activity identity.

The location will be the centre the participant uses. The researcher will join with the participant as they engage with the activities they attend at the centre (usually as part of a morning/ afternoon). Reflections related to their physical activity history/ sporting activity history will be sought from the participant as they engage with the activities. Observation of the participant will help inform findings. The participant and researcher will then meet very soon after the activities conclude (i.e. within twenty minutes) with the aim of exploring the aim of the contact in more depth.

The following questions will guide this meeting (N.B. the order in which each is addressed, whether or not every item is in fact addressed, whether or not different questions and topics are addressed, will be determined by their relevance and usefulness to the context of each participant). Each point can potentially be expanded upon in conversation.

1. How did you feel when you were doing…(that activity)?
2. How did your body feel when you were doing…(that activity)?
3. What, if anything, did you find physically difficult when doing…(that activity)?
4. Can you tell me a bit more about how you feel when you are doing…(that activity)?
5. How will you feel when you get home later?
6. Describe some of the things that go through your mind (1) before; (2) during; and (3) immediately after, and (4) in the days following an exercise session
7. Would you come back again?"; "How do you feel about coming back again?"; "What are the reasons you wish to come back?"
8. How does it feel when you are in the room/ space where the activity takes place? Can you tell me a bit more about how that feels?
9. How does it feel doing that activity alongside the other people? Can you tell me a bit more about how that feels?
10. What do you like about doing (that activity)?
11. What don't you like about doing (that activity)?
12. What are the reasons you are doing the activity we took part in today?

The following questions will be used with participants with stronger memory, either exclusively from the previous ones, or in combination with them.

i. Have you played sport/ taken part in physical activities during your life?
ii. Can you tell me about those?
iii. What did it feel like to do those?
iv. Tell me a bit more about how it felt?
v. Who have you done sport/ taken part in physical activities with? Can you remember how that felt?
vi. Where have you done sport/ taken part in physical activities? Can you remember how that felt?
vii. What are the reasons you have taken part in sporting/ physical activities during your life?
viii. How has/ does taking part in sporting/ physical activities make you feel about yourself?

References

This template is based upon consultation with people with dementia and family carers on research topic and methods, January-November 2017, and researcher reflection up to and including 5th January 2018. It is also based upon the following references:

Genoe, M. R., and Dupuis, S. L. (2011) '"I'm just like I always was": a phenomenological exploration of leisure, identity and dementia', *Leisure/Loisir*, 35(4), pp.423–452. doi: 10.1080/14927713.2011.649111.

Lundberg, N., Tanaguchi, S., McCormick, B., and Tibbs, C. (2011) 'Identity Negotiating: Redefining Stigmatized Identities through Adaptive Sports and Recreation Participation among Individuals with a Disability', *Journal of Leisure Research,* 43(2), pp.205-225. doi: 10.18666/JLR-2016-V48-I5-6897.

Morgan, D., and Krueger, R. (1998) *The focus group kit*. Thousand Oaks, California: Sage.

Oliver, E.J., Hudson, J., and Thomas, L. (2016) 'Processes of identity development and behaviour change in later life: exploring self-talk during physical activity uptake', *Ageing and Society*, 36 (7). pp. 1388-1406. doi: S0144686X15000410.

APPENDIX 9: Interview protocol for carers / family supporters.

Interview protocol for carers/ family supporters, Spring 2018

1. Tell me about X…

2. How would X describe himself?

3. How would a good friend describe X?

4. Tell me about yourself, tell me a little bit about your life history.

5. How would X describe you?

6. How would a good friend describe you?

7. Tell me about your life with X. How did you meet?

8. Tell me about the important moments in your lives together, i.e. over the time you have been together. What are the reasons those moments are important?

9. How do you spend your time together? What is (are the things that are) important to you both about the time you spend together?

10. Tell me about how dementia entered your lives.

11. How has dementia affected X?

12. What sort of impact has dementia had on your lives together?

13. What part, if any, has sport/ physical activity had in your life? (Researcher to explore the history of such engagement, i.e. before this relationship, during the relationship and before dementia, and subsequently)

14. How did you come to attend the leisure centre/ gym? (Researcher to clarify *history* of this engagement in relation to dementia. Also, to explore the motivations of carer and X for engaging with the activities offered by the leisure centre/ gym)

15. Tell me about what X does at the leisure centre/ gym?

16. What does X enjoy? What does X look forward to? (Researcher to explore the detail behind this)

17. What does X not enjoy? Is there anything he looks forward to less? (Researcher to explore the detail behind this)

18. Do you believe there is any impact upon X's sense of himself from engaging in the way he does with the activities offered by the leisure centre/ gym? If so, has this changed over the time he has been attending? If so, how?

