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# MORE THAN TEA AND CAKE: A REALIST EVALUATION OF MEMORY CAFES IN CORNWALL

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# UNIVERSITY OF PLYMOUTH

## **MORE THAN TEA AND CAKE: A REALIST EVALUATION OF MEMORY CAFÉS IN CORNWALL**

by

**LISA BURROWS**

A thesis submitted to the University of Plymouth  
in partial fulfilment for the degree of

**DOCTOR OF PHILOSOPHY**

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### **Author's Signed Declaration**

At no time during the registration for the degree of Doctor of Philosophy has the author been registered for any other University award without prior agreement of the Doctoral College Quality Sub-Committee. Work submitted for this research degree at the University of Plymouth has not formed part of any other degree either at the University of Plymouth or at another establishment. This study was financed with the aid of a studentship from the National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care (CLAHRC) South West Peninsula (PenCLAHRC).

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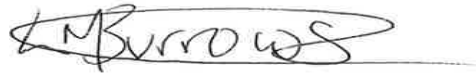
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A handwritten signature in black ink, appearing to read "L. N. Burrows", written over a horizontal line.

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# MORE THAN TEA AND CAKE: A REALIST EVALUATION OF MEMORY

## CAFÉS IN CORNWALL by LISA BURROWS

### Abstract

**Background:** Memory cafés are a growing community based response to supporting people living with dementia and their carers. They are now well established in the UK and elsewhere; with over forty cafés in Cornwall. Despite their growth, there has been little research into their structure, aims and impact.

**Aims:** The aim of this research was to explore how and why memory cafés work for people living with dementia and their carers.

**Methodology:** Realist methodology is a theory driven approach that seeks to explain why a programme works, for whom and in what circumstances. The research consisted of three stages. Firstly, the development of initial programme theories through a realist review. Secondly, the testing and refinement of those theories, and the development of new theories through a realist evaluation. Thirdly, the formulation of a conceptual platform from the programme theories of how and why memory cafés work. The realist evaluation used ethnographic approaches of observation and in-situ interviews in four memory cafés, to enable a greater understanding of the café structures, processes and reported benefits.

**Results:** A conceptual platform comprising twelve core processes of how and why memory cafés work was developed from nine programme theories. Cafés generally adopted a volunteer-led, more structured approach or a guest-led, unstructured approach. Memory cafes are multi-faceted; providing a safe place where people with dementia and their carers can meet with others in a similar

situation, and engage in a range of activities. Furthermore, they provide a place of continuity for a carer once their loved one has passed away. They create opportunities for humour and laughter, outside of normal routines and can be a source of information on other services. Most importantly they enable the development of relationships.

**Conclusions:** Memory cafés provide a valuable community based service to people living with and affected by dementia.

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## **List of abbreviations**

None used

## **Keywords**

Dementia, memory cafés, carers, volunteers, realist, ethnography

### **‘If it wasn’t for this café we wouldn’t see anyone’**

In January 2015, our memory café opened in St Agnes in Cornwall. After months of meetings, emails, form filling, buying equipment, and setting up a bank account, we were ready to go. We had advertised the café in various places around the village; the GP surgery, shops, the community hall and the village paper but we felt a sense of trepidation as 2pm arrived, as to whether anyone would arrive. I had previously worked in the area as a primary care dementia practitioner, supporting people in the communities living with dementia and their families, so I was aware that there may people that would be interested. Gradually, people started to walk through the door and took a seat. We shared a cup of tea, whilst people introduced themselves, chatted, and some started on the word searches that were on the table. We played music bingo that day, where you have a bingo card with various song names on it. A CD is played that has the introductions of the different songs, and the bingo card is marked off. The introductions of the songs led to the guests and volunteers to continue singing the rest of the songs. At the end of the session, we said thank you and that we hoped the session had been enjoyable. One of the carers asked to say something, she expressed how grateful that she was that the café had been opened and said ‘If it wasn’t for this café, we wouldn’t see anyone’. I was so struck by what she said that in two hours, the café could make a difference. I was aware from starting our café, they had grown in Cornwall, the UK, and elsewhere. I wanted to know more, to answer the questions that were in my head – Why are they growing?, How are they helping people living with and affected by dementia?, How do they work?.

I hope this thesis in some way, answers those questions.

# **1 Chapter 1: Introduction**

## **1.1 Dementia**

It would be familiar to start this thesis, in the same vein as the many books and articles that have been published about dementia care; citing the growing numbers, the global crisis and the burden of supporting individuals living with dementia. This negative standpoint in which dementia is framed reinforces it as a stigmatised and feared condition (Clarke & Wolverson, 2016). Dementia challenges us to consider what it means to be a person and who we will be, when our memories fail. However, an increasing focus of understanding the lived experiences of people with dementia shows that positive experiences are possible. Understanding how to create these positive experiences is a vital part of dementia care and research. Therefore, this thesis will take a different approach, and look at a way in which communities can support people living with and affected by dementia. Memory cafes are an increasing community based response to supporting people with dementia and their carers. However, to date there has been little research into how and why they work. Dementia not only impacts the individual but their relationships with others, and how they are viewed by society. This thesis explores memory cafes thus at the individual level, the relationship level and the societal level. As a starting point, it is important to first consider the different theoretical approaches to dementia and the historical context of dementia research.

## **1.2 Different theoretical perspectives on dementia**

- **Biomedical**

Biomedical understandings of dementia have historically dominated and influenced dementia research (Downs, 1997). The history of defining dementia, in particular Alzheimer's disease as a condition distinct from normal ageing can be traced back to the work of Alois Alzheimer, a German neuropathologist (Holstein, 1997). He described a female in her early fifties that initially presented with memory loss and disorientation, who over the next five years, developed depression, hallucinations, then dementia and death. His pathological examination revealed atrophy and lesions in the cerebral cortex, as well what he determined were unusual clumping and distortion of cortical neurofibrils (Holstein, 1997). From this he surmised that 'senile dementia' a condition of old age could occur in younger individuals. At around the same time another German neuropsychiatrist cautiously coined the term Alzheimer's disease. Following 13 reported cases between 1904 and 1911, of clinical symptoms and specific organic changes in the brain, Alzheimer's disease was determined as a new disease category (Holstein, 1997; Innes, 2009). This identification of Alzheimer's disease occurred at a time when there was a generally accepted view that mental disorders were due to changes in brain pathology (Holstein, 1997). If relationships between behaviour and changes in brain pathology could be identified, this would elevate mental disorders from being classified as a syndrome, to a disease. As such this would lead to better diagnosis and possible treatment options (Holstein, 1997). The discovery by Alzheimer and other colleagues was seen as an important advancement in recognising the value of the psychiatric profession.

Despite this initial enthusiasm for the identification of a disease distinct from normal ageing, what proceeded was contention of what separated the two. It wasn't until the 1960s that neuropathology was accepted as the marker for Alzheimer's disease regardless of age. However, it still remains a contested issue. Whitehouse (2008) argues that Alzheimer's disease cannot be differentiated from normal ageing processes. Moreover, there is no one biological profile of Alzheimer's disease, as no two courses of the illness are the same. The 'Nun Study' (Snowdon, 2003) also found that individuals with the same type, location and amount of neuropathic lesions could display a wide range of clinical presentations, from no symptoms through to severe symptoms. Harding and Palfrey (1997) also argue that there are benefits to society if dementia is medicalised.

*Society needs dementia to be medicalised, as it is classified as a disease it holds out the prospect of a cure for ageing and death (Harding & Palfrey, 1997, p. 139).*

This acceptance of a dementia disease process separate from normal ageing, has had serious ramifications in terms of how diagnosed individuals were managed and viewed, that still persists today. The biomedical view of dementia focuses on the disease, the management of symptoms and the loss of abilities. According to Lyman (1989) the biomedical model has three main features; firstly, dementia is a pathological and an abnormal condition, secondly, it is organic in aetiology and processes through stages, and thirdly, dementia is diagnosed using biomedical assessments and subject to medical management. Medical texts in describing the trajectory of the disease, have also referred to individuals as having no awareness or sense of self. As such, this can lead to

depersonalisation, where individuals are viewed as having limited human value (Adams & Bartlett, 2003). For the majority of lay people, media outputs are a main source of information, and articles such as 'Dementia is a living death' (Hill, 2008), reinforces the notion that dementia is a condition to be feared. This view that people living with dementia lose their sense of self, can lead to a focus on 'body maintenance' where people are only kept, clean, watered and fed (Adams & Bartlett, 2003, p. 7) with little focus on emotional well-being (Kitwood, 1997).

Bond (1992) argues that this control of people living with dementia, is a result of medicalisation which asserts expert control, social control, individualisation of behaviour and de-politicisation of behaviour. Here the medical profession are seen as the experts in the condition and determine a diagnosis. Medicalisation also individualises behaviour rather than examines societal structures that can influence that behaviour. However, there are important aspects of the biomedical model. It has developed understandings about brain pathology and in the absence of a cure, what can be done to maximise brain health. It can help families frame what is happening and what the trajectory of the situation may be. Moreover, it has alerted many countries to develop dementia strategies (Alzheimer's Disease International, 2019) and the World Health Organisation has also adopted a global action plan on dementia (WHO, 2017). Addressing issues of diagnosis, post diagnostic support and treatment options for people with dementia and their families though, can take a homogenised approach where individual experiences are ignored. This was highlighted by Christine Bryden in her book on living with dementia, where she talked about presenting images of her brain scans at a conference, and then was challenged by

members of the medical profession who refused to believe the scans were hers (Bryden, 2005). The biomedical approach has been increasingly deconstructed for being narrow and limited (Lyman, 1989), and for failing to account for individual narratives and the socially caused difficulties (Estes & Binney, 1989; Harding & Palfrey, 1997) that people living with and affected by dementia often experience.

- **Psychological**

During the late 1980s and early 1990s, two social psychologists, Tom Kitwood (UK) and Steven Sabat (US) challenged what had been the dominant paradigm of dementia, the biomedical model, and began developing an alternative viewpoint, one that focused on the individual (Innes, 2009). Kitwood's contribution was that of personhood in relation to people with dementia, which he defined as:

*A standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust (Kitwood, 1997, p.8).*

Kitwood argued that personhood was primarily destroyed by the actions of others and not the neurodegenerative changes, a concept he coined as 'malignant social psychology' (Kitwood, 1997, p. 45-49). He identified seventeen elements that people with dementia may experience and, whilst he used the term malignant, he acknowledged that it was not always a result of evil intent but due to cultural inheritance. The seventeen elements included treachery, disempowerment, infantilisation, intimidation, labelling, outpacing, invalidation, objectification, ignoring, imposition and disparagement. In response to this he developed 'positive person work', which included recognition, negotiation and

collaboration as a way to improve the well-being of people with dementia (Kitwood, 1997, p.90-91). However, this framework has been criticised for being difficult for carers to understand and interpret (Innes, 2009). Also, Davis (2004) expressed concern about the pseudo-scientific framework Kitwood operated within, and stated that a certain loss of personhood should be accepted.

The work of Steven Sabat in the US challenged the thinking that individuals with dementia gradually lost their sense of self as the disease progressed. He proposed the concept of three selves. Self-one reflects personal singularity, for example 'I like' or 'That's mine'. Self-two considers characteristics held by an individual such as 'I am good at' or 'I can't do that', and finally self-three relates to roles and relationships which require the cooperation of others. Sabat proposed that self-one could be maintained, even in individuals with advanced dementia, self-two could be supported by the positive interactions and affirmation of others but self-three was the most vulnerable to damage (Kelly, 2010). Sabat also looked at the concept of self in relation to cognitive testing, which is widely used as part of determining a diagnosis and ongoing monitoring of people with dementia. The use of cognitive testing focuses on deficits, rather than trying to understand the person and the meaning behind behaviours attributed as symptoms of dementia (Sabat, 2005).

Criticisms of Sabat's work include that it fails to account for the experiences of spouses and families who may experience grief and distress, when seeing their loved ones change (Innes, 2009). However, a more recent study by Kelly (2010) looked at expressions of self in people with dementia living in long-stay

facilities, in which she concluded that recognising and supporting expressions of self are essential in optimising well-being for people with dementia. Research also supports that the self remains throughout the trajectory of dementia (Caddell & Claire, 2010), including the advanced stages (Hubbard, Tester & Downs, 2002).

In addition to the work of social psychologists, the late 1980s saw a greater focus on dementia from other psychological fields; cognitive and behavioural. A number of therapies were proposed, aimed at ameliorating the symptoms of dementia; memory therapy (Burnside, 1988), Resolution Therapy (Stokes & Goudie, 1990), Reality Orientation (Holden & Woods, 1995), Reminiscence (Norris, 1986) and Validation Therapy (Feil, 1982). Whilst positioned as helping the individual, Harding and Palfrey (1997) argue they were used to assist diagnosis, assessment and the modification of particular behaviours. One of the first approaches utilised by psychologists for people living with dementia, was Validation Therapy (Stokes, 2000). Feil's validation theory suggests that there is a need to accept the subjective reality/viewpoint of the person with dementia, and acknowledge there is a reason behind all behaviour (The Validation Training Institute, 2011). This focus on accepting the person's reality as they experience it, avoids re-orientating to the here and now, for example if a person is asking for their parents. According to Stokes (2000) Feil's approach has led more to an appreciation of validation as a response to individuals experiencing the later stages of dementia, rather than it being considered as a form of therapy per se. A Cochrane review found there was a lack of empirical evidence to support the use of validation therapy, and there was no significant difference with other therapies or social contact (Neal & Barton Wright, 2009). Resolution

therapy, which has origins in validation therapy (Stokes & Goudie, 1990), shares the assumption that there is a meaning behind all behaviour but searches for the cause in the here and now, rather than what may have happened for the person in the past.

Stokes has developed this work further with a functional analysis approach, where behaviour (B) is examined in the context of what happened immediately before (A) and what occurred after (C). This approach shifts the focus from seeing the behaviours as intrinsic to the individual to considering extrinsic factors, such as an interaction or the environment. A functional approach to the analysis of behaviours can be beneficial (Moniz-Cook, Stokes & Agar, 2003) as there is increasing evidence that behaviour is an expression of an unmet need (Cohen-Mansfield, 2008). Functional analysis involves collecting key details about the person's life history. However, the collecting of such information should not be used for the purposes of managing a particular behaviour (Cohen-Mansfield, 2008) but to benefit the person living with dementia. Reminiscing about life history has been identified as good practice (Moos & Bjorn, 2006), and is more effective when tailored to individual needs (Bruce & Schweitzer, 2008). A Cochrane reviewed outlined that it is a popular intervention and there is some evidence to suggest it can improve mood (Woods *et al.*, 2009).

Cognitive based approaches include cognitive therapy, cognitive stimulation and most recently cognitive rehabilitation. Cognitive therapy can benefit an individual by exploring their thoughts on diagnosis and facilitating a more adaptive way of viewing the condition (Bryden, 2002). Cognitive rehabilitation is

more flexible in its approach (Clare, 2009), as it focuses on individual goals and adapts to the natural trajectory of cognitive decline (Oyebode & Clare, 2008).

Cognitive stimulation has evolved from reality orientation, with the aim of reducing cognitive decline (Cantegeil-Kallen, Rotrou & Rigaud, 2009), by using focused sessions. A study by Woods *et al.* (2006) on cognitive stimulation therapy found that quality of life is independent of cognitive function for people living with dementia but interventions aimed at improving cognitive impairment can enhance quality of life. Aspects or combinations of these therapies are used in psychosocial interventions for people with dementia and their carers and are discussed further in section 1.3.

In addition to the development of therapies, one of the most useful contributions of psychological approaches to dementia is person-centred care. The term 'person-centred' has evolved from the work of Carl Rogers and client-centred psychotherapy (Brooker, 2004), however, it wasn't until the work of Kitwood that therapeutic relationships were considered in relation to dementia care. Kitwood emphasised the importance of authentic communication and relationships for people living with dementia to ensure well-being is enhanced (Kitwood, 1997). The concept of person-centred care has since become pervasive in best practice guidelines and government reports. Standard 2 of the National service Framework for Older People (Department of Health, 2001), focuses specifically on person-centred care. It outlines the need for people to be treated as individuals and to be supported to make decisions about their care. According to Brooker (2007) the commitment to person-centred care is to be applauded but the definition shares only a tenuous link with what Kitwood envisaged.

There are two writers who have attempted to consolidate and contextualise what is meant by person-centred care in relation to older people (McCormack, 2004) and dementia care (Brooker, 2004), (Innes 2009). McCormack (2004) considered the term in relation to nursing practice and identified four key concepts; being in relation, being in a social world, being in place and being with self. According to McCormack (2004, p.37):

*The reality of the challenges of everyday practice means that we shouldn't chase after an ideal of person-centredness, but instead strive for a constant state of 'becoming more person-centred' in our practice.*

Brooker (2004) also identified four elements; valuing people with dementia and those who care for them (V), treating people as individuals (I), looking at the world from the perspective of the person with dementia (P) and a positive social environment in which the person living with dementia can experience relative wellbeing (S). It is important to note the similarities between the two contextualised approaches.