19. In terms of support/ assistance, what helps X engage with what goes on at the leisure centre/ gym?

20. What, if any, are the difficulties/ barriers to X’s engagement with what goes on at the leisure centre/ gym?

21. Researcher to explore specific points of interest and relevance to the research question that have emerged from his prior research contacts with X…

APPENDIX 10: Interview protocol for centre workers.

Interview protocol for centre workers

Your role, qualifications and experience:

1. Tell me about your job/ role?
2. How long have you worked in this role/ job? Tell me a little bit about how you came to work in this role.
3. What formal qualifications do you have for the job you do?
4. What formal qualifications do you have for working with people with dementia?
5. Do you follow any occupational standards in the work you do with people with dementia?
6. What sense do you have of the qualifications other colleagues working in leisure and fitness have for working with people with dementia?
7. Have you heard the term “dementia friend”? If so, what does it mean to you?
8. How well trained do you feel to work with people with dementia?
9. How well are you able to apply the training you have received in your work?
10. Would further training assist you offer a service to people with dementia? If so, what new areas of knowledge would be most helpful?

The work you do with the research participant(s), and the background to this:

11. Tell me how you came to work with X.
12. Tell me about X. What is she/ he like?
13. What are the reasons that X engages with the services you provide, in your opinion?
14. Tell me about the work that you do with X.
15. What has informed the work that you do with X, and (then ask about) what has informed your approach with people with dementia more generally?
16. Ask about X’s carer (if she/ he has one) and the working relationship they have with the practitioner.
17. What changes/ adaptations have you made to the approach you take because of dementia? (with X specifically, and also with other people with dementia, include environmental issues). What has informed these approaches?
18. What are the aspects about where you work that enable you to work well with X? (These can include environment and design of facilities, relationship with colleagues, organisation of services etc). Then, apply this question more widely to people with dementia more generally.
19. What are the aspects about where you work that are barriers to enabling you to work well with X? (These can include environment and design of facilities, relationship with

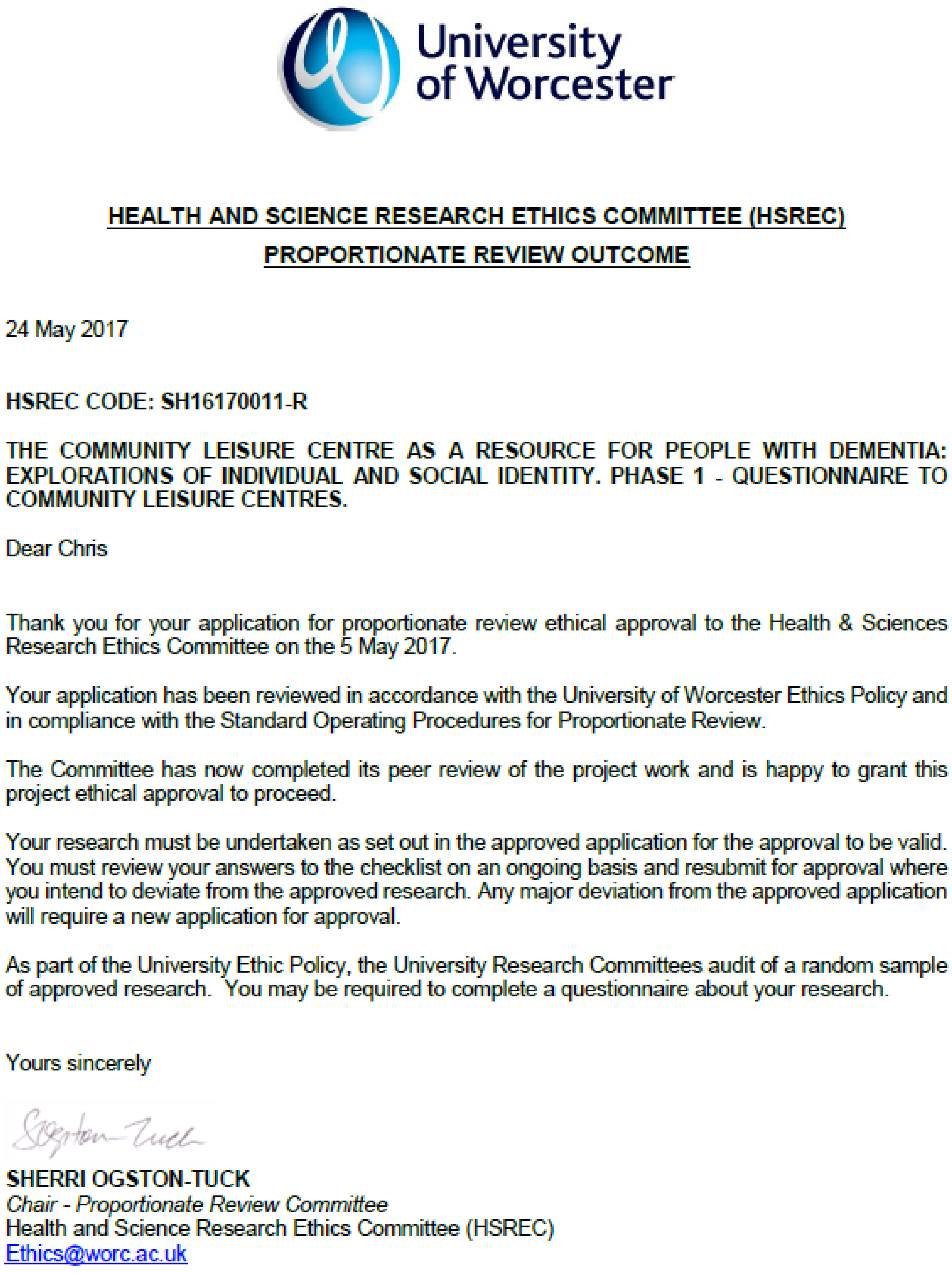
colleagues, organisation of services etc). Then, apply this question more widely to people with dementia more generally.