A more recent study by Edvardsson, Fetherstonhaugh and Nay (2010) looked at what person-centred care means to people living with dementia and their carers; knowing the person, welcoming family, providing meaningful activities, being in a personalised environment and experiencing flexibility and continuity. However, despite this work, person-centred remains often an elusive term (Innes, 2009), with continued research seeking to provide frameworks to improve understandings and enhance practice, (see McCormack & McCance, 2017). Person-centred approaches, whilst raising awareness of the individual and how interactions and practice can affect personhood and a person's sense of self, fail to consider how the individual asserts aspects of their identity (Kelly,

2010). Baldwin (2008) asserts that principlism, the dominant ethical framework in healthcare, is not compatible with a person-centred ethic. Professional codes of conduct, whilst providing a set of rules to protect both patients and professionals, fail to acknowledge the uniqueness of individuals and relationships. Such rules focus on 'doing' not 'being'. Person-centred concepts are also apolitical (Bartlett & O'Connor, 2007), and the person is seen only in relation to their role as a recipient of care (Bartlett & O'Connor, 2010); not as a social actor. Moreover, they do not consider wider societal structures that impact on the person with dementia (Innes & Manthorpe, 2013).

- **Sociological**

Sociological approaches challenge often assumed homogeneity of groups of people, by examining diversity and inequalities in society. Studies have focused on differences within and between people based on age, gender, race, ethnicity, sexuality, disability and geographical location. There is increasing evidence showing how these factors affect the experience of people living with dementia (Innes, 2009), as people hold a number of roles, not just that of having dementia. Research has explored dementia in younger people (Beattie *et al.*, 2002; Beattie *et al.*, 2004; Roach, Keady & Bee, 2012; Svanberg, Spector & Stott, 2011) and ethnicity (Boise, 2008; Iliffe & Manthorpe, 2004; Mukadem *et al.*, 2011a; Mukadem, Cooper & Livingston, 2011b) and rural areas (Blackstock *et al.*, 2006; Innes, Morgan & Kosteniuk, 2011; Morgan, Innes & Kosteniuk, 2011). More recently research has looked at dementia in the Lesbian, Gay, Bisexual, Transgender, Queer (LGBTQ+) community (Barrett *et al.*, 2015; Peel, Taylor & Harding, 2016; Westwood & Price, 2016). However, this research

alerts us to the differences between people of an associated group, and that services should meet individual needs not group needs (Beattie *et al.*, 2002; Iliffe & Manthorpe, 2004).

Sociological approaches also examine the stigma and marginalisation that people may experience. According to Goffman (1968), stigma is where individuals or groups of individuals are assigned certain attributes that diminishes them to something less than a whole person. The stigma faced by people with dementia is a specific sort, argues Behuniak (2011), which is socially constructed from media and academic portrayals of people with dementia as 'zombies'. Such images illicit feelings of fear and disgust and ultimately lead to the dehumanisation of people with dementia (Behuniak, 2011).

The application of 'labels' to individuals with dementia can further compound the stigma and marginalisation they experience (Nuffield Council on Bioethics, 2009). The labelling of someone as having dementia can strip the person of their characteristics and social personae (Sabat, 2008). It also places people in categories throughout the trajectory of dementia, such as, in relation to the stage of dementia (mild, moderate or severe) or behaviours including 'wandering', 'challenging' and 'aggressive'. However, receiving a diagnosis and the label of dementia can help people living with dementia and their families to access certain services (Alzheimer's Disease International, 2011). The most recent edition of the Diagnostic and Mental Disorders (DSM-V, 2013), used in America, has now removed the term dementia, replacing it with major and minor neurocognitive disorder. The ICD-10 (WHO, 2010), used in the UK, still includes

the term dementia as a diagnostic criteria. Stigma and labels shape how an individual is perceived, which impacts on their interactions with others, and can then influence how they see themselves (Nuffield Council on Bioethics, 2009). Research by MacRae (2011) found that stigma can lead to negative experiences but conversely, positive social interactions and supportive relationships can reduce the negative experiences of living with dementia.

The impact of stigma whether perceived or actual, should not be underestimated for people living with an affected by dementia (Nuffield Council on Bioethics, 2009). This stigma is multifactorial, as dementia encompasses issues associated with mental illness (due to the associated symptoms), old age and increased dependency. People may prefer to keep quiet about what is happening or find that others don't understand what is happening, so become increasingly isolated. Feeling included in 'everyday' society can become increasingly challenging for people with dementia, due to building design, sensory overload, and lack of awareness and understanding by the general public (Nuffield Council on Bioethics, 2009). Research by Brittain *et al.* (2009) looked at the importance of outside spaces for people with dementia. Their qualitative data revealed that outside spaces can be both therapeutic and frightening, highlighting that experiences are not universal. Bartlett & O'Connor (2007) highlight how personhood has in some way tackled the discrimination experienced by people living with dementia, by raising their status as people. However, according to Bartlett & O'Connor (2007) a personhood approach has limitations, as it lacks a political dimension. They suggest a shift in frame of reference, from personhood to citizenship.

Citizenship expands the research agenda to include wider socio-political issues and sees people as having an inherent set of rights and responsibilities. The disability movement has been at the forefront in challenging the denial of citizenship that people living with disabilities experience. The concept of citizenship in dementia is a positive and encouraging framework. However, its application in an increasingly risk adverse culture (Robinson *et al.*, 2007) may be problematic. Furthermore, Behuniak (2010) argues that citizenship when applied to people with dementia has limitations, as cognition and person are linked in law. This creates difficulties when an individual is deemed to not have capacity and decisions are made by others, thus curtailing their rights as citizens. Behuniak (2010) proposes a political model where both the potential vulnerability of the individual and their right for dignity, humanity and citizenship are met.

- **Gerontological**

Gerontology, the study of ageing, takes a multi-disciplinary approach, combining the biological, psychological and sociological approaches and therefore can provide a more holistic approach to dementia. It particularly focuses on the social and structural factors that may lead to discrimination and lack of access to services based on age. Estes and Binney (1989) warn against the biomedicalisation of ageing and the application of medical solutions to old age, rather than examining environmental and social issues. Moreover, Hulko (2009) discusses the problematisation of dementia and the need to stop intervening and seeing something as a problem, when this may not be viewed

as the case by all people with dementia. She suggests the need for community development, with a more expansive definition of normalcy, through acknowledging the strengths of marginalised communities.

For people with dementia they may experience interrelated oppressions due to age, cognitive impairment, gender, ethnicity and social status. Hulko's (2009, p.131) work on intersectionality, identified the integral nature of social identities in shaping the trajectory of dementia. Her interviews with people living with dementia highlighted that experiences were varied, ranging from 'not a big deal' to 'a nuisance' to 'hellish', and were related to their social locations. The application of intersectional analysis in dementia studies is, also supported by O'Connor, Phinney & Hulko, (2010, p.38) who propose that research needs to:

*...move beyond an understanding of difference per se, to an examination of how different social locations operate together and separately to construct subjective experience.*

In relation to ageism, McHugh (2003) identifies three aspects; society, image and place. He discusses the divergent narratives of later life; that of sickness and dependency or virtue and self-reliance, in what he calls bipolar ageism. Later life expectations have historically been dominated by associations with loss, decline and regret, however, the theory of gerotranscendence (Tornstam, 1997, Tornstam, 2011) captures how individuals describe their experiences of later life. Gerotranscendence has three dimensions; cosmic, self and social. The study of gerotranscendence has identified that experiences are not universally negative, and people have reported increased life satisfaction, reduced focus on occupation and heightened sense of affinity with others. Later life also brings about an emancipation from roles expected in mid-adult life

(Stirling, 2016). However, mid-life values are often imposed on later life, for example a time for contemplation can be construed as depression or slowing down (Stirling, 2016; Tornstam, 1997), thus acting as a barrier to achieving more positive experiences.

The cosmic dimension is where time is redefined, with the past and present experienced more as one (Stirling, 2016) and there is greater joy in daily experiences (Patterson & Wolverson, 2016). The cosmic dimension has been found to be positively associated with negative life events, and as a diagnosis of dementia is viewed as a negative event, the cosmic dimension may be of particular relevance to people with dementia (Patterson & Wolverson, 2016). The concept of growth is discussed by Patterson and Wolverson (2016) in relation to adversity and illness, and they consider whether growth is possible for people with dementia. They suggest that it can be a time for finding meaning, for living in the moment, creating new perspectives and focusing on the needs of others through activism. This growth may be experiential rather than based on cognitive appraisals (Patterson & Wolverson, 2016). However, concepts of successful ageing can be too narrow, which is of particular issue when 'ageing well' is used to shape national and international policies (Ehni *et al.*, 2018).

Recent years have seen a rise in people living with dementia and talking about their experiences. Bryden's (2005, p.162) story on living positively with dementia, talks about how the initial fear of being diagnosed with dementia was replaced by becoming who she really is, once the layers were stripped away. Wendy Mitchell's (2018) best-selling book 'Somebody I used to Know' is her

story of being diagnosed with dementia and the challenges this has brought but also who she has become as a result of dementia. She highlights how dementia can be a time of both positive and negative experiences. Positive psychology draws attention to the fact that negative and positive experiences can co-occur and interact, and can contribute significantly to the development of psychosocial interventions (Stirling, 2016).

### **1.3 Psychosocial interventions**

Psychosocial interventions were introduced in response to the recognition of the psychological and sociological dimensions of living with dementia. The term is sometimes synonymously used with 'non-pharmacological' intervention, meaning no drug treatment (McDermott *et al.*, 2018). In the absence of a cure and treatments that can significantly affect the course, psychosocial interventions have become a large area of research in dementia care (Moniz-Cook *et al.*, 2011). However, less than 5% of funds allocated to dementia research look at care (Brown, 2018). INTERDEM is a pan-European network of researchers specifically looking at psychosocial interventions for people with dementia (INTERDEM, 2019). It was set up in response to the methodological challenges of conducting research in this area, in particular, limited RCTs, lack of multi-centred studies, difficulties in defining dosage when the intervention is multi-component and the need for concept informed outcome measures (Moniz-Cook *et al.*, 2011). Applying the Medical Research Council methodology for complex interventions (MRC, 2006) a number of multi-centred RCTs are being

conducted to develop the evidence for psychosocial interventions that can be implemented into practice.

Psychosocial interventions are wide ranging and include signposting, intensive communications methods, standard psychological therapies and therapies to promote well-being (Moniz-Cook & Manthorpe, 2009). They can be provided on an individual basis or in groups and at times include carers (Moniz-Cook & Manthorpe, 2009), with a focus on improving psychological and/or cognitive functioning (Moniz-Cook *et al.*, 2011). Psychosocial interventions can be more psychological in focus, such as cognitive behavioural therapy, or social, such as drop-in support groups. However, at times it can be difficult to differentiate which components are psychological and which are social (McDermott *et al.*, 2011). Moniz-Cook and Manthorpe (2009, p.27) recommend the following stepped framework for psychosocial interventions, in early dementia.

1. Step 1 interventions should occur at the time of diagnosis
2. Step 2 interventions should include those that are evidence based, such as cognitive stimulation
3. Step 3 interventions are about social inclusion and having the opportunity to engage with others
4. Step 4 interventions include individual and group therapy

In addition to the plethora of studies into psychosocial interventions, there are now a number of systematic reviews of the evidence. A synthesis of the systematic reviews identified that there is a need for more methodologically rigorous studies that use larger sample sizes, also that interventions need to identify if their target is psychological or social (McDermott *et al.*, 2018). The review found there is good evidence for multi-component exercise including

walking and grouped based cognitive stimulation. Also, that social integration is important. They recommend interventions that promote social interaction such as peer group support, and understanding long-term effects of interventions targeting specific outcomes. Despite the varied evidence, The British Psychological Society (2014) have published a guide on psychosocial interventions in early stages of dementia. They list a number of interventions including; animal assisted therapy, cognitive approaches, post-diagnostic support, creative arts, counselling, life story work, music therapy and memory/dementia cafés.

#### **1.4 The evolution of memory cafés**

The Alzheimer café concept was created by Dr Miesen, a clinical psychologist in the Netherlands. It came about in response to his clinical practice, and the need for people living with and affected by dementia to have somewhere to speak openly about what was happening. He also wanted to create something different to the traditional types of support groups that had mainly focused on the partners of people living with dementia, by providing a space where they could attend together. According to Miesen and Jones (2004, p.302):

*The Alzheimer Café concept is about breaking through the pain of denial, acknowledging and providing space for the expression of the numerous emotions and practical difficulties that are involved in having and learning to continue living with this chronic, long-term illness.*

The Alzheimer café was about having a place where dementia could be named and discussed with others in a similar situation, to help mitigate the negative feelings. Miesen claimed that dementia could be seen as a trauma, drama and

a tragedy (Miesen & Jones, 2004). Trauma was in relation to the disruption dementia causes in the daily lives of people with dementia and their carers, and the emotional upheaval this may bring. Drama considers the unpredictable events and challenges that might occur, and tragedy is about the emotional impact on outsiders (health professionals/volunteers) on working closely with people with dementia. Miesen viewed the Alzheimer café as a type of guided self-help and group therapy (Miesen & Jones, 2004, p.307).

*The Alzheimer Café is intended to offer persons a safe place, where they express themselves and can be listened to, thus finding some comfort in their struggle of isolation and loneliness, at least for a while.*

From one café the concept grew across the Netherlands, with cafés adapting to the needs of different areas but maintaining the original concept. Miesen viewed the cafés as an intervention, with aspects of both education and support (Miesen & Jones, 2004). The educational focus involved various outside speakers visiting but around this, there was opportunities for people attending to spend time talking with each other. The cafés were also open to health professionals, students and friends of people with dementia. The Alzheimer Café had three main aims:

1. Providing information about the medical and psychosocial aspects of dementia
2. Emphasising the importance of speaking openly about problems
3. Promoting the emancipation of persons with dementia and their families by preventing isolation

Whilst Miesen acknowledged that these aims sounded therapeutic, he also emphasised the importance of people with dementia and their families being able to exchange experiences with others (Miesen & Jones, 2004). The

educational themes followed the course of the illness, and included talks from neuropsychologists, community health nurses and former carers. Miesen and Jones (2004) also emphasised the importance of the location, layout and background music, to ensure people felt relaxed. They cautioned against music dominating the session, so that the aim of the café is not changed. In addition to the speakers on dementia, the cafés had an information stand, with resource material that people could take away. The café sessions were divided into four parts; arrival and introduction, the presentation or the talk in the form of an interview, the discussion and the informal get together at the end. Miesen and Jones (2004) provide a comprehensive guide on setting up and running an Alzheimer café.

The first Alzheimer café in the UK opened in 2000, with the concept being adopted by the Alzheimer's Society in 2002 (Thompson, 2006). The Alzheimer café and the Alzheimer café UK concept are patented, and they are now established in Belgium, Italy, Greece, Australia, USA and Japan. New cafés have to adhere to the original aims and philosophy, whilst being free to adapt to local and cultural needs (Thompson, 2006). According to Thompson (2006) there was some initial confusion with understanding the aim of the Alzheimer café, with them being set up as social group and not including the educational aspect. In the UK, some of the first Alzheimer's cafés were set up as a collaboration between the Alzheimer's Society and Older Adult Services, as part of the dementia care pathway (Thompson, 2006). The cafés are held once a month.

An evaluation by Thompson (2006) of one of the first Alzheimer's cafés in the UK, looked at whether it was meeting the three objectives of the Alzheimer café concept and standard 7 of National Service Framework for Older people (Department of Health, 2001). Participants talked about the café providing them a place to share experiences and being with others in a similar situation. Also, that the café was a supportive environment, particularly around having professionals available to speak to. Participants spoke of the café providing a social outlet and a wider circle of people from which to gain emotional support. The fact that the café was a less formal setting and had created a new social circle was considered an important aspect. However, these connections did not extend outside the café. Participants also found the educational talks useful, as it had expanded their knowledge on the medical aspects and personal implications. Limitations of the evaluation were that there was a risk of acquiescence, as the researcher was known to participants through being a facilitator at the Alzheimer café.

In Australia, the Vic Memory Lane cafés, based on the Alzheimer café concept, were introduced in 2002. Access to the Memory lane cafés was through the Alzheimer's Australia Memory Loss programme. The cafés were delivered four to eight weekly, and included a speaker providing educational information or entertainer. An evaluation on the cafés comprised; focus groups, surveys, staff consultation, service provider interviews and researcher observations. The themes identified from the focus groups were enjoyment, social inclusion and peer support, and education and information. Attendees also expressed that they were not able to give feedback or contribute suggestions for future sessions. The survey that was sent out to 402 people on the Memory Lane café

programme revealed that people did not attend due to the distance of travel (Dow *et al.*, 2011). The authors concluded that the cafés were a beneficial service.

In a personal reflective account of an Alzheimer café in the UK, Morrissey (2006a) reported that it provided a significant role in the provision of educational, mental health and emotional support. He also acknowledged the need for research on the different approaches that might be used in providing the cafés, and to identify which approach benefits which attendees. As Miesen considered the Alzheimer café a combination of group therapy and support groups, it is important to discuss the development of both forms of groups for people with dementia and their families.

## **1.5 Groups for people with dementia and their carers**

Hornillos and Crespo (2011) provide a useful historical review of support groups for families of people living with dementia. They differentiated between three stages; the first (late 1970s-1985) focused on subjective impressions, the second stage (1985-1995) applied more rigorous methodology resulting in doubts about the efficacy of support groups, and the third stage (1995-present), where research on support groups has had less of a focus than others on interventions, and more on the application of qualitative research methods leading to an interest in groups processes. The first support groups for carers appeared in the late 1970s and were seen as an intervention with little formal structure, where the group encouraged attendees to talk. Research examined carers opinion on the group and little else. From 1985 more rigorous

methodology examined support groups with the use of experimental and quasi-experimental designs. These groups were time limited, around 6-8 weeks and quantitative psychometric measures were used to record and measure symptoms. This period was seen as pivotal in the study of support groups for carers of people with dementia. However, theoretical models were lacking and groups were designed in a pragmatic way. Also, as the interventions were multi-component, it was difficult to isolate the effects of each component. The application of an objective approach using standardised measures revealed no difference between intervention and control and thus called into question the efficacy of support groups (Hornillos & Crespo, 2011).

Subsequently, research shifted towards examining the effectiveness of, 'manualised stress-management interventions' (see Dröes *et al.*, 2004; Logsdon, McCurry & Teri, 2007) that differ from community-based support groups (Hornillos & Crespo, 2011, p.8). There remained some interest in exploring community support groups with researchers expressing the idea that lack of effective results was not due to the support group itself but the research designs that had been applied. With the focus on outcomes and not theoretical frameworks or processes.

They also highlight the difficulty in defining a support group due to the different forms; closed and open. A closed group is time-limited and does not accept new members due to it running for a specific duration and following a set agenda. In comparison an open group often meets less frequently with new members attending as they wish. Open groups do not follow a set programme or agenda with the facilitators being less prescriptive. There has been a number of

systematic reviews on support groups, however, they have not drawn any firm conclusions due to the different types of groups, the variation in the methodological approaches used and the lack of theoretical frameworks (Hornillos & Crespo, 2011). Also, much of the research has focused on closed groups as their very nature makes them more suited to pre-post research designs used to assess effectiveness. The authors argue long-term support groups may be more abundant in community settings and ‘...may reflect benefits that have not been identified in studies of short-term, semi-structured support groups’ (Hornillos & Crespo, 2011, p.3). They conclude that support groups remain a black box and there is a need to unpack their functioning through different research approaches to gain a better understanding of how they work.

In relation to people living with dementia, two systematic reviews have looked at the evidence of support groups (Leung, Orrell & Orgeta, 2015; Toms *et al.*, 2015). Leung *et al.* (2015) looked at randomised controlled studies only, and two studies met their inclusion criteria. They conclude that the limited data suggests that support groups may be of psychological benefit but state that firm conclusions cannot be drawn due to the small sample size and the heterogeneous characteristics of the studies. Toms *et al.* (2015) conducted a narrative synthesis of data from 29 papers and concluded support groups seem acceptable to people with dementia. The qualitative studies reported subjective benefits but there was limited evidence of positive outcomes from the quantitative data. They also comment that whilst qualitative studies will remain useful in this area of study, there is a need for mixed methods randomised controlled studies or comparison group studies. However, as most community

support groups are open-ended, such an approach would be difficult as highlighted by Hornillos and Crespo (2011).

A shift towards understanding the theoretical foundations of a programme for people with dementia is highlighted in the paper by Windle *et al.* (2017), which looked at visual art programmes. They used a realist review to uncover what works, for whom, how, why and in what circumstances, and a qualitative exploration of stakeholder perspectives. Through synthesising the findings of these two studies, they concluded that effective programmes are achieved through provocative and stimulating aesthetic experience and, dynamic and responsive artistic practice. They suggest the framework has the potential to be applied to other art activities. Moreover, that there is need to understand the theoretical basis of an intervention for service development, evaluation and implementation.

This understanding of a theoretical basis may in some way help with the lack of clarity and the blended functions groups may play. Toms *et al.*, (2015, p.1462) highlight the difficulty between differentiating between support groups, therapy and psychosocial interventions. They found that over half the support groups reviewed provided psycho-education and some also had elements of therapy. Furthermore, groups categorised as self-help, self-management and education had other additional components. They suggest that it is difficult to categorise interventions as therapy, support, self-help and education. Thus, interventions described as psychosocial may also combine elements of a support group and a support group may also provide psychosocial and educational components. However, all types are united in the fact that they bring people together. Bender

and Constance's (2005) description of a psychoeducation groups for people living with dementia considered their findings in relation to Yalom's work on group psychotherapy. They identified with Yalom's therapeutic factor of universality where group members feel a relief of not being alone in their condition. Yalom emphasises the importance of human connections and interdependence.

*Interpersonal relatedness has clearly been adaptive in an evolutionary sense: without deep, positive, reciprocal interpersonal bonds, neither individual nor species survival would have been possible (Yalom, 1995, p.19)*

## **1.6 Memory cafés today**

Since the introduction of Alzheimer's café concept, more informal types of cafés have evolved from this and are called dementia cafés, memory cafés, or have an independent name such as the Poppy café (Halley *et al.*, 2005). The concept has even been introduced into a hospital setting (Hope & Pope, 2004). They remain mainly a community-based intervention for people with dementia and their carers, and they are now well established in the UK and elsewhere. The growth in the number of cafés is evident from the memory café directory ([www.memorycafes.org.uk](http://www.memorycafes.org.uk), 2019), which outlines the cafés available globally. However, there is currently no clear statistics on the exact number in the UK and elsewhere, as café providers have to list their cafés on the website. A twitter search of the hashtags #DementiaCafés #MemoryCafés, also reveals how widespread memory cafés have become.

In the UK, they are in general run by volunteers and are provided once or twice a month. The use of the term café appears consistent; a place where individuals can meet and share experiences over a cup of tea and cake in a relaxed environment (Jones & Redwood, 2010) and, according to Halley *et al.* (2005) this environment is crucial for their success. These cafés adopt a less clinical, didactic approach (Capus, 2005) than the first ones devised by Meisen, and have evolved to be a place where individuals can socialise and form friendships. Memory cafés differ from other types of group support for people with dementia and their carers by enabling them to attend together. The importance of peer support, where people with dementia and their carers can talk to others and share advice, was emphasised in the National Dementia Strategy (Department of Health, 2009) with memory cafés cited as one way of providing this. The peer support model has a long history of development within the disability and mental health movements but has only recently been considered in relation to people with dementia (Ward *et al.*, 2012). Memory cafés are generally run and facilitated by volunteers and the peer support model literature is limited on the role and impact of a volunteer or facilitator running a group (Ward *et al.*, 2012). However, a recent study by Semple, Willis and de Waal for the Health Innovation Network (2015) acknowledged that peer support can occur through a group that is facilitator led. They found that peer support groups have positive outcomes for people with dementia, their carers and volunteers, concluding that they create positive social value that is greater than the cost of investment. Thus, Kelly and Innes (2014) argued that, in times of financial austerity memory cafés provide a cost-effective service for people with dementia and their carers.

Current UK policy guidance emphasises the need for people with dementia to remain at home as long as possible. However, a report by the Alzheimer's Society, 'The hidden voice of loneliness', found that a third of people with dementia had lost friends and over a third felt lonely, with difficulties in maintaining social relationships cited as a cause (Alzheimer's Society, 2017). As a consequence, informal carers may then become the main source of social contact for people with dementia. This can lead to people with dementia and their carers finding it difficult to engage in activities, and may lose contact with their communities. Therefore, memory cafés may help with supporting people with dementia and their carers, and increase their social contacts. In addition to providing a place for people to meet, memory cafés may also provide a range of activities from singing, quizzes, gardening and crafts. Intuitively memory cafés appear to make sense and their growth would seem to suggest that they are meeting a need for people with dementia and their carers.

In terms of outcomes for people with dementia and their carers that attend memory cafés, the evidence remains unclear. There are implied and suggested benefits such as mitigating contracting social networks (Commission for Rural Communities, 2008), normalising emotions (Capus, 2005), providing information and support (Halley *et al.*, 2005), and facilitating friendships (Kelly & Innes, 2014; Dow *et al.*, 2011) by bringing people together who are in a similar situation (Kelly & Innes, 2014; Miesen and Jones, 2004). The challenge in identifying outcomes is further compounded by the unique feature of memory cafés, where the person with dementia and their carer receive support from the same service. Brodaty (2007) state that interventions which include both the person with dementia and their carer, are more likely to be successful but

acknowledge the difficulty in establishing outcome measures that can be used to capture the impact for both groups. It is clear however, that the lack of rigorous methodology into their benefits and theoretical underpinning clarifying whether they are a support group, peer support, guided self-help or a form of group therapy has resulted in a mixed method of delivery, which adds further to the complexity surrounding this social intervention. It is possible that memory cafes incorporate aspects of these different interventions. Peer support groups involve people using their experiences to help others by creating a sense of community and acceptance (Ussher *et al.* 2006). Family interventions focus on the provision of support to the whole family when a member is experiencing a particular condition, and reinforce how the family can impact on the individual's experiences of that condition (Withnell & Murphy, 2012). Through group therapy, a number of factors including hope, universality and imparting information are provided (Yalom, 1995).

Currently, the evidence to support the claims of the benefits arising from attendance at memory cafes is limited, and the lack of rigorous research into their theoretical underpinnings and the experiences of people that use them, makes it difficult to draw clear conclusions on how and why they might be working. Morrissey (2006b) in his reflective account of memory cafés highlights the need to uncover the mechanisms that may bring about the reported benefits. Thus, there is a clear need for more research into memory cafés.

### **1.6.1 Café culture**

As previously mentioned, the term café is consistent. Cafés have a long history in Britain, starting in the late 17<sup>th</sup>, early 18<sup>th</sup> century. Historical sociologist Habermas (1989) emphasised the importance of the coffeehouse for public

discourse and its key role in the development of modernity (Laurier, Whyte, Buckner, 2000). Whilst cafés were previously used as meeting places for public debate, they have now become a place where people meet with friends, they study or work, or just spend time on their own. Today the UK is particularly becoming a café society (Laurier & Philo, 2005), and cafés are present in urban and most rural areas. Despite this, the social sciences have provided little ethnographic accounts of café society (Laurier & Philo, 2005). An ethnography by Laurier and Philo (2005) found that cafés are diverse but provide a key meeting place for neighbourhoods (Laurier & Philo, 2005). They are an informal (Laurier, Whyte, Buckner, 2000) and an important social space (Tjora & Scambler, 2013).

*Cafés are now inevitably about networks and connectedness (Tjora & Scambler, 2013, p.2)*

Cafés can also be described as providing a ‘third space’ (Oldenburg, 1999), which are places that are not home or work but provide a space where connections can be made with others.

## **1.7 Rurality and dementia**

Two thirds of people with dementia live in rural areas (Alzheimer’s Society, 2018a; Innes, 2009). Despite this, the majority of social research on dementia has an urban focus (Blackstock *et al.*, 2006) with urban care models applied to rural areas (Innes, 2009). The pervasive concept of the ‘rural idyll’ has often led to the overshadowing and distortion of problems experienced by older people living in rural areas (Blackstock *et al.*, 2006). Consistently research has

revealed the same problems for older people living with dementia in rural areas (Blackstock *et al.*, 2006; Commission for Rural Communities, 2008; Wenger, Scott & Seddon, 2002), centralisation of amenities, poor transport links, lack of specialised services and a lack of services in general. Scottish research has shown that in rural areas, communities provide support to people with dementia rather than formal organisations, highlighting the importance of community organisations in rural areas (Innes, 2009). Living in a rural area can add another layer of jeopardy (Alzheimer's Society, 2018a) that people with dementia may experience, and lead to feeling excluded from the place in which they live. Furthermore, carers may feel increasingly cut off from their wider family if they live outside the rural area (Ehrlich *et al.*, 2015).

Two systematic reviews have explored dementia care in rural and remote settings in relation to formal or paid care (Morgan *et al.*, 2011) and informal/family caregiving (Innes *et al.*, 2011). In relation to formal and paid care, they found that research is mainly descriptive and based on small sample sizes. Furthermore, it was limited to small amount of countries with no comparative studies, despite the fact that the majority of people living with dementia globally reside in rural areas. They conclude that there are successful programmes such as memory clinics but there is a 'need for a range of rural dementia care models that can be adapted to local needs' (Morgan *et al.*, 2011, p.32). For informal/family caregiving they found the research focused on the experiences and barriers to formal service provision. Also, that, rural cultures and perceptions of dementia including stigma was a reoccurring theme. They concluded that there is a lack of focus on how rurality impacts on caregiving in

dementia, outside of access to services, with the majority of caregivers operating with little support from formal services.

Research looking at the social geographies of mental health found that individuals experience both inclusion and exclusion and warn against how these terms are used in policy (Parr & Philo, 2003; Parr, Philo & Burns, 2004). For older people, Wenger (2001) suggests that growing older in a rural area is neither worse nor better than growing old in an urban area but they are subjectively different experiences. She highlights the provision of support from voluntary sectors and the need for a rural model for health and social care. Manthorpe, Malin and Stubbs (2004) found that village populations were different and that for some older people close social networks existed and for others it did not. Also, access to services varied, with healthy retired couples generally viewing retirement as a positive experience. However, they did find that villages have single isolated very old women in poor health which is a group similarly found in urban areas.

Carers of people living with dementia in rural areas are typically female with carers in general using formal services when experiencing a crisis or stress, such as an acute health problem (Wenger *et al.*, 2002). Contact with GPs was high whilst the limited provision of services from social services was tolerated due to understandings about lack of funding. Therefore, health services may be utilised more in the absence of social services support. The authors recommend community based dementia specialists. A study by Blackstock *et al.* (2006) found that people living with and affected by dementia identified both positive and negative experiences of living in a rural area but concluded overall that it

was positive. The authors recommend unpacking the multi-faceted relationships of living with dementia and living in a rural area. Not all rural areas are the same and will have different community norms (Innes, 2009). Thus, it is important to understand how geographical location can affect experience, even within and across rural locations. The Commission for Rural Communities' (2008) report on service needs and delivery following a dementia diagnosis suggests that there is still considerably more research that needs to be done to understand the experiences of people living with dementia and their families, living in a rural area.

### **1.7.1 Dementia support in Cornwall**

Cornwall (Kernow in Cornish) is a county in south west England that borders the sea on three sides. It is recognised as a Celtic nation with its own language. It has rich mining history dating back to the middle ages. As mining declined, china clay extraction became more important. Today, fishing, agriculture and tourism are considered vital aspects for the economy (Cornwall Guide, 2019). However, Cornwall is one of the poorest parts of the United Kingdom but has areas that have higher than average house prices due to the increase of second home owners. Cornwall has a population of just under 550,000 with around 21.6%, aged 65 years of age and over (Cornwall Council, 2012).

The Caring for People with Dementia in Cornwall report (Cornwall Council, 2009) suggests that, by 2028, almost 30% of Cornwall's population will be aged 65 years and over. The report also highlights that cultural traditions may lead to self-reliance and a fear of being seen as a failure if they require support.

Cornwall and Isles of Scilly dementia roadmap provides information about the dementia journey and the services available (Dementia Roadmap, 2019). This

includes statutory services (primary and secondary), with primary services being GP practices and secondary including community mental teams that provide support to people with dementia and their carers. There is also social services and the voluntary sector support such as Age UK and the Alzheimer's Society. Other services include an independently run day centre (Reflections, 2019), a community interest company providing activity groups, cognitive stimulation and training (Memory Matters, 2019) and an organisation providing nature and outdoor activities (Sensory Trust, 2019). The Dementia roadmap also lists the memory cafés available in Cornwall, describing them as providing 'a friendly supportive environment where people can meet, talk, and learn more about dementia and what support is available'. However, data from mapping the services, including memory cafés in the South West (Robens *et al.*, 2015) identified that there was no standard service model.

## **1.8 Terminology**

For the purpose of this thesis the term memory café will be used, as this appears to be the most widely used term. No abbreviations for persons living with dementia will be used, as this does not recognise them as individuals. The term carers will be used to refer to spouses, siblings and friends that accompanied people living with dementia to the memory cafés. The term carer appears to be the term widely used by the memory cafés. Collectively, people that attend the cafés were referred to as guests and attendees. The term guest is mainly used throughout the thesis. Lastly, the individuals facilitating and running the café will be referred to as volunteers.

## **1.9 Background to thesis**

Researchers do not always belong to the social worlds they are researching, however, for this research, I have insider knowledge and experience. The reasons I have chosen this area of study are twofold. Firstly, in my clinical experience as a registered mental health nurse working with people with dementia and their families living in rural settings, I have found that many feel isolated from their communities. Furthermore, accessing services that are typically held in central locations can be difficult to attend due to limited transport options. Secondly, I have co-developed, and continue to run, a memory café for people with dementia and their carers in a village in Cornwall. In setting up the café, I explored the research available and found there was little to support what memory cafés do and what factors were triggering their growth throughout the United Kingdom. From speaking to others, I was aware that they may run differently. Thus, this research was undertaken in response to a real-life situation that had relevance to people's lives and mine; the need to understand how and why memory cafés work. The word thesis derives from the Greek word *tithenai*, meaning to place or to position. This thesis is my position on memory cafés, including how and why they work.