20. How do your colleagues feel about the sort of responsibilities you describe?
21. Has X changed in the time that you have known her/ him? If so, please tell me about that. Have the reasons X engages with the leisure centre/ gym changed? If so, please tell me about that.

Exploring the leisure centre/ gym context, and of providing services to people living with dementia in leisure centres (NB these questions are taken from the Phase 1/ Consultation with centres research themes):

22. How important is dementia to the potential offering of leisure centres/ gyms?
23. In your view, to what extent do leisure centres/ gyms wish to engage with dementia?
24. In your experience do people with dementia participate in services and activities offered within leisure centres/ gyms? If so which services and activities? (consider swimming the gym, and also including social activities – such as use of the café).
25. Does participation happen within classes and activities for people with dementia, and/ or mainstream classes activities? What is your view about which of these works best for people with dementia?
26. Earlier findings suggest leisure centres want to offer people with dementia more, but that what they offer is insufficiently communicated/ publicised to attract participants. What is your view on this?
27. Do you work in partnership with other people, departments and/ or organisations to provide a service to people with dementia? If so, can you tell me more about these, and whether they are useful and effective?
28. Earlier findings suggest that dementia must compete with other policy and practice priorities of leisure centres/ gyms. Would you agree with this? If so, can you tell me a bit more about this?

APPENDIX 11: Ethical Approval for Questionnaire



University of Worcester

HEALTH AND SCIENCE RESEARCH ETHICS COMMITTEE (HSREC)

PROPORTIONATE REVIEW OUTCOME

24 May 2017

HSREC CODE: SH16170011-R

THE COMMUNITY LEISURE CENTRE AS A RESOURCE FOR PEOPLE WITH DEMENTIA: EXPLORATIONS OF INDIVIDUAL AND SOCIAL IDENTITY. PHASE 1 - QUESTIONNAIRE TO COMMUNITY LEISURE CENTRES.

Dear Chris

Thank you for your application for proportionate review ethical approval to the Health & Sciences Research Ethics Committee on the 5 May 2017.

Your application has been reviewed in accordance with the University of Worcester Ethics Policy and in compliance with the Standard Operating Procedures for Proportionate Review.

The Committee has now completed its peer review of the project work and is happy to grant this project ethical approval to proceed.

Your research must be undertaken as set out in the approved application for the approval to be valid. You must review your answers to the checklist on an ongoing basis and resubmit for approval where you intend to deviate from the approved research. Any major deviation from the approved application will require a new application for approval.

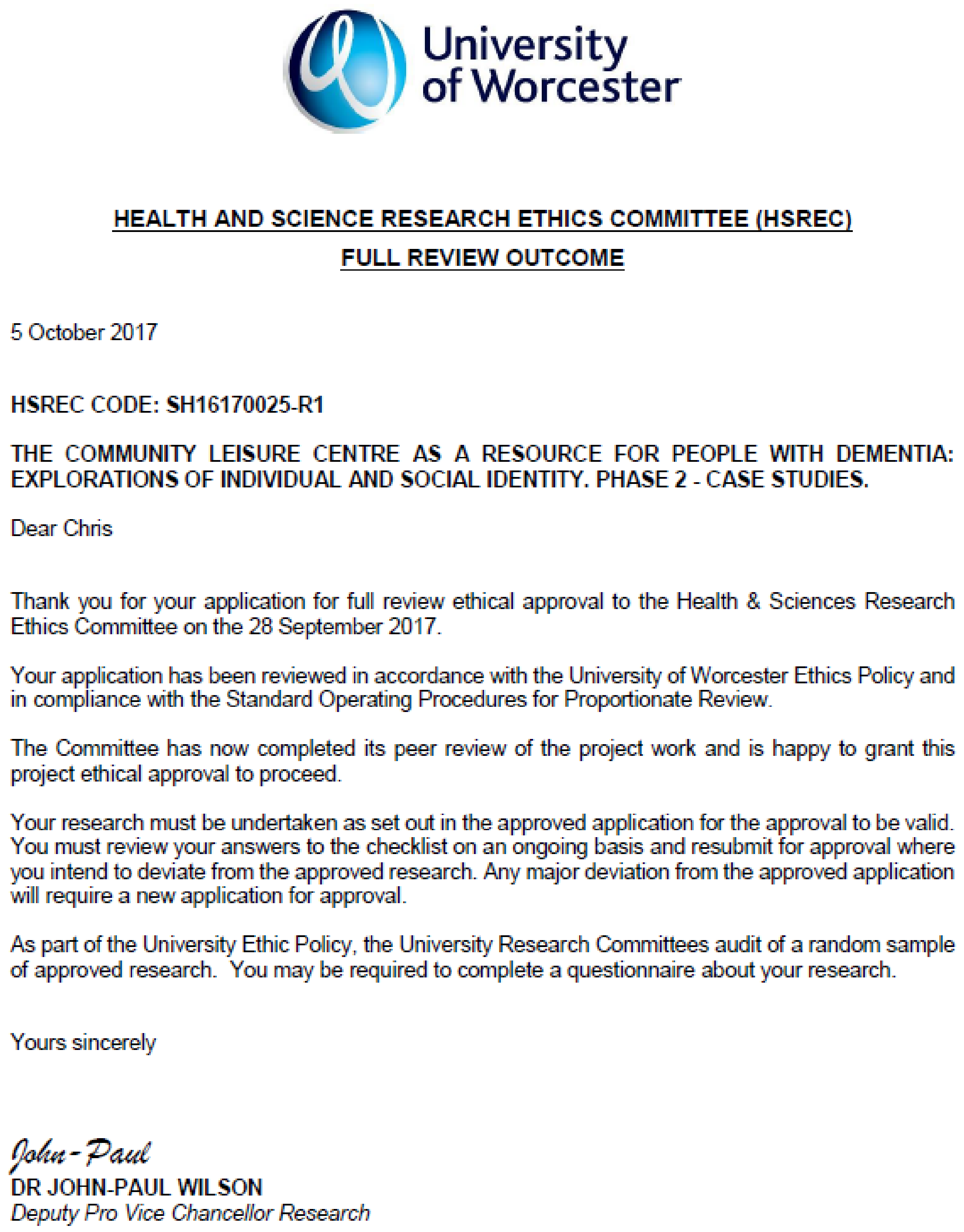
As part of the University Ethic Policy, the University Research Committees audit of a random sample of approved research. You may be required to complete a questionnaire about your research.

Yours sincerely

SOgston-Tuck

SHERRI OGSTON-TUCK
Chair - Proportionate Review Committee
Health and Science Research Ethics Committee (HSREC)
Ethics@worc.ac.uk

APPENDIX 12: Ethical Approval for Substantive Research



University of Worcester

HEALTH AND SCIENCE RESEARCH ETHICS COMMITTEE (HSREC)

FULL REVIEW OUTCOME

5 October 2017

HSREC CODE: SH16170025-R1

THE COMMUNITY LEISURE CENTRE AS A RESOURCE FOR PEOPLE WITH DEMENTIA: EXPLORATIONS OF INDIVIDUAL AND SOCIAL IDENTITY. PHASE 2 - CASE STUDIES.