## **1.10 An overview of the thesis**

### **1.10.1 Thesis objectives**

- I. To develop programme theories on how and why memory cafés work through a realist review of the literature

- II. Test and refine the programme theories from the review, and develop new programme theories using ethnographic methods and a realist evaluation of memory cafés in Cornwall
- III. From the programme theories develop a conceptual platform of the core processes of memory cafés

### **1.10.2 Thesis structure**

The thesis consists of seven chapters that provide a consecutive approach to the development of conceptual platform of memory cafés using realist methodology. The thesis builds upon the current literature outlined in chapter one (introduction) on how memory cafés may be a beneficial intervention for people with dementia and their carers. However, current evidence is limited on how and why memory cafés work, and what processes bring about benefits.

Chapter two sets out the methodology and methods used, outlining realist research and ethnography, and the challenges and possibilities of using both approaches to develop, test and refine programme theories. Despite theoretical discussions on how the two approaches can complement each other, there is currently limited practical guidance. Chapter three details the realist review and provides an explanation of how the programme theories were developed from the literature, through identifying concepts and the links between the concepts.

This leads onto chapter four, which provides the details of the cases (memory cafés) used for the primary data collection and details the contextual situation of each café and their differences and similarities, in how they were structured. Chapter five refines the programme theories from the realist review and outlines new programme theories developed from the in-situ interviews and observations conducted at the cafés.

From the programme theories, the conceptual platform of the core processes of how and why memory cafés work is the main focus of chapter six. The core processes are discussed in relation to the wider literature and current models in dementia care. This brings together the findings in relation to the research on dementia at an individual, relational and societal level. This leads on to a section of reflexivity and then the general strengths and limitations of the thesis. The chapter concludes with how the thesis makes an original contribution to research and what paths future research may take.

Chapter seven, the final chapter summaries the main aspects of the previous chapters and draws together the key messages from the thesis.

### **1.11 Chapter summary**

This introduction has provided an overview of the different theoretical perspectives on dementia; biological, psychological, sociological and gerontological. It has outlined the development of psychosocial interventions and support groups for people living and affected by dementia, and the difficulty research has in determining how they work. Theoretical approaches that unpack the ‘black box’ of an intervention have been recommended as a way of exploring how and why they work. The adoption of an approach that recognises that different things will work for different people, for different reasons is important, especially where the evidence base on which interventions are implemented is limited, as in the case of memory cafes. For this reason, a realist approach was utilised in this research. This introduction has also explored some contextual factors associated with the issues of living with

dementia in rural areas, and the support services available in Cornwall. It has provided the historical context to the development of memory cafés, and highlighted the current limited nature of research associated with this social intervention. Therefore, it has provided a rationale for the research being presented in this thesis, which explores how and why memory cafes work for different people in Cornwall. The next chapter, chapter two, provides justification for and details of the methodology and methods utilised in the research captured within this thesis.

## **2 Chapter 2: Aims and Methodology**

### **2.1 Background**

This chapter outlines the philosophical and methodological approaches underpinning this thesis. It explores realist approaches to research, beginning with an exploration of realism and the relating positions on epistemology and ontology. There then follows a discussion on ethnography and how it can align with realism, which forms the overarching theoretical perspective to this study. The aim, objectives and research questions are stated, along with an explanation about how the application of realist and ethnographic methodology was used to answer these questions, through the chosen method of ethnography conducted within four case studies (memory cafés). To finish, the chapter details the process of data collection and analysis to develop, test and refine theories to culminate in a conceptual platform of how and why memory cafés may be working.

Memory cafés are an active social programme, implemented in varying contexts, and involve different groups (volunteers, people with dementia and their carers/family). Therefore, this has implications for the choice of research methodology. The widely accepted gold standard approach to research, the randomised control trial, views human agency as a contaminator and seeks to mitigate it through the processes of placebos, randomisation and blinding, attempting to reduce the research to a more closed system (Robson, 2011). Real world research takes place out in the 'field' and not in the laboratory (Robson, 2011). Social programmes are established and shaped by human understanding and interaction (Pawson & Tilley, 1997). They are open, complex

and often change in response to human volition. They cannot be sealed in a vacuum, void of any external influences. As memory cafés are contingent on the people that facilitate them and use them, a methodology was required that acknowledged both differences and complexity. Realism, therefore, provides an appropriate approach to open, fluid and complex programmes (Robson, 2011).

## **2.2 My identity as a researcher**

My identity as a researcher has been shaped by my clinical experience as a mental health nurse. In working with individuals with mental health problems, it is often necessary to dig below the surface of what the person is saying. This is reflected in how I view programmes and that they are not just a black box with an input and output. Therefore, I come from the standpoint where I'm interested in how and why programmes work. My own beliefs hold that there is a need to unpack the black box to provide explanatory theories of what is being observed, and the choices people make when exposed to or using the programme. For me, to understand how outcomes occur, we need to understand the way people respond to a programme and the processes behind the delivery of that programme. Therefore, my beliefs align to a realist approach to research.

## **2.3 Aim, Objectives and Research Questions**

- Aim

The aim of this research was to explore how and why memory cafés work for people living with dementia and their carers living in Cornwall.

- Objectives
  - To generate programme theories from a realist review
  - To test and refine those programme theories through a realist evaluation of memory cafés in Cornwall
  - To develop a conceptual platform about memory cafés
- Research questions
  - How are memory cafés structured and delivered?
  - What are the benefits for the people that attend?
  - What are the mechanisms that explain these benefits?

## 2.4 Realism

Realism is rooted in the philosophy of science and social science, providing a post-positivist standpoint (Pawson, 2006a) that centres the divergent epistemological poles of positivism and relativism (Pawson & Tilley, 1997). It is a methodological orientation that focuses on the mechanics of explanation and how this can advance scientific knowledge (Pawson, 2006a). Realism does not favour particular methods; instead it acknowledges that the aim of the methods chosen is to uncover insights that generate theory (Emmel *et al.*, 2018). Thus, it starts with theory and ends with theory, with a preference for the middle range level; theory that is specified at the level of abstraction that can be empirically tested.

There are two main camps in realism. The first is critical realism, generally associated with the work of Bhaskar (1975) that incorporates other versions of realism; including experiential realism, constructive realism, subtle realism, emergent realism and natural realism (Maxwell, 2012). The second is empirical

realism; also referred to as scientific realism, emergent realism and middle-range realism (Pawson, 2006a). This division between critical and empirical realism relates to their standpoints on 'open systems'. Critical realism proposes that there are numerous explanations but some will be mistaken, so there is a need to be critical of the thought and actions forming the false explanations (Pawson, 2006a). Empirical realism, on the other hand, whilst acknowledging the need to adjudicate between alternate explanations, recognises that within open systems there will be other explanations that may remain uncovered, so clear conceptualisation, critical comparisons and discovering patterns are necessary for making explicit the explanatory propositions chosen (Pawson, 2006a). This applied approach of realism to evaluation, formed the foundation of the seminal text of Pawson & Tilley (1997), 'Realistic Evaluation' outlining a methodology for evaluating social programmes.

Realism asserts there are ways of understanding how social programmes work through the basic building blocks of social science, the nature of reality, the constitution of the social world and the stratification of reality (Pawson, 2006a). These questions of ontology and epistemology are discussed in the next section.

#### **2.4.1 Ontology and epistemology**

As humans we make assumptions about knowledge and reality (Crotty, 1998). Ontology is the study of being (Crotty, 1998), that is the nature of reality (Denzin & Lincoln, 2008), whilst epistemology considers the nature of knowledge (Crotty, 1998) and the relationship between the researcher and what is known (Denzin & Lincoln, 2008). There is an interrelationship between the theoretical stance of the researcher, the methodology and methods chosen and views on

epistemology and ontology. Research rarely starts with epistemology (Crotty, 1998) but with a real world issue that the researcher seeks to explain. However, the real world issue selected by the researcher and the methodology used to provide answers will often be shaped by the researcher's views on knowledge and reality (Gray, 2009).

Issues of ontology consider whether social entities can, and should, be considered as having a reality external to social actors or can, and should, be considered as social constructions shaped from the perspectives of social actors (Bryman, 2012). Realism asserts that there is a mind-independent reality that is knowable, albeit partial. The aim of the realist research is to get closer to that reality. It rejects the notion of multiple realities (Maxwell, 2012) but accepts there will be multiple perspectives of reality. These perspectives may all provide valuable explanations of a phenomenon. In the case of memory cafés they are a 'real' phenomenon but individuals that use the café may have different perspectives on what the café provides and what they get from it. Furthermore, as memory cafés are comprised of individuals that can be grouped into people living with dementia, their carers/family and volunteers; these groups collectively may value the café and what it provides in different ways.

Realism views reality as being stratified, where human action is embedded within wider social processes and structures (Pawson & Tilley, 1997). Implied actions only make sense because of their context within a wider set of social rules and institutions. It is widely accepted that social connections are beneficial for people with dementia and their carers. However, these abilities to form social connections are shaped by wider structures, such as provisions to make

contact with others and the stigma of dementia. Social programmes are social systems, where there is interplay between the individual and the institution, agency and structure and micro and macro processes (Pawson & Tilley, 1997). Considering this in relation to causal language, causal powers do not reside in particular objects or individuals but in wider social relations and structures (Pawson & Tilley, 1997). One action leads to another, thus human action needs to be understood in terms of its location within different layers of social reality (Pawson & Tilley, 1997). Realist researchers seek to move beyond what is immediately visible to identify causal powers that are less evident.

The premise behind what constitutes causation is central to a positivist view of science, in that does x cause y? This is known as a successionist view of causation. However, it does not answer the how and why questions (Robson, 2011). A realist approach has a different view on causation, known as generative causation; what is it about x that causes y (Robson, 2011). It views mental states such as meanings, beliefs, values and intentions held by people as real phenomena (Maxwell, 2012). Pawson and Tilley (1997) use the example of CCTV being placed in car parks as a measure to reduce crime. CCTV does not intrinsically inhibit car crime, thus as a physical object it has no causal powers. However, it is the reasoning and reactions (generative mechanisms) that are triggered by the context in which CCTV is installed that has causal influences. For example, cars parked in CCTV blind spots (context) will be more vulnerable if the mechanism is increased apprehension of offenders, due to video evidence. The role of context and mechanisms will be discussed further in the next section, 2.7.1.

Questions of ontology cannot be separated from social research involving social actors (Bryman, 2012) and will shape questions of epistemology. Epistemology considers how things can be known and making sense of the world. The relationship between theory and research is typically viewed as deductive or inductive. Deductive theory involves the formulation of a hypothesis that is deduced from previous knowledge. The hypothesis is tested empirically, using the collection of data, analysis of the findings to conclude whether the hypothesis should be confirmed or rejected, culminating in a revision of theory (Bryman, 2012). In contrast in an inductive approach, theory is the outcome of research. The collection and analysis of data are used to develop theory, as seen in research using grounded theory (Bryman, 2012). However, it is important to note that inductive and deductive approaches are not distinct strategies; both will involve part of the other. Realist research uses retrodution as a mode of inference, in that mechanisms are identified from similar situations and postulated (Sayer, 1992) to explain the observed patterns or regularities (Meyer & Lunnay, 2013).

Theory on groups for people with dementia, groups for carers of people with dementia and the reason why people volunteer in dementia care will provide insights and understandings into memory cafés but it will not provide a complete picture, as knowledge of something is contextual and partial. Realism does not claim that we can achieve absolute infallible knowledge. Human understanding and action is not linear. Therefore, the aim for realist researchers is to move towards greater truth, by testing and refining theory; theory is central to explaining reality (Robson, 2011).

The combining of these standpoints on ontology and epistemology seeks to bridge what is real and our knowledge of it, as Sayer (1992) states:

*The most simple and basic idea of realism is that the nature of the world is largely independent of an observer's ideas about it, and it is this that both explains the adequacy and fallibility of our knowledge, such as it is (Sayer, 1992, p.viii).*

To summarise, realism has four key concepts; mind independent reality, ontological depth (stratified reality), generative causation and retroductive reasoning that encapsulates its aims of explanation about the reality of social programmes and our knowledge of them.

## **2.5 Methodology**

### **2.5.1 Ethnography**

Ethnography has a rich heritage in anthropology, where the researcher immerses themselves in the setting to gain a detailed description of a culture or subculture (Holloway & Galvin, 2015). Today, the notion of culture in ethnography is broader, with a view that agency and action rest on social meanings and within social relationships (Van Maanen, 2011b). Consequently, ethnography has moved from being a marginal approach within certain areas of social science to having a more central position (Hammersley, 1992).

Ethnography seeks to provide in-depth understandings of a culture or social phenomenon, in its own context, as it happens naturally. These thick descriptions are both theoretical and analytical, building a clear picture of what is happening (Holloway & Galvin, 2015), thus giving a sense to the reader of 'being there' (Van Maanen, 2011a). It is focused on the 'how' and 'why', not the

'how much' or 'how many' (Van Maanen, 2011b). By being in the setting, the researcher seeks to uncover the insider (emic) perspective and make tacit knowledge explicit (Holloway & Galvin, 2015). It can be considered as a methodology, method and product. As Van Maanen (2011a, p.xiii) explains:

*It rests on the peculiar practice of representing the social reality of others through the analysis of one's own experience in the world of these others. Ethnography is therefore highly particular and hauntingly personal, yet it serves as the basis for grand comparison and understanding within and across a society.*

An ethnographic approach can inform human understandings through the rich descriptions collated by the researcher. The fieldwork provides the means for how a culture is known, so the strange and unfamiliar become familiar (Van Maanen, 2011a). Observation involves the researcher using all their senses and through the collection of field notes, the researcher captures what they see and what they are told. The combining of temporal and contextual observations and interviews, enables the researcher to capture what people do and say rather than what they think they do or say (Booth, 2015) and reflect reality as it happens (Robson, 2011). It is a common method of research within nursing, with even the term 'ethnonursing' being coined (Holloway & Galvin, 2015). The aim of this is to understand a certain area of practice and then use this knowledge to make recommendations for improvement. It is an organic, flexible approach enabling the researcher to observe changes over time. Fieldnotes are used to capture the researcher's reflections of their observations and interviews, where they interpret and make inferences. As such, ethnography involves three overlapping tasks; fieldwork, headwork and textwork (Van Maanen, 2011b).

Historically, ethnography has involved spending long periods within a single culture but, as Van Maanen (2011a) highlights, multi-site ethnography is becoming more popular. The use of multiple sites or case studies enables patterns to be explored within case and across case, and gain a deeper understanding of context. Case studies are also particularly suited for answering how and why questions and generally involves direct observation and interviews (Yin, 2009). Therefore, they fit well within a realist approach.

Ethnography is generally considered an inductive approach in which initially no preconceptions or theories guide the researcher. Historically, an ethnography was written as a long narrative account of the culture being studied. Today, using an inductive approach where theories are generated from the data, the data are collected, organised, coded and summarised, with codes being reduced to larger categories, and patterns and regularities identified to develop themes (Holloway & Galvin, 2015). Also, variations are identified that do not fit with the rest of the data and relevant literature is used to interrogate what has been found. Ethnography involves both description and the development of theory, however, this focus of reproducing a social phenomenon 'in its own terms', implies there is a single, objective description of a phenomenon (Hammersley, 1992). With this selecting of explanations based on what the researcher sees as relevant or true (Hammersley, 1992), it questions whether others can truly be represented (Van Maanen, 2011a). These issues are addressed in the sections, 2.5.3, the application of realism with ethnography and 2.6, reflexivity.

### 2.5.2 Tales of the field

Ethnography provides a written account of a culture or social phenomenon (Van Maanen, 2011a). How these tales (Van Maanen, 2011a) are written are generally classified as realist, impressionist and confessional. Realist tales are the most prominent; where the researcher is mainly absent from the text with a focus on authentically presenting what was observed and heard. In contrast to realist tales are confessional tales where the researcher is more present. This approach has become increasingly popular and can be written in conjunction with a realist tale. It focuses on the actual doing of the fieldwork and the self-reflection of the researcher. The subject matter is the researcher and what they have come to know from doing the research whereas in realist tales what the author knows or claims to know is the subject matter. For impressionist tales, the researcher presents the events that rarely happen and the individual voices. It can appear novelistic with events told in a chronological order where the researcher aims to illustrate rather than make claims about the field work. In addition to the three main types of tales presented there are further types including; critical, formal, literary and jointly told tales. Van Maanen (2011a) acknowledges that the borders between these different types of tales are not distinct and the researcher can present an ethnography combining different types of tales. He concludes:

*Thus, for me, the point and purpose of ethnography is to render the actual – to figure out what is going on in some part of the world and get the word(s) out the best way we can (Van Maanen, 2011a, p. 173).*

This is the understanding and approach used in the thesis.

### **2.5.3 Realism and ethnography**

The goal of ethnographic research is to get close to and provide the true nature of social phenomenon (Hammersley, 1992). Therefore, like realism there is a commitment to naturalism where the social world is studied in its natural state (Hammersley & Atkinson, 1995). Realism and ethnography also fit with the view that there that is a mind-independent reality and apply similar thinking around theorising. In ethnography, the term 'foreshadowed problems' is used to describe when the researcher starts with a problem or issue; therefore they have a theory about what is going on and potential lines of inquiry (Hammersley & Atkinson, 1995). In realism, retrodution is used to postulate ideas about what might be happening based on similar situation. As such, realism and ethnography share several strands of compatibility.