Dear Chris

Thank you for your application for full review ethical approval to the Health & Sciences Research Ethics Committee on the 28 September 2017.

Your application has been reviewed in accordance with the University of Worcester Ethics Policy and in compliance with the Standard Operating Procedures for Proportionate Review.

The Committee has now completed its peer review of the project work and is happy to grant this project ethical approval to proceed.

Your research must be undertaken as set out in the approved application for the approval to be valid. You must review your answers to the checklist on an ongoing basis and resubmit for approval where you intend to deviate from the approved research. Any major deviation from the approved application will require a new application for approval.

As part of the University Ethic Policy, the University Research Committees audit of a random sample of approved research. You may be required to complete a questionnaire about your research.

Yours sincerely

John-Paul

DR JOHN-PAUL WILSON
Deputy Pro Vice Chancellor Research

APPENDIX 13: Participation Information Sheet (Person living with dementia).

Participant Information Sheet

Understanding your experience of using a leisure centre, and what it means to you

Invitation

We would like you to be part of a research study.

This research will explore what it is like to use the services of community leisure centres.

Please take time to read this document, and ask the researcher (Chris Russell) if you have any questions. His contact details are at the end of this document.

What is the purpose of the study?

The aim of the study is to increase understanding of how people affected by dementia use community leisure centres, and what leisure centres might do to improve what they offer to people with dementia.

The study will explore how people living with dementia use community leisure centres, and what their experiences is like.

The study also explores how using community leisure centres makes people feel about themselves.

Why have I been invited to take consider expressing an interest in taking part?

You are receiving this Participant Information Sheet because you have identified yourself as someone using a community leisure centre, who is also living with dementia.

You are well placed to provide information that can help us learn more about the experience of using community leisure centres.

What will happen to me if I wish to express an interest in taking part?

Chris Russell, the researcher, will meet with you and fully explain what taking part entails. He will answer all your questions. If you decide that you do not want to take part that is absolutely fine. You do not need to give a reason for this and we will not contact you again.

If you do decide to proceed then Chris will meet with you on up to 4 occasions over a 9 month period.

Chris will interview you about your views and experiences and ask you about what it is like to use the services at your community leisure centre. He will explore what this means to you.

Where you meet will be up to you, but Chris can visit you at home. The meetings will be relaxed and informal. Chris is interested in your opinions and the pace of the discussion will be set by you. There are no right or wrong answers. It is expected that most interviews would last about an hour.

It is preferable that one of the meetings will be held at your community leisure centre.

The research will involve Chris joining you in some of the activities you do at the leisure centre so he can get a direct experience of what the leisure centre is like for you. These observations will also be included as part of the research.

Chris Russell will also ask you which other people are important to you as you use the community leisure centre. It may be that a friend or family member or members of staff at the community leisure centre could provide some interesting perspectives on the research. If it is OK with you, Chris will meet with these people to interview them. These interviews will help understand your experiences of using the community leisure centre.

We expect the research to begin between November 2017 and February 2018.

The research is time limited, and following the end of the research it would not be expected that you would see Chris again. You will receive a report on all our findings if this is of interest to you.

Are there any disadvantages risks to taking part?

The aim of the research is positive, to improve the service community leisure centres offer to people with dementia.

We will never tell anyone about your diagnosis of dementia unless you give us permission to do so. Although we would never tell anyone without your permission, it is possible that other people will learn that you have dementia because you are participating in the research. If you are concerned about this, please discuss it with the researcher. If you are very concerned about this it would be best not to take part in the research.

Handling, access by others and storage of data

The research data (e.g. interview transcripts) will be securely stored.

The data will only be available to the researcher, and to colleagues at the University of Worcester who are supervising his work, and supporting him in his studies.

What will happen to the results of the research study?

The research is being carried out as part of PhD research exploring the use of community leisure centres by people with dementia.

The final findings of this study will be reported as part of a dissertation, and shared with community leisure centres. They may also be published in academic journals and/ or at conferences.

Confidentiality & the use of photographs

Unless you have given express consent for us to do so, we will not disclose any information relating to your diagnosis of dementia to any other person who participates in activities with you at the community leisure centre

Unless you give consent for us to do so, we will not disclose any information relating to your diagnosis of dementia to any staff member or person in a management role relating to the community leisure centre.