However, there is an inherent contradiction within ethnography that causes conflict when applying realist thinking. Ethnographers view people as constructing the social world through their perceptions and interpretations (Hammersley, 1992). Therefore, their goal is to explain these multiple perspectives rather than judge which one is more 'true'. By doing so, ethnographers create a social world based on these multiple perspectives rather than representing some independent reality of a social phenomenon as accurately as possible. This results in relativism, which is at odds with ethnography's commitment to realism; i.e. producing the true nature of social phenomenon. In contrast, a commitment to realism means viewing people's perceptions and beliefs as a result of contact with reality or of cultural bias (Hammersley, 1992). Thus, the ethnographer makes judgments on which

perceptions are the most valid, making a value judgement on whether an account is true or false, rather than seeking to explain.

Hammersley (1992) proposes a solution to this conflict, subtle realism, the key elements of which are:

- Defining 'knowledge' as beliefs, in whose validity we are reasonably confident (assessment of claims must be based on judgements of plausibility and credibility)
- There are phenomena independent of our claims about them which those claims may represent more or less accurately (reality independent of the mind)
- The aim is to represent reality whilst acknowledging that representations will always be from a particular perspective making some features of the phenomena relevant and others irrelevant (thus, there can be multiple, non-contradictory and valid descriptions and explanations of the same phenomenon) (Hammersley, 1992, p.50-52)

This also fits with what Maxwell (2012) suggests, as a joining of ontological realism (a real world independent of perceptions and constructions) and epistemological constructivism (understandings of the world are shaped by individual perspectives and standpoint). He posits that not only are they compatible but 'ontology has important implications for research that are independent of those of epistemology' (Maxwell, 2012, p.13). Subtle realism retains the idea that research investigates independent, knowable phenomenon (Hammersley, 1992). However, it denies that we have direct access to a social phenomenon (Hammersley, 1992), which aligns with a realist approach of getting closer to reality and reflecting that reality. It maintains a commitment to viewing people's views and beliefs as constructions about the world but those

accounts may not necessarily 'true' or 'rational' (Hammersley, 1992), with the researcher adjudicating between different accounts (Pawson, 2006a).

Hammersley (1992) argues the truth or falseness of that account should bear no implications for how it should be explained. These accounts may provide information about events the ethnographer has not witnessed or provide a means of triangulation with the researcher's observations. Within realism, mechanisms are considered hidden, thus not immediately observable, so these accounts may provide useful insights into what the mechanisms may be. Understanding an account may help with assessing validity (Hammersley, 1992) and with the selecting of programme theories that are the most plausible for explaining the how and why of a social phenomenon.

A commitment to ethnography also has implications for data collection and analysis when using a realist approach, with the testing and refining of already proposed programme theories. Applying a traditional inductive ethnographic analysis to this study would have involved the development of programme theories from the data. Alternatively, data could have been considered only in relation to whether it supported or refuted the programme theories developed from the review. By combining both approaches, it enabled programme theories to be tested and refined and new programme theories to be developed. The process of how programme theories are generated, tested and refined is outlined in 2.9 with the combination of a realist review and realist evaluation into memory cafés.

## 2.6 Reflexivity

Researchers are social beings and bring to their area of research their aims, expectations, habits and experiences. There is a growing recognition that it is difficult for the researcher to keep these separate from the research process (Finlay & Gough, 2003). These perspectives can intrude at all stages of the research from the choice of research area, formulating the research questions, methodology, methods and data analysis and interpretation. The researcher cannot separate themselves from the social world being studied (Hammersley & Atkinson, 1995). Therefore, it is important that researchers make their values and preconceived ideas explicit. As researcher with experience of running a memory café, I have thoughts about what makes them work, both on a local level within communities and also in the wider social structures. Also, researchers may influence the way participants behave and respond just by the very nature of being there and changing the usual nature of the setting. The way people respond to the researcher may provide useful information on how they would react to other situations (Hammersley & Atkinson, 1995), such as new members joining an established group. Furthermore, as behaviour and attitudes change depending on context, how I see each café in the study and how they see me, has influenced the data collection and analysis. As Dean (2017, p.8) writes:

*Reflexivity is the way we analyse our positionality, the conditions of a given social situation. This is both our position in social structures and institutions, and the thinking through of how such a position arises, and the forces that can stabilise and distort that position.*

From the outset, when I was first introduced to members at the cafes, I was very open about who I was, that I was interested in finding out how and why

memory cafes worked and that I had set up and continued to run a memory café in Cornwall. Whilst I felt this was an important stance to take to ensure open and transparent relationships with the cafes, it may have influenced the responses from participants. They may have felt it difficult to express negative viewpoints, due to seeing me as part of the wider memory café community. I addressed this by conveying to participants the need to hear both positive and negative experiences.

In the current health and social care climate of outcome measures and evidence-based practice, it is important to reflect on how these conclusions were established. Many situations will have hierarchal structures, even if they are not explicit. There is potential for power imbalances between the researcher and the participants, and different groups of participants. Reflexivity prioritises a critical awareness of the self and ensures biases, values and assumptions are thought about and examined in the same way as the data (Dean, 2017). It involves researchers critically asking questions about what they see and what they are told, as they question themselves (Dean, 2017). I was aware that in my position as a researcher and a memory café volunteer, this could potentially create a power imbalance. For this reason, the café where I volunteer was not selected as one of the cases for this research. I was aware that both of these roles could result in a reluctance from members to speak to me or that they might choose to answer a question in a particular way. To minimise the risk of these happening, I adopted an insider stance (Milligan, 2016) and took the approach of joining in with the café activities, helping to set up the sessions and pack away, along with the other volunteers, in the hope this would help me to be accepted as one of the team, and cement the relationship between

researcher and participant. Milligan (2016) highlights the different stances that researchers adopt; insider, outsider and inbetweeners.

In relation to a realist approach, where inferences are made from the data and theories are formed, reflexivity strengthens this process of theory development, to illustrate how conclusions have been made and to ensure trustworthiness and credibility of the research (Emmel, 2013). However, despite this recognition about the fundamentality of reflexivity, there is little structured guidance on how to be reflexive (Dean, 2017). Kara (2015, cited by Dean, 2017, p.16) provides some useful questions to aid with reflexivity, including:

- How does my identity affect my research practice?
- What are my biases and assumptions?
- How do my emotional responses affect my research practice?
- What are the political aspects?
- Am I being as honest and transparent as possible?

Ultimately, by being reflexive the researcher aims to make it clear to the reader how their biases, values and assumptions have influenced the research process, this is discussed further in Chapter 6.

## **2.7 Methods**

### **2.7.1 Context – Mechanism – Outcome**

To address how explanations of social programme are conceptualised and contextualised within a realist framework, there is a realist heuristic:

Mechanism + Context = Outcome (Pawson & Tilley, 1997, p.xv)

Each of these key terms are defined below.

- Mechanism

The concept of generative mechanisms is well established within many social sciences and natural sciences disciplines (Dalkin *et al.*, 2015). Mechanisms incorporate both structure and agency, and describe what is about a programme that brings about changes or effects (Pawson & Tilley, 1997).

Structure influences human agency which in turn influences structure (Dalkin *et al.*, 2015). However, some realists (such as Bhaskar) view the catalyst for change as residing within the structural element and others (such as Pawson & Tilley) within the human agency element (Dalkin *et al.*, 2015). As previously highlighted, all social programmes are situated within wider social structures and processes, with mechanisms occurring at all levels. For realist researchers, evaluation takes place at the level of social programmes so the mechanisms of interest are those of human agency and action. Therefore, realists view mental processes such as concepts, meanings and intentions as real. Maxwell (2012, p.18) explains:

*Concepts, meanings, and intentions are as real as rocks; they are just not as accessible to direct observation and descriptions as rocks. In this way they are like quarks, black holes, the meteor impact that supposedly killed the dinosaurs, or William Shakespeare: we have no way of directly observing them, and our claims about them are based on a variety of sorts of indirect evidence.*

Within the two camps of realism; (critical and empirical) there are key components of what constitutes a mechanism (Dalkin *et al.*, 2015). Mechanisms are not immediately observable (often hidden), sensitive to different contexts and generate outcomes (Dalkin *et al.*, 2015). Astbury and Leeuw (2010, p.368) define a mechanism as:

*underlying entities, processes, or structures which operate in particular contexts to generate outcomes of interest.*

Pawson & Tilley (1997) view a mechanism as the combination of resources provided by a social programme and users' reasoning in response to the resources. Moreover, that mechanisms will only activate under the right conditions, thus mechanism + context = outcome. Dalkin *et al.* (2015) posit that mechanisms are not activated, like an on/off switch, but instead operate along a continuum like a dimmer switch when human volition is involved. For example, an individual's reasoning in response to the resources provided by social programme, such as confidence can be considered along a scale, rather than confident or not confident. When considering this in relation to memory cafés, there will be mechanisms about people's choices and capacities they derive from being part of that group (Pawson & Tilley, 1997, p.66). This highlights the mutual relationship between mechanism and context, in realist explanations one cannot be present without the other. Dalkin *et al.* (2015) also suggest that the separation of resource and reasoning needs to be made clear, as it can be difficult to determine what contributes to a programme contextually or mechanistically. The separating of resource and reasoning can help operationalise the difference between what is context and what is a mechanism.

- Context

Mechanisms are contingent on context (Emmel *et al.*, 2018). Context provides the specific conditions to activate a mechanism and, in combination, lead to an outcome (intentional or unintentional). Context in realist terms is broader than spatial, institutional or geographical locations (Pawson & Tilley, 1997). Pawson (2013, p. 37) outlines four contextual layers:

1. Individuals – the characteristics and capacities of the various stakeholders in the programme
2. Interpersonal relations – the stakeholder relationships that carry the programme
3. Institutional settings – the rules, norms and customs local to the programme
4. Infrastructure – the wider social, economic and cultural setting of the programme

These contextual layers are intertwined and fluid, and understanding their influences is important for the success of the programme. A recent investigation highlighted in the Guardian (Devlin, 2018) found that high profile findings in the social sciences in the last decade were not replicable. It is possible that a lack of focus into the contextual conditions of the initial studies resulted in a lack of replication. At any given time, there will be a number of contextual constraints that impact on the implementation of a programme. Ultimately, context constrains the choices of the stakeholders and users of a programme (Pawson, 2013). Unpicking the contextual conditions and the mechanisms they trigger and identifying patterns (demi-regularities) can help determine programme success or failure (Pawson, 2013).

- Outcomes

Outcomes are the key measures on which programme effectiveness is assessed. Identifying regularities and uniformities are often the cornerstone in determining if a programme will continue or be implemented in another area. However, the repetition of a formula, in itself, will not bring about successful outcomes (Pawson, 2006a). Thus, a programme delivered in Cornwall will not necessarily be implemented or work the same way as it does in Coventry.

Contextual constraints of a programme are localised and temporal and will impact on the resources and reasoning provided to users. As such realists look for outcome patterns rather than outcome regularities (Pawson, 2006a).

The mechanism + context = outcome formula provides a useful analytical function to explain how a programme works. Within a programme there may be a number of mechanism-context-outcome configurations that identify patterns and demi-regularities, which contribute to the development of middle-range theories. The methods open to realist researchers to generate, test and refine these programme theories are varied, as no one method is favoured more than another. It is the way a method is used to answer the explanatory questions of the research and the theories that are generated that is important (Pawson, 2013). For this research, due to the limited literature available, a realist review was conducted to develop programme theories that could be tested in a realist evaluation. An ethnographic method of spending time in the setting, using participant observation and interviews formed the key methods for data collection. This is discussed in the next section.

## **2.8 Patient and Public Involvement Consultation**

Patient and public involvement contributed to the study from its initial conception. Meetings with the Cornwall Memory Café Network forum, where an initial leaflet was provided about the research (Appendix 1), and the Alzheimer's Society leadership group, comprising of people living with dementia, ensured the research questions were relevant and the methods of data collection were appropriate. They commented on their own experiences of attending memory

cafés and felt the research was needed. An information poster on the research and the participant information sheets (Appendix 2 & 3), were also piloted with people that attended one memory café in Cornwall that was not included in the research. The feedback indicated that the purpose of the research, and what taking part involved were clear. There were some suggestions in relation to wording which were changed.

## **2.9 Realist Review and Realist evaluation**

### **2.9.1 Realist Review**

Realist reviews are theory driven and explanatory. They focus on how and why an intervention works, not just if it works, by using programme theories rather than the programme itself as the unit of analysis. Programme theories express how and why a programme is working, typically presented in context, mechanism, outcome configurations. The Medical Research Council guidelines for complex interventions, address the need for understanding the theoretical basis of an intervention, to enable evaluation and future developments (Medical Research Council, 2006). The purpose of a realist review is to:

*...articulate underlying programme theories and then to interrogate the existing evidence to find out whether and where these are pertinent and productive (Pawson, 2006, p.74).*

It applies an iterative approach, where the stages of identification, appraisal, extraction and synthesis overlap to develop and refine programme theories: thus, enabling new ideas and theories to be explored, in light of emerging data. Evidence can be sought from related programmes that may work in similar ways, and utilise sections of information from studies that otherwise would be

excluded in a traditional systematic review, due to methodological limitations (Pawson, 2006). The RAMESES publication standards (Wong *et al.*, 2013, p.6) emphasise that realist reviews are particularly well suited to reviews of 'complex social programs that involve human decisions and actions'. Memory cafés can be described as complex social programmes due to the fact they involve different groups of people (people with dementia, carers and volunteers), they are open-ended so are in a constant state of flux, and are based in different communities and countries. The realist review is reported in Chapter 3.

### **2.9.2 Realist Evaluation**

Realist evaluation originated in criminology and social science and is now becoming increasingly applied to healthcare and complex interventions (Moore *et al.*, 2015; Tolson and Schofield, 2012). According to the Medical Research Council's guidelines, realist evaluation is 'useful in understanding how intended outcomes are achieved and how unanticipated outcomes emerge' (Moore *et al.*, 2014, p. 42) by identifying causal mechanisms and contextual factors (Moore *et al.*, 2015). It shifts the focus of evaluation from about individuals and groups, to working with individuals and groups.

The evaluation being reported here explored how and why the memory cafés (the cases) work and the benefits reported by people with memory problems/dementia and their carers. It also investigated the views of the volunteers that facilitate the cafés. Evaluating multiple viewpoints provided more comprehensive, in depth data to build an explanatory picture. Memory cafés are not time limited interventions, as people with dementia and their carers are able

to attend as little or often as they like. Also, as memory cafés are facilitated by volunteers, the people at each café and for each session change to some degree every time. Therefore, memory cafés are in a constant state of flux and a realist evaluation was identified as the most suitable methodology to facilitate the impact of these changes to be examined, by unpicking how and why the service works. Realist evaluation can take a number of different research designs but should be selected to ensure the development of context-mechanism-outcome configurations, which provide explanatory theories of how and why a programme works (Pawson and Tilley, 1997). The methods for data collection were observation and in-situ interviews, chosen as most aligned to address the research aim, the nature of the setting and the need to obtain multiple viewpoints. This is discussed further in 2.9.6.

The realist review and realist evaluation were not conducted in two distinct stages. They overlapped initially, to take account of the iterative nature of realist enquiry whereby the researcher oscillates between theory and observation. Programme theories developed in the review were explored, tested and refined during the evaluation, and new programme theories developed. As Pawson (2013, p.15) explains:

*Realist evaluation is avowedly theory-driven; it searches for and refines explanations of programme effectiveness (Pawson, 2013, p. 15).*

### **2.9.3 Quantitative data**

Quantitative data were obtained from the Cornwall Memory Cafés webpage, which details all the cafés throughout Cornwall

(<https://www.cornwallmemorycafés.co.uk/the-network/>). The Cornwall Memory Café Network forum, also provided further information on when the cafés

opened. The quantitative data provides details on where the cafés are located and how they have grown since the first cafés opened. The details are located in chapter four (section 4.2). The data guided the recruitment of the cafés for the realist evaluation. Figure 2.1 provides an overview of the research project.

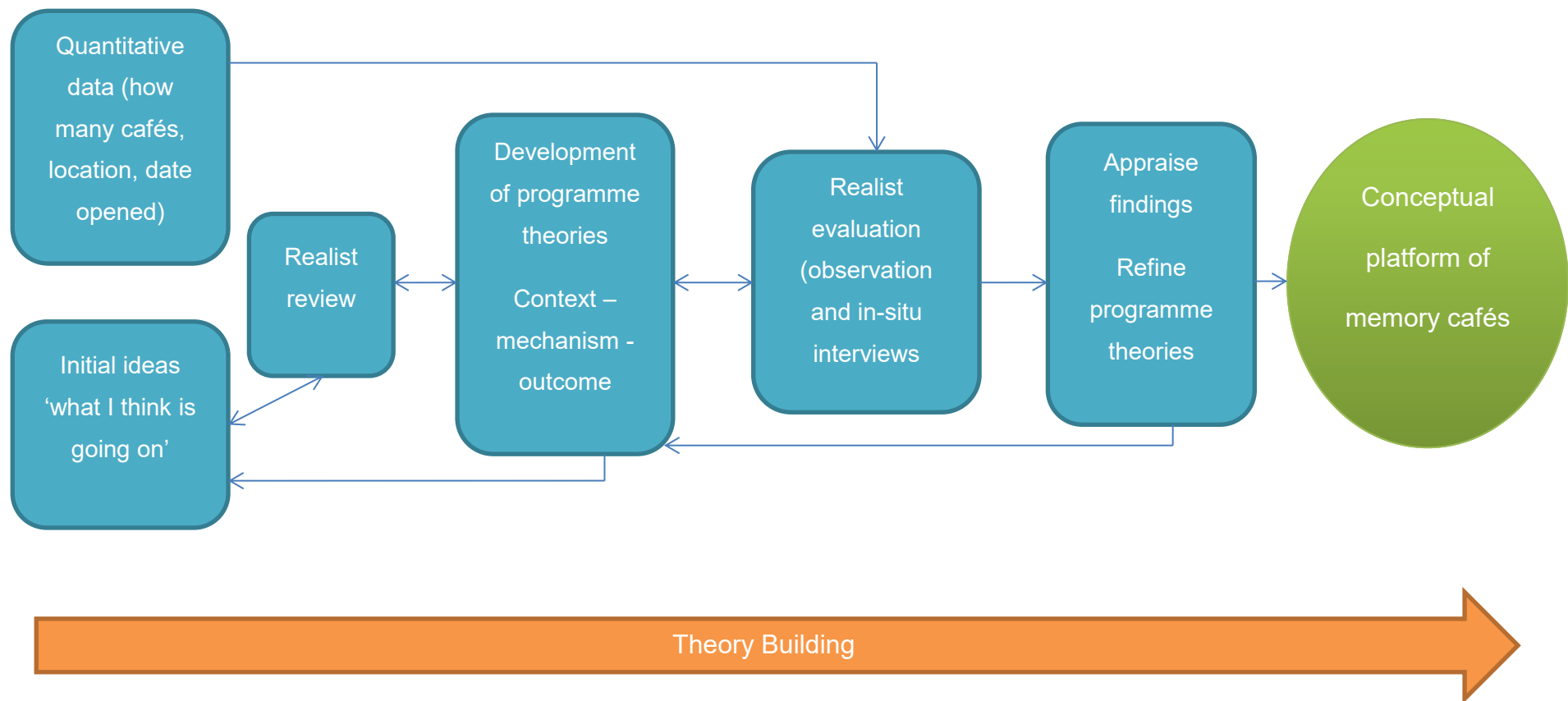


Figure 2.1: Overview of research project

#### **2.9.4 Recruitment of cases**

Memory cafés in Cornwall were recruited using non-random purposive sampling to ensure variation in the sample and to meet the research aims (Bryman, 2012; Maxwell, 2012). In purposive sampling, decisions are taking by the researcher based on specialist knowledge of the topic and the individuals most likely to provide relevant and in-depth data (Hunt & Lathlean, 2015). Theoretical sampling was also taken into consideration to select cases that would be relevant to the development of theory (Emmel, 2013; Maxwell, 2012). Insider knowledge gained from being involved in the development and running of a memory café in Cornwall and through regular attendance at the Cornwall Memory Café Network forum meetings, assisted with the recruitment process.

Memory cafés were selected based on the basis of size, geographical location, funding status (i.e. independently run or by the Alzheimer's Society) and how long the memory café has been running. Geographical location took into account where the cafés were situated in Cornwall, such as being by the coast or inland and level of deprivation. A brief overview of the research was given at one of the Cornwall Memory Café Network forum meetings; this raised awareness of the likely contact being made to the cafés. A number of the cafés put themselves forward for involvement in the project as they were interested in the research. The profile of the cafés were discussed with the supervisory team and those to be invited to participate in the study were agreed. Any refusals were to be noted and further discussions would be held to decide on whom to approach next. All the cafés approached agreed to take part. The majority of the cafés in Cornwall at that time were independently run, however, there were three that were affiliated to the Alzheimer's Society. Therefore, the need to

ensure that this mix was reflected in the sample was recognised and consequently, it was agreed that four cafés would form an appropriate number for the case studies for this research, and so these were recruited, and included one from the Alzheimer's Society.

All the independently run memory cafés in Cornwall had a committee, which acted as a gatekeeper (Bryman, 2012) to their café and the people that use them. Maxwell (2012) highlights the importance of developing relationships with gatekeepers and so firstly the chairpersons of the cafés were contacted by telephone by way of introduction to explain who the researcher was leading the research, the purpose of the research and what would be involved. Following this a letter/email was sent out re-confirming details of the telephone conversation along with posters and information leaflets about the research (Appendix 2 & 3). Hard copies of the posters and leaflets were also posted out if required to avoid the café incurring printing costs. The posters and information were for sharing and discussing with guests at the cafés to ensure they were all happy for the researcher to attend, regardless of whether individually they wanted to take part. Following affirmation of this, each was visited to provide information sheets, answer questions, build relationships (McKeown *et al.*, 2010; Murphy, 2007) and to reassure them that the researcher was a 'safe practitioner' (Pratt, 2002). I have previous experience of working with people with dementia through the memory café and as a registered mental health nurse for many years. Prior knowledge and skills has been identified as important when conducting research with people with dementia (Beuscher & Grando, 2009; Murphy, 2007; Hubbard, Downs & Tester, 2003). This visit allowed assurances to be given that no data would be collected unless the

guests had consented to take part. If any attendees of the memory café had objections to the research, then the plan was that another café would be approached to take part in the study, in accordance with the requirements from the ethics committee at the University of Plymouth. The letter confirming ethical approval is located in Appendix 4.

### **2.9.5 Recruitment of participants**

Any adult attending the memory cafés was eligible for inclusion in the study, with exclusion only on the grounds of the person lacking capacity to consent to being involved in the project. The literature supports the inclusion of people with dementia within research (Dewing, 2002), that they should be encouraged to do so (Robinson, 2002) and have a right to be involved (Hughes, 2014; King, Hopkinson & Milton, 2016). The cognitive competency-based approach to informed consent does not position the person as an equal in the process (Dewing, 2002). The Mental Capacity Act (2005) and process consent (Dewing, 2007) were utilised to maximise informed consent (Pratt, 2002) for potential participants. Process consent has five stages; background and preparation, establishing a basis for capacity and other abilities, initial consent, on-going consent monitoring, and feedback and support (Dewing, 2007, p. 62). McKeown *et al.* (2010) propose that the Mental Capacity Act (2005) and process consent complement each other, with the skills of the assessor maximising the person's abilities (Dewing, 2007). Ethics approval was granted for the study from the University of Plymouth (Appendix 4). In addition, a research partnership agreement was agreed with the Alzheimer's Society to enable one of the cases to be a café run by them (Appendix 5).

A reflective diary was maintained to capture notes about how consent was obtained (Dewing, 2002), continually monitored (McKeown *et al.*, 2010) and how ethical principles were adhered to throughout the study (Cowdell, 2008). Capacity to consent was rechecked throughout the study by adhering to the Mental Capacity Act (2005) and whether participants were able to understand, retain, weigh up and communicate their decision.

To ensure that informed consent was obtained, guidance from the Royal College of Nursing (2011, p. 3) was used. All potential participants were provided with the following information:

- The purpose of the research
- How long their involvement will be
- Who is involved in the research
- The practicalities and procedures of being involved
- Possible benefits and risks
- How data will be managed and used
- How long and where the data will be stored
- The purpose of the consent form
- What is expected if they agree to participate
- How information will be provided to them during the study
- That their participation is voluntary
- That they can withdraw at any time without explanation and this will not affect their ongoing care
- That the study has been approved by an ethics panel

All of these points were covered whilst going through the participant information sheets with potential participants. Time was also given to answer any questions the potential participants had, and for them to discuss the study with others. A

consent form was then completed (Appendix 6). Participants were required to initial each statement and sign, print name and date at the bottom of the form. If the person had difficulty writing due to sight problems or physical disabilities, then verbal consent was taken, with a written record confirming that consent had been given and witnessed and signed by carer (King, Hopkinson & Milton, 2016). Consent was re-checked with all participants at each period of data collection.

### **2.9.6 Data collection**

Data were collected using observation and in-situ interviews with people with dementia, their carers and the volunteers that facilitate them. The application of multiple qualitative methods were applied to gain a 'broader and more secure understanding' of what was happening (Maxwell, 2012, p.106). Observation provides a direct way of understanding the phenomenon of interest in a real context, with interviewing eliciting people's perspectives and checking what the researcher has observed (Maxwell, 2012). The memory cafés were visited several times during the data collection period of ten months. The combination of observation and interviews is recommended practice when working with people with dementia (Beuscher & Grando, 2009, Hubbard, Downs & Tester, 2003 and Murphy, 2007). According to Hubbard (2003, p. 360):

*"Participants reflect upon, and within the immediacy of experience to give meaning to that experience."*

This is also echoed by Nygård (2006, p.104)

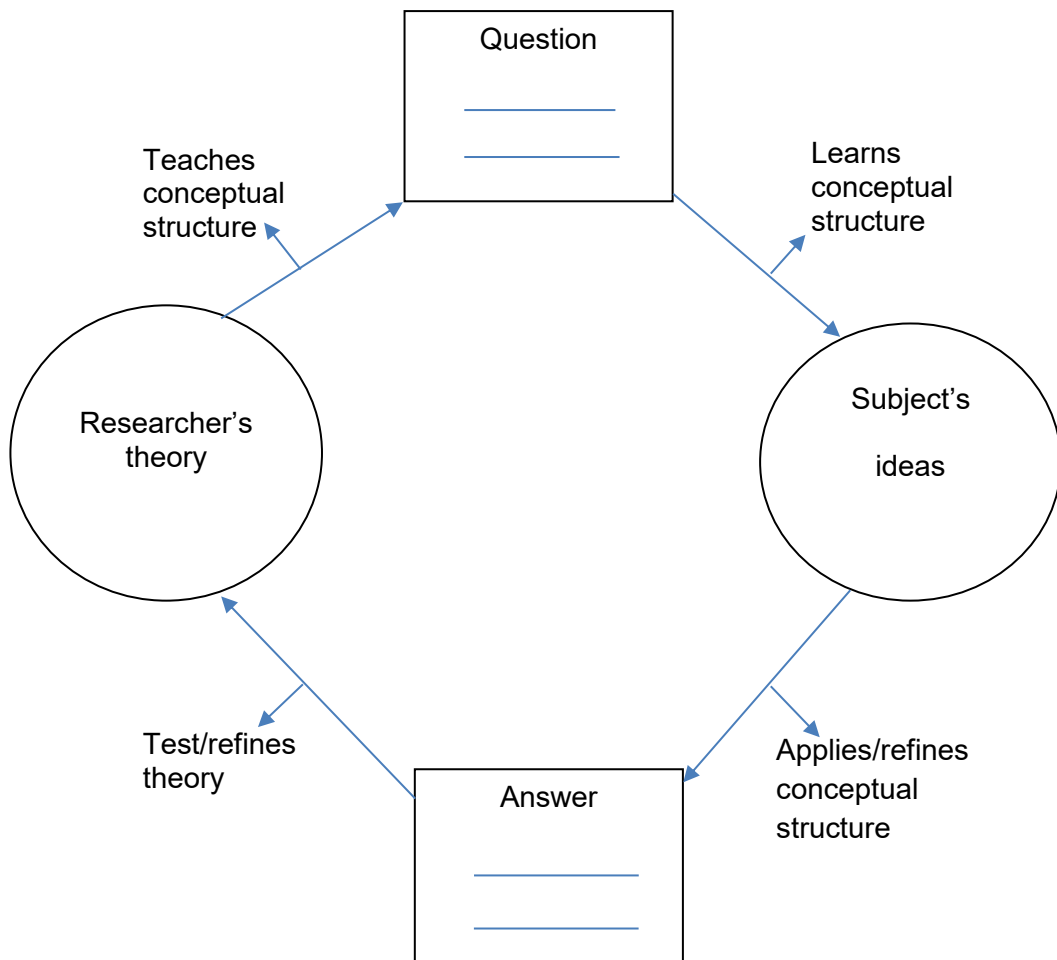
*"...when interviews and observations are combined and performed in a natural context, the comments made and actions executed will be more closely connected to the experience."*

Asking questions at the time something is happening is a 'natural process' (Hubbard, Downs & Tester, 2003) and addresses the importance of physical and temporal immediacy (Murphy, 2007) and context (Innes, 2009) for people with dementia. Focus groups and one to one interviews were considered as methods for data collection, however, they would have been limited in providing the contextual understandings of how the cafes worked. The questions that the guests were asked were based on the programme theories generated from the realist review and also what has been observed during the memory café sessions. Realist interviews (Pawson & Tilley, 1997) adopt a teacher-learner relationship with questions exploring participants' views of the programme theories, see Figure 2.2. The programme theories were phrased in lay language. Due to the iterative nature of the data collection, where the content of the cafés varied each time and participants were not always there, a decision was taken to allow a more natural approach, to questioning of guests, responding to what was happening but linking to the programme theories from the review, rather than adopting the usual more prescriptive approach. For example:

- The literature suggests that....
- I have observed....
- What do you think about....

The in-situ interviews enabled a flexible approach to asking questions by using the programme theories from the review as a guide, as well as asking ad-hoc questions as things happened in the café. However, this meant interviews were often brief, disjointed and conducted over multiple sessions. Also, as participants did not always attend each session, some content had to be

revisited before proceeding with follow-up questions. When typing up field notes from each café visit, notes were made on what needed questions needed to be asked and to which participant at the next visit.



**Figure 2.2:** Adapted from, Basic structure of the realist interview (Pawson and Tilley, 1997, p. 165)

In addition, it was important that peoples' stories of why they first attended and why they stay were captured, as these would provide further explanatory information on how and why memory cafés work.

Each memory café was assigned a letter – A, B, C and D. All participants were also assigned a code once consent form was completed. People living with memory problems/dementia in memory café 'A' were assigned codes AP1, AP2 and so on. Carers were assigned code AC1, AC2 and so on. Volunteers were assigned codes AV1, AV2 and so on. For participants in memory café 'B' the codes started with B, memory café 'C' the codes started with C and so on. When making notes during the periods of data collection, the assigned codes were used to ensure that no participant identifiers were recorded. Verbatim quotes were also captured where appropriate to support data analysis.

It was important to be immersed in the settings (Holloway & Galvin, 2015) acting as a 'social-participant-as-observer', in order to be open about the research and take part in the activities (Cowdell, 2008). Such an approach can raise issues around subjectivity but reflective notes were made about what was observed and how my presence may have affected those observations (Robson, 2011). However, sharing about who I am was necessary for establishing trusting relationships. Also, spending time in each memory café before data collection (McKeown *et al.*, 2010) was important and useful to meet with café attendees and have conversations outside the research (Hellström *et al.*, 2007a). Some initial reflections have been included in chapter 4.

An observation schedule was used for the observations of the memory cafés at each visit (Appendix 7, 8, 9, 10 & 11). On one side, descriptive observations (Robson, 2011), were documented: layout of the room, weather, activities, numbers attending, other activities that day and refreshments provided. On the reverse side, there was an area to make notes around the structure of the

session, volunteers' characteristics and reflections. This enabled the explanatory theories to be examined in relation to these factors and provide areas of further discussion with participants using the in-situ interviews. Details from individual interviews and observations were made in a notebook. Each café had a different colour notebook and in these, 'jotted notes' (Bryman, 2012, p. 450) were made during the periods of data collection, as it was important to make a record at the moment of occurrence (Robson, 2011). These jotted field notes were transferred to 'full field notes' (Bryman, 2012, p. 450) at the end of each data collection period. Notes from each observation and in-situ interviews were written up in full before the next observation. For observation to be useful it needs to be conducted rigorously (Angrosino & Rosenberg, 2011) with a clear record of what has been observed and reflections on those observations. Thus, a research diary was also completed to facilitate reflexivity during data collection and analysis (Clarke & Keady, 2002), and points identified were discussed with my supervisory team. This was to help ensure credibility of the data (Cowdell, 2008) and provide evidence of how an ethical focus was maintained (Christie, 2007). Data collection and data analysis, in line with a realist approach were iterative, facilitating retrodution of the patterns and regularities being observed to uncover what was causing them.

### **2.9.7 Data analysis**

Patterns, similarities and differences within cases and across cases were explored, by reflecting on:

- Are they working?
- Are they working the same?
- Are they working differently?

An initial analysis of the cases (Chapter 4) detailed the location, layout, format of the sessions, activities and attendees. This provided the contextual details on the differences and similarities and the conditions in which the programme theories are situated. Photographs from the cases were not possible due to anonymity but mock photographs have been provided to represent how the cafés sessions were laid out.

The programme theories developed from the realist review also provided a framework from which to analyse the data (See Chapter 5). All notes from observations of the cafés, individual observations and interviews and reflections were uploaded to NVivo 11 (QSR International, 2015). The aim was to use this as the platform to code data to the existing theories and to look for new theories. Whilst it was useful for some initial coding, the data were viewed on flip chart sheets and colour coded for observations, interviews and reflections (Appendix 12). This enabled notes, and post it notes to be added to the flip chart sheets and moved as necessary.