Your identity will remain confidential, unless you decide that you agree to it becoming known. For example, we might ask to use photographs of you to help the public understand the research better, and to enhance the impact of the research. We will ask your permission to do this, and will not take or publish any photograph of you without your permission.

Please note, in the unlikely event there is a clear risk of serious harm to you or other people we may have to alert others to this in a way that identifies you.

Do I have to take part?

No, your participation is voluntary.

If you choose not to take part this will not impact in any way on you.

If you decide you do not wish to take part in the research this will end your involvement and you will receive no further contact from us.

Who is organising the research?

Chris Russell is a PhD student at the University of Worcester. He is leading the research.

The research is supervised by an experienced academic, Professor Dawn Brooker, her contact details are also contained at the end of this document should have any queries.

The research has been approved by the University of Worcester Health & Sciences Research Ethics Committee.

What if I withdraw from the research?

You can withdraw from the research. You do not have to give a reason. There will be no adverse consequences for the services you are receiving.

If you have already provided information as part of the research we would like to include that, because it will strengthen the quality of the study. You will be asked about whether you agree to this before the research begins.

What happens next?

Please use this information to decide if you would like to learn more about the proposed research. If you would like to take part please contact Chris Russell to express your interest in doing so.

If you have any questions, concerns or complaints about this study please contact one of the research team using the details below.

Thank you for taking the time to read this information

Student researcher:

Chris Russell (PhD Student)

Email: c.russell@worc.ac.uk

Tel: 01905 542 557

Supervisor:
Professor Dawn Brooker
Email: d.brooker@worc.ac.uk
Tel: 01905 855 250

If you would like to speak to an independent person who is not a member of the research team, please contact

John-Paul Wilson
Deputy Pro Vice Chancellor Research
Graduate Research School
University of Worcester
Henwick Grove
Worcester WR2 6AJ
01905 542196
j.wilson@worc.ac.uk
PIS_PWD_IV_v2_15817

APPENDIX 14: Consent Form (Person living with dementia)

Exploring the experience of using community leisure centres

Lead researcher: Chris Russell

Contact details:
The Association for Dementia Studies, University of Worcester, Henwick Grove, Worcester, WR2 6AJ

Tel: 01905 542 557

Email: c.russell@worc.ac.uk

- **Please read this form carefully.**
- **Please tick or circle to indicate your response.**
- **If you are willing to participate in this study, please sign and date the declaration at the end.**
- **If you do not understand anything and would like more information, please ask Chris Russell** (his contact details are set out above).

Please initial Yes/ No To indicate your view:

I have had the research satisfactorily explained to me in verbal and / or written form by the researcher.	**YES**	**NO**
I confirm that have had sufficient time to consider whether I want to take part in the study	**YES**	**NO**
I understand that I may withdraw from this study at any time without having to give an explanation.	**YES**	**NO**
I know who to contact and how to contact them if I have any concerns about the research	**YES**	**NO**
I understand that interviews and observations with me will be audio recorded. I give my consent to this.	**YES**	**NO**
I understand that photographs of me may be taken by the researcher. This is to help others contribute to the research, and to help promote the findings of the research. For these reasons the photographs may be made public. I give my consent to this.	**YES**	**NO**

I understand that all information about me will be treated in strict confidence and that I will not be named in any written work arising from this study.	**YES**	**NO**

I freely give my consent to participate in this research study and have been given a copy of this form for my own information.

Signature: …………………………………………………………………..……….

Date: ………………………………………………………………………………….

APPENDIX 15: Summary of Research for Observations

My Name is Chris Russell. I am a PhD student studying at the University of Worcester.

My research is exploring community leisure centres, in particular what it is like to participate in activities provided by them.

Today I hope to observe the activity that you are taking part in.

My intention is observe what is going on and consider how this relates to the aim of the research.

You are not a direct participant in the research, but I want to be sure that you are happy for me to stay in the room, and perhaps take part in the activities alongside you and other group members.

I will not be filming, taking photographs or audio recording what goes on. I will write up my reflections on what I have observed after the session.

You will not be named or identified in any way as a result of the observation.

The results of today’s observation will form part of the final PhD study, which will be published as an academic dissertation. Its results will be shared with community leisure centres with the aim of enabling them to use findings to improve their service. Its findings may also be used at academic conferences.

You will not be named, or be able to be identified in any of the published results or articles.

By taking part today you consent to my involvement on the basis described here.

You have the right to withhold your consent. Please alert me to any concerns or questions that you have. If you do not wish me to stay in the room to observe I will leave and the observation will not take place.