The first step of analysis involved looking within each memory café and mapping which café had generated data related to the programme theories developed from the review, in some way. This, in conjunction with the descriptive data, enabled similarities and differences to be considered within each case in relation to, for example numbers and activities provided. For the next step, data on the flip charts were identified again and examined to see what related to each programme theory and the relevant information from the full field notes were copied and pasted into a new document under the heading of the programme theory. The data were then interrogated and a narrative

formed around each programme theory, where inferences were made about what the data may indicate, culminating in a refinement of theory where necessary. As previously discussed, mental processes are considered real entities within realist research but as they are not directly accessible, their meanings are inferred by the researcher based on participant's accounts and other evidence (Maxwell, 2012, p.139) The third step involved returning to the data and identifying information that did not map to the existing programme theories. Again, using post it notes, patterns and regularities were identified, grouping the data under new potential theories. The data were then interrogated to reveal the information of further narratives, where inferences could be made about unexpected information or information that had not been identified during the review process. New programme theories were developed providing additional explanatory and plausible propositions of how and why memory cafés work. As the notes obtained from speaking to people were in jotted form, they were adapted into natural language, however, they have not been changed if grammatically incorrect or disjointed to ensure the voice of the person is truly represented. Quotations and observations were used to support and evidence the inferences drawn. These programme theories were member checked with participants from the cafés after the period of data collection, to ensure they felt it was representative of their views. Furthermore, the findings from the study were presented to the Cornwall Memory Café Network forum, to permit early feedback and sense checking.

The final stage was the development of a conceptual platform (Pawson, 2013; Pearson *et al.*, 2015) using the programme theories that had been refined through the findings arising from the review and evaluation. Conceptual

platforms are useful for representing the core set of processes of how a service is proposed to work (Pearson *et al.*, 2015) that can be reusable and potentially applied to other services (Pawson, 2013). Pawson describes a reusable conceptual platform as:

*Rather than starting each inquiry from scratch, a stock of recyclable conceptual frameworks is created to distinguish different classes of interventions and to set out their component theories. All evaluations then operate within a common set of programme theories, each inquiry being capable of adding to and refining that framework' (Pawson, 2013, p. 86).*

## **2.10 Chapter summary**

This chapter has outlined the methodology and methods used. It details the epistemological and ontological positions of realism and provides a rational for a realist approach for the research. The realist stages of review and evaluation are explained in how they develop programme theories. It also provides a discussion of the application of ethnography with a realist approach and how they can complement each other by testing and refining programme theories by being 'in the field'. The recruitment of the cases is detailed, with a rational for their selection. An explanation for the data collection methods chosen are given, in relation to the nature of memory cafés and the participants that attend. The process for data analysis is outlined, and how the programme theories were tested and refined, and how new programme theories were developed, to develop a conceptual platform of memory cafés. The next chapter, chapter three, is the realist review stage of the research.

### **3 Realist Review: Exploring the impact of memory cafés for people with dementia and their carers: a realist review**

#### **3.1 Introduction**

This chapter details the realist review section of the research project, outlining how the initial programme theories were developed. As previously discussed in section 2.9.1, realist reviews are theory driven and explanatory.

#### **3.2 Review questions**

The review aimed to explore the following questions:

1. What philosophy informs how memory cafés are structured and delivered?
2. What are the mechanisms that determine how and why memory cafés are working?
3. What are the experiences for people with dementia and their carers?

The review questions were purposely broad due to the initial examination of the literature that revealed a lack of research relating specifically to memory cafés. As the review progressed it became apparent that answering question one would be the most difficult due to the lack of explicitness on the philosophy of memory cafés. However, the included papers do provide insights into how the philosophy of a memory café may affect the structure and delivery. To our knowledge, this was the first realist review that has looked specifically at memory cafés and it was conducted with guidance from the RAMESES publication standards for realist reviews (Wong *et al.*, 2013).

### **3.3 Methods**

#### **3.3.1 Study protocol**

The protocol for this realist review was registered with PROSPERO: International prospective register of systematic review, 'Understanding the impact of memory cafés for people with dementia and their carers: a realist review' (2015, registration number CRD42016035257). Changes from the review protocol are outlined in Appendix 12.

#### **3.3.2 Process and initial programme theory development**

A template developed by Pawson (2006a, p.103) was utilised as a guide for the review which details six iterative steps; identifying the review question, searching for primary studies, quality appraisal, extracting the data, synthesising the data and disseminating findings (See figure 3.1). The first step was to identify some of the core features of memory cafés. Pawson (2006a) refers to this as concept mining and theory formation, where key terms, ideas, and hypotheses that begin to provide some explanation are extracted from the literature. We initially looked at commentaries and descriptions on memory cafés, dementia cafés and Alzheimer's cafés available online. My personal experience of setting up and running a memory café contributed to this knowledge and insight. From notes taken, the potential territory of memory cafés was mapped; 'What I think might going on', outlines these initial ideas on how and why memory cafés may work (See figure 3.2). These initial ideas or folk theories (Pawson & Tilley, 1997), provided avenues to explore within the literature.

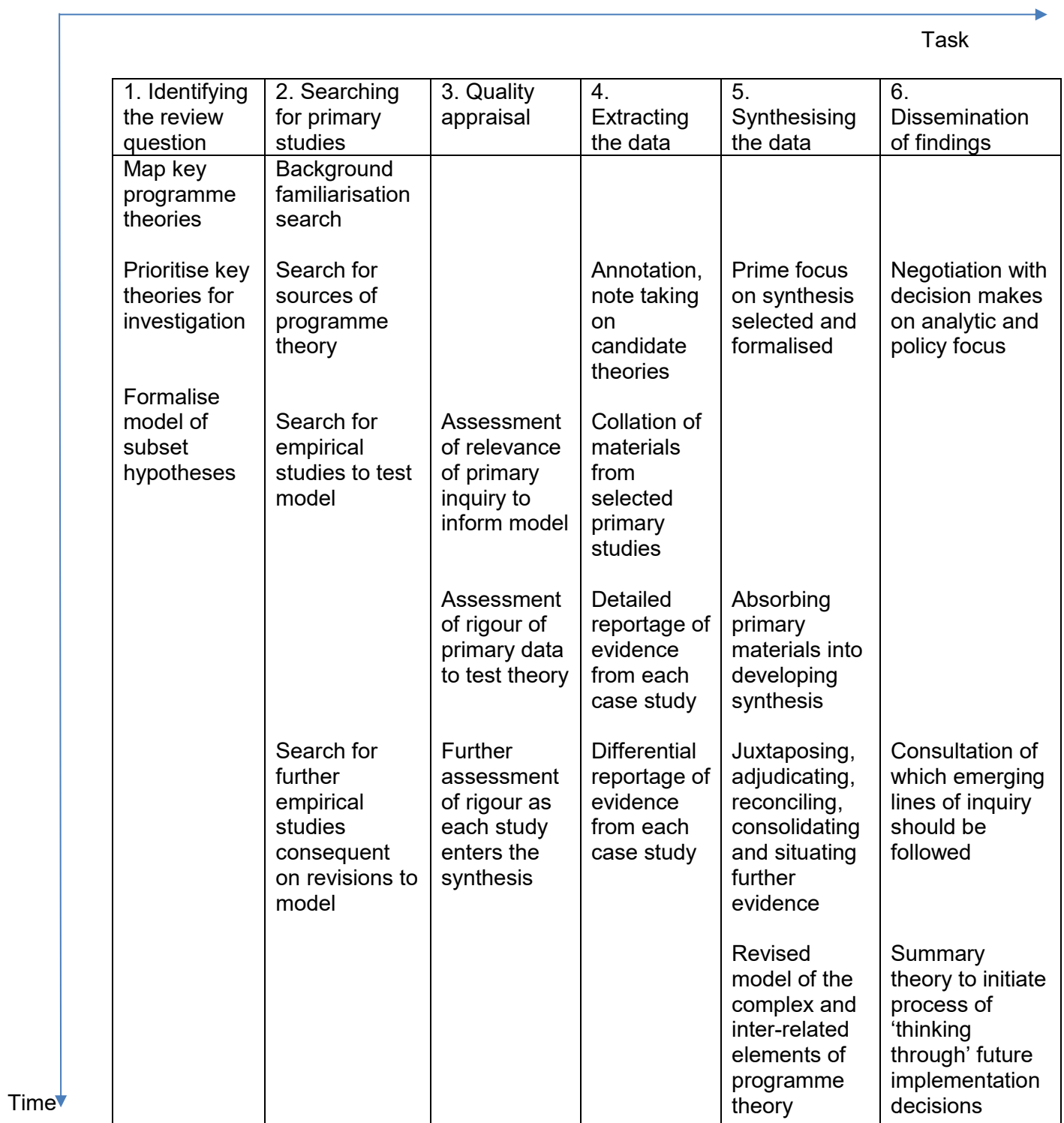


Figure 3.1: Adapted from, A task-and-time template for realist synthesis (Pawson, 2006a, p.103)



**Figure 3.2: Initial mapping exercise**

### 3.4 Search strategy

The search strategy was purposive and intentionally inclusive and focused on a broad range of sources. The search terms were agreed with the review team (Appendix 14) and a health services librarian and entered into the following databases; CINAHL (Cumulative Index to Nursing and Allied Health Literature), MEDLINE (Life sciences and Biomedical), EMBASE (Biomedical), Social Care Online (Social care and Social work), COCHRANE, AMED (Allied and Complementary Medicine) and PsycINFO (Behavioural science and Mental health). The literature search was ongoing throughout the project to minimise the risk of not identifying a useful paper. Following familiarisation with the literature and the potential programme theories, backward and forward citation chasing (Greenhalgh & Peacock, 2005) was utilised and key word searches in

Google Scholar, grey literature (websites including Alzheimer's Society) carried out. A further search on SocIndex did not reveal any additional studies to include.

### **3.5 Selection and appraisal of documents**

There were no restrictions on the type of study designs included. Papers were considered by asking the question 'is this study good enough to provide some evidence that will contribute to the synthesis?' (Pawson, 2006a, p.88) by considering two criteria:

- Relevance, how they contribute to theory development and
- Rigorousness, whether the method used is credible and trustworthy (Rycroft-Malone & Burton, 2015).

The interpretation of relevance and rigour was different at each stage. At title/abstract screening stage papers were considered for inclusion if they were group based and for people with dementia and or carers. Whereas, at full text screening, the focus was on how the papers may contribute to the development of programme theories that would build up plausible explanations of how and why memory cafés work. In line with a realist approach, study selection and appraisal of documents were iterative processes. The interpretation of relevance was broad to ensure ideas from a wide range of sources were explored. The papers included at full text screen provided an initial foundation for the review and as the papers were read through, other references and terms were hand searched. For example the included paper by Tarrant *et al.* (2016), whilst not specifically about people with dementia, was on psychological

connections in a group for people with aphasia. The paper provided useful insights that were relevant to the literature already included in the review and so met the criteria of contributing to theory development. Whilst it is important to note that the search did not identify other papers of this nature, there may have been others located that could have also had some relevance but, as Pawson (2006a) acknowledges, a review has to stop at some point. On a similar note, terms identified in the papers such as 'value' of support groups for people with dementia, identified the social return on investment study (Semple, Willis & de Waal, 2015), which also contributed to theory development. The studies retrieved by hand searching are shown in Figure 3.3 (p. 86), in the flowchart of included and excluded studies.

Citation details were stored and managed by using the Endnote software programme (Endnote X9, 2019). Title and abstract screening were conducted independently by two reviewers (LB and AH). Abstracts were screened for their relevance to the review questions and initial programme theories. Full text screening was conducted independently by two reviewers (LB and AH) by considering how they contributed to theory development of how and why memory cafés work. Disagreement on inclusion was resolved by discussion between LB and AH.

To quality appraise the papers a form was used that had been adapted with permission from the original author (Jagosh, 2012), (Appendix 15). The form was specifically designed for use in a realist review. It scores relevance and rigour separately, using scores of none, low, medium or high. There was also a section to outline how the paper may contribute to programme theories and a

section for study characteristics. The studies were all quality appraised by LB, with a sample of papers being quality appraised by the supervisory team. The discussions around the quality appraisal of the papers ensured 'explicitness and reflexivity' (Rycroft-Malone *et al.*, 2015) and enabled LB to check ideas against the rest of the review team. These discussions were useful in refining the programme theories and considering other avenues for exploration.

### **3.6 Data extraction**

To extract the data a bespoke data extraction form was created. The first sheet detailed study characteristics with full citation details, study design, data collection methods and results (Appendix 16, 17 & 18). The second sheet detailed the rigour and relevance score, concepts used in the paper and theories or models used. It also contained extracted data for context, mechanism and outcome for the papers. Mechanisms were examined for resource and reasoning; resource being what someone gets from the intervention and reasoning, their response to the resource (Dalkin *et al.*, 2015). Data were extracted that contributed to theory development and documented in the form of notes, annotations and direct quotes. Data extraction was completed by LB and a sample checked with BK, JML and RG. During this period, the articles selected at the full text stage were revisited, to ensure, that in light of the data being extracted, no pertinent information had been missed. The papers varied in the amount of data relevant to each section, with some for example having more data related to mechanisms. Each piece of extracted data for context, mechanism and outcome was given a code.

### **3.7 Analysis and synthesis processes**

The extracted data were read and re-read to establish familiarity and develop thinking and refinement around the programme theories. Data analysis and synthesis were undertaken by LB with results regularly discussed with BK, JML and RG, to ensure credibility and trustworthiness of the inferences being made. The spreadsheets were printed off enabling text to be read as one complete document. The process was iterative and the patterns of contexts, mechanisms and outcomes were explored through comparing and contrasting of the data. Due to the amount of data generated, the codes were then transferred to a third excel spreadsheet and a process of comparing and contrasting codes completed. Patterns and similarities in the codes were identified and colour coded into groups, for example codes such as social isolation, new social networks and combined support were grouped into the overarching concept; social connectedness. This process was discussed and agreed with reviewers (BK, JML and RG). Particular attention was paid to locate repeated patterns (demi-regularities), such as social connections between group members, in accordance with Pawson (2006a) steps of juxtaposing, reconciling, adjudication, consolidating and situating the evidence.

### **3.8 Formation of programme theories**

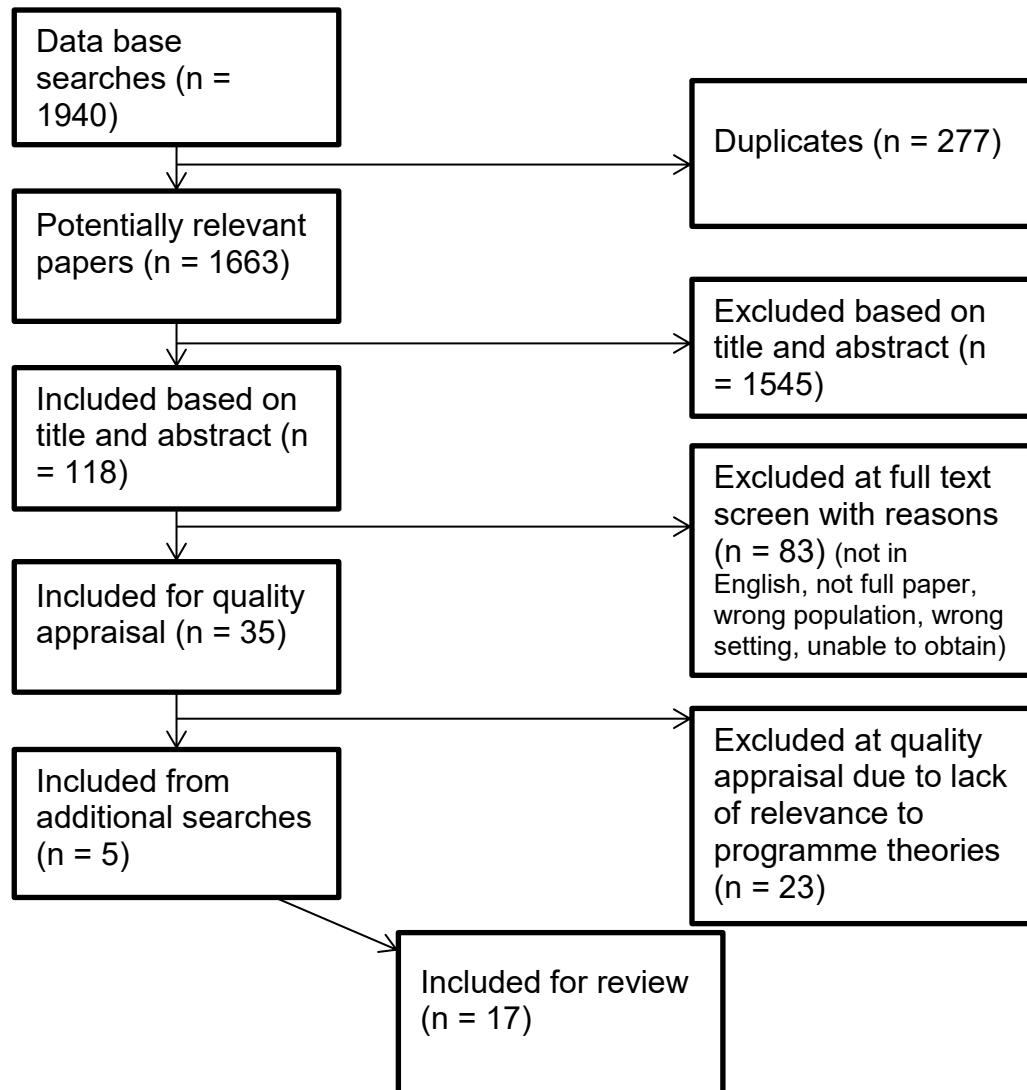
To guide the process of programme theory development the work of Walker and Avant (2014) and Rycroft-Malone *et al.* (2015) were utilised. Walker and Avant

(2014) outline a process of theory development; moving from concepts, to statements and then theories. According to Walker and Avant (2014, p.59):

‘A concept is a mental image of a phenomenon, an idea, or a construct in the mind about a thing or an action’.

A statement then shows how two or more of the concepts can be related.

Finally, theories are identified that present these relational concepts and statements in a predictive and prescriptive format. Similarly, a chain of inference shows how themes across papers may be linked. These links are not necessarily explicit but identify plausible relationship between concepts/themes and outcomes (Rycroft-Malone *et al.*, 2015). Programme theories were then generated from the chains of inference formed from the data.



**Figure 3.3: Flow diagram of article selection and inclusion**

### 3.9 Findings

The initial database search returned 1940 papers, 1663 after duplicates removed. After abstract screening, there were 118 papers for full text screening. Papers were then screened using the assessment of relevance and rigour outlined in the methods section, resulting in 35 papers for quality appraisal.

Following quality appraisal, 23 papers were excluded due to not providing information to generate plausible programme theories, and additional searching added another five papers (See figure 3.3). Ongoing discussion throughout these stages was fruitful in refining our thoughts on the programme theories and for further avenues for potential sources. Out of the 17 papers that remained, only 5 were specifically in relation to memory cafés. The included papers provided insights through both author comments and participant comments, of how and why memory cafés are working and what the outcomes may be for people that use them.

The included studies selected (See table 3.1) comprised of RCT (n=1), mixed methods (n=2), qualitative (n=4), case study (n=2), reflective report (n=5), systematic review (n=1), survey (n=1) and social return on investment study with qualitative data from focus groups and interviews (n=1). In line with a realist approach, even methodologically weak studies, were included since these may provide what Pawson (2006b) describes as ‘nuggets’ of relevant information that can contribute to theory building. The characteristics of the included studies are outlined in Table 3.1.

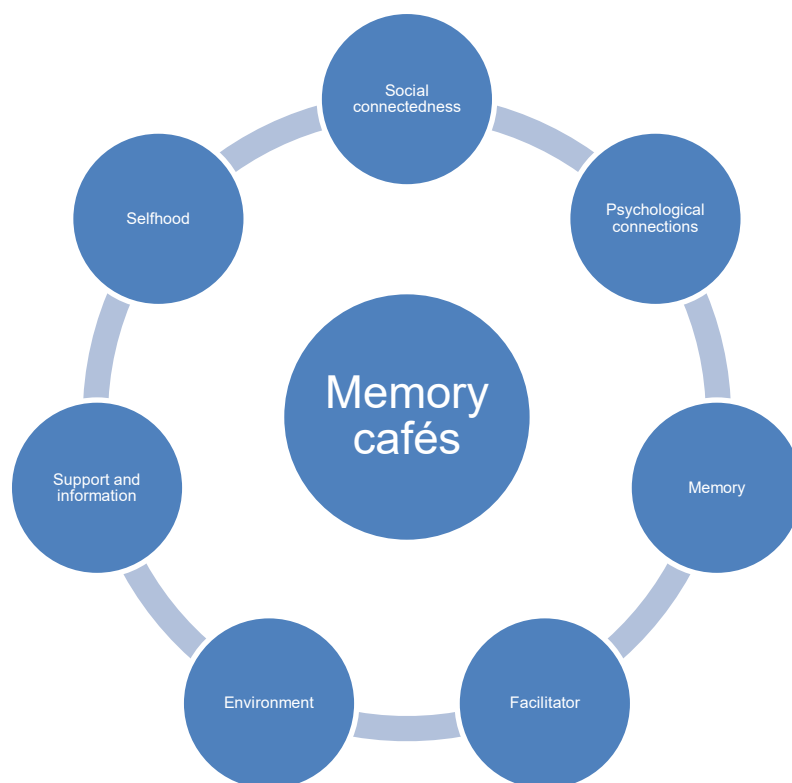
**Table 3.1: Table of included studies**

Author and date	Article aim	Methodology
Bender, M. & Constance, G. (2005)	Description of the setting up of a long-term support and self-help group.	Reflective account
Capus, J. (2005)	Setting up of an Alzheimer café.	Qualitative
Cuijpers, P. <i>et al.</i> (1996)	Description of Dutch support groups, review of the international literature and report of a study among 110 participants of support groups in which the change mechanisms of the groups were examined.	Mixed methods
Earle, S.S. (2006)	Reflections on 12 years of facilitating Alzheimer's caregiver support groups.	Reflective account
Halley, E. <i>et al.</i> (2005)	Descriptive account of an Alzheimer café.	Reflective account
Hedman, R. <i>et al.</i> (2014)	To describe using positioning theory, how people with moderate AD positioned themselves in a support group for people with AD. In this study, a secondary analysis is performed on data from one of the support groups for people with AD.	Qualitative
Kjallman, A. <i>et al.</i> (2014)	Explore the experience of four couples in long-term ongoing structured support groups.	Case study
Kritz, F. (2016)	Setting up a memory café.	Reflective account
Laakkonen, M-L., <i>et al.</i> (2016)	To investigate the effect of self-management group rehabilitation for persons with dementia and their spouses on their-health	RCT

	related quality of life, cognition and costs of health and social services.	
Mason, E. <i>et al.</i> (2005)	To investigate the mutual support processes that occur in dementia support groups and how members perceive the groups.	Qualitative
Minnema, N. (2008)	Setting up a memory café.	Reflective report
Offord, R.E <i>et al.</i> (2006)	Aim of the study to investigate relationships between people with a dementia by analysing interpersonal interactions within a 'Coping and Forgetting' group for people with dementia.	Qualitative
Semple, A. <i>et al.</i> (2015)	Impact of peer support group interventions for people diagnosed with dementia. Focus of this SROI is on the value gained from peer support groups to the individual, carers and families, and others associated with the groups.	Social return on investment study with qualitative
Synder, L. <i>et al.</i> (2007)	Effectiveness of support groups for people with Alzheimer's disease.	Survey
Tarrant, M. <i>et al.</i> (2016)	Group singing for people with aphasia - exploring participants' experiences. The study sought to identify key design feature that could be used to create a new framework for group-based health interventions.	Qualitative
Toms, G.R. <i>et al.</i> (2015)	Investigated the effectiveness of support group interventions for people with dementia. Explore participant characteristics, examine the content, structure and theoretical basis of the support groups and consider negative outcomes and feedback.	Systematic review
Ward <i>et al.</i> (2012)	Exploring friendships of people with dementia that are in the early stages of the condition and the benefits of looking beyond the family.	Case studies

### 3.9.1 Overarching concepts

Seven overarching themes were formulated from the included papers; social connectedness, psychological connections, memory, facilitator, environment, support and information and selfhood, see figure 3.4 (below).



**Figure 3.4: Overarching concepts formulated from review**

These overarching concepts were developed by looking at the words and terms used in the papers with corresponding extracted data from the articles (See table 3.2).

**Table 3.2: Concepts linked to terms used in articles and corresponding data**

Concepts	Terms	Articles	Examples of supporting evidence from included articles (author and participant)
Social connectedness	<p>Socialising</p> <p>New social network</p> <p>Benefits not always clear</p> <p>Group support</p> <p>Health outcomes</p> <p>An anchor</p> <p>Isolation</p> <p>Stress and burden</p> <p>Social contact</p> <p>Homogeneity of group</p> <p>Combined support</p> <p>Group characteristics</p> <p>Groups within groups</p> <p>Lack of connection</p> <p>Problem solving</p> <p>Not being able to speak out</p> <p>Tolerating others</p>	<p>Bender &amp; Constance (2005)</p> <p>Capus (2005)</p> <p>Earle (2006)</p> <p>Halley <i>et al.</i> (2005)</p> <p>Hedman <i>et al.</i> (2014)</p> <p>Kjallman <i>et al.</i> (2014)</p> <p>Laakkonen <i>et al.</i> (2016)</p> <p>Minnema (2008)</p> <p>Ward <i>et al.</i> (2012)</p> <p>Tarrant <i>et al.</i> (2016)</p> <p>Offord <i>et al.</i> (2006)</p>	<p>'Participants described a sense of appalling loneliness, of 'not going at all', of feeling 'horribly stuck on my own' and 'completely alone'...'the companionship and support received within the support group was contrasted by these participants with the social isolation experienced outside it'. (Mason <i>et al.</i>, 2005, author and participant comments, p.102)</p> <p>'When you are left at home, it is lonely and coming here you have friends and you meet people you haven't met before'. (Semple <i>et al.</i>, 2015, participant comment, p13)</p> <p>'The leaders noted that attending the group was the only time that one member went out of the house. For a number, it was their only regular social event, indicating a huge increase in socialisation'. 'Clients saw this socialising as a successful accomplishment (which it was - all interactions are work) and increases in self-esteem were noted on home visits'. (Bender &amp; Constance, 2005, author comment, p.30)</p> <p>'For families who find themselves becoming increasingly socially isolated, the café may provide a secure base and provide a new and different network' (Capus, 2005, author comment, p.591)</p> <p>'Before the memory café started there seemed to be nothing specifically aimed at people in our situation, and as a carer it has given me the chance to meet and share with other carers. It has given my husband a safe environment where he can enjoy the company of others' (Minnema, 2008, participant comment, p.21)</p>

		<p>Semple <i>et al.</i> (2015)</p> <p>Synder <i>et al.</i> (2006)</p>	<p>'It would be nice to talk and get to know others more'. 'I think we are supposed to talk more with each other and take part in each other's experiences, but that hasn't really happened. I guess we are just shy'. (Kjallman <i>et al.</i> 2013, author comment, p.295 )</p> <p>'The positive attitude. It's uplifting. The reason for being here is not funny, but everyone is laughing' (Synder <i>et al.</i>, 2006, participant comment, p.17 )</p>
Psychological connections	<p>Friendships</p> <p>Affective empathy</p> <p>Normalising emotions</p> <p>Hope</p> <p>Well-being</p> <p>Loneliness</p> <p>Shared diagnosis</p> <p>Similar experiences</p> <p>Discussing difficult topics</p> <p>Not feeling alone</p> <p>Shared identity</p> <p>Trust</p> <p>Positive communication</p> <p>In the same boat</p> <p>Belonging/acceptance</p> <p>Humour</p> <p>Reciprocity</p>	<p>Bender &amp; Constance (2005)</p> <p>Capus (2005)</p> <p>Earle (2006)</p> <p>Halley <i>et al.</i> (2005)</p> <p>Hedman <i>et al.</i> (2014)</p> <p>Kjallman <i>et al.</i> (2014)</p> <p>Mason <i>et al.</i> (2005)</p> <p>Ward <i>et al.</i> (2012)</p> <p>Tarrant <i>et al.</i> (2016)</p> <p>Offord <i>et al.</i> (2006)</p>	<p>'The results from the group discussions and from our experience in setting up and organising the café suggest that it provides an important venue in which, through meeting with others in a similar position, carers may be helped to normalise the emotions that the experience of caring has evoked in them and the changes in relationships that have occurred since the onset of dementia. People with dementia may be helped to normalise their changes in functioning and supported in coming to terms with living with dementia'. (Capus, 2005, author comment, p.591)</p> <p>'You can get isolated on your own and think you are the only one...And you also learn some people have different ways of coping with things' (Semple <i>et al.</i>, 2015, participant comment, p.13).</p> <p>'My wellbeing has certainly improved...I love coming to the group...I love the prevailing sense of humour which is always present'. (Semple <i>et al.</i>, 2015, participant comment, p.13).</p> <p>'...the relief of not being alone in one's condition...These psychological gains were probably greater than the educational gain'. (Bender &amp; Constance, 2005, author comment, p.30).</p> <p>'The others in the group have the same problems so it's easier'. 'It is good to just talk'. 'just listening helps a lot'. (Kjallman <i>et al.</i>, 2013, participant comment, p.294)</p>

		<p>Semple <i>et al.</i> (2015)  Synder <i>et al.</i> (2006)  Kritz (2016)</p>	<p>‘For those participants who found it hard to communicate due to their language or memory difficulties, a vital feature of this anchor was the presence of an environment where all communication was accepted and facilitated’ – ‘You can talk without making yourself look silly’ (Mason <i>et al.</i>, 2005, author and participant comment, p.98).</p>
Facilitator	<p>Paid workers  Volunteers  Professionally led  Trained facilitators  Facilitators leading the group</p>	<p>Halley <i>et al.</i> (2005)  Hedman <i>et al.</i> (2014)  Kjallman <i>et al.</i> (2014)  Mason <i>et al.</i> (2005)  Ward <i>et al.</i> (2012)  Offord <i>et al.</i> (2006)  Semple <i>et al.</i> (2015)  Kritz (2016)</p>	<p>‘Age Concern Wandsworth recruits and trains the volunteers. This includes specific training about dementia, as many of the volunteers have not had any personal or professional experience of dementia before joining the project’. (Halley <i>et al.</i>, 2005, author comment, p.593).  ‘In the present study there were no signs of the facilitator hampering participants’ activity in the group. With most participants being in a moderate stage of AD, the presence of the facilitator was important in holding the conversation together’. (Hedman <i>et al.</i>, 2014, author comment, p.18).  "The facilitators spoke of realising the need to 'stand back' from the groups, to support rather than lead and the anxieties and uncertainties attached to the co-productive way of working’ (Ward <i>et al.</i>, 2012, author comment, p.297)</p>
Memory	<p>Underestimating memory  Ability to contribute  Emotional memory</p>	<p>Bender &amp; Constance (2005)</p>	<p>'In considering how relationships in the group developed in this way, we concluded that participants were able to form 'implicit' memories of each other and the group. This would mean that participants were able to build on their relationships over the weeks, despite their impaired ability to</p>

	<p>Implicit memory</p> <p>Memory stimulation</p> <p>Reducing anxiety</p> <p>Reminiscence</p>	<p>Kjallman <i>et al.</i> (2014)</p> <p>Mason <i>et al.</i> (2005)</p> <p>Offord <i>et al.</i> (2006)</p> <p>Semple <i>et al.</i> (2015)</p>	<p>recall details such as others' names or specific conversations'. (Offord <i>et al.</i>, 2006, author comment, p.190)</p> <p>'The combination of decreased anxiety and high relevance of an event seemed to aid memory'. (Bender &amp; Constance, 2005, author comment, p.30).</p> <p>'The contacts that are made between people with similar interests, lead to discussion and mental stimulation. These are the most important factors, in delaying the onset, or slowing the progress, of dementia and, which, in any case, certainly increase the person's well-being'. (Ward <i>et al.</i>, 2012, participant comment, p.295)</p>
Environment	<p>Safe environment</p> <p>Locally based</p> <p>Non-stigmatising</p> <p>Non-clinical</p> <p>Non-didactic</p> <p>Unstructured</p> <p>Open</p> <p>Café style</p> <p>No fixed model</p> <p>Confidential</p> <p>Informal</p> <p>Room layout</p> <p>Activities</p> <p>Group size</p> <p>Ownership</p>	<p>Bender &amp; Constance (2005)</p> <p>Capus (2005)</p> <p>Earle (2006)</p> <p>Halley <i>et al.</i> (2005)</p> <p>Hedman <i>et al.</i> (2014)</p> <p>Mason <i>et al.</i> (2005)</p> <p>Minnema (2008)</p> <p>Ward <i>et al.</i> (2012)</p>	<p>'Our findings from the evaluation underlined the value of local and accessible opportunities for sociality and support in a context where many participants had lost their driving license as a result of their diagnosis and found travelling over distance by public transport challenging'. (Ward <i>et al.</i>, 2012, author comment, p.299)</p> <p>'The café brings together people with dementia , their carers , and concerned professionals in an informal environment where they can socialise together without embarrassment, share information about the condition, and provide support to each other'. (Capus, 2005, author comment, p.589)</p> <p>'Many carers choose not to attend carers' groups, even if there are no practical difficulties such as arranging transport or providing replacement care. The café offers a way of providing support for carers without the anxiety of wondering what is happening to the person for whom they care'. (Halley <i>et al.</i>, 2005, author comment, p.594)</p>

		Tarrant <i>et al.</i> (2016) Semple <i>et al.</i> (2015) Kritz (2017)	'Finally, the café experience, with its emphasis on providing a non-clinical, non-didactic, non-pathologizing, non-stressful and unstructured ambience offers a unique environment for those involved in dementia care and those who are living with dementia to meet as equals and share understanding and insights, co-working towards solutions'. (Capus, 2005 author comment, p.591)
Information and support	Group type Learning Solving problems Psychoeducation Different types Sharing information Knowledge	Bender and Constance (2005) Cuijpers <i>et al.</i> (1996) Earle (2006) Hedman <i>et al.</i> (2014) Laakonen <i>et al.</i> (2016) Mason <i>et al.</i> (2005) Toms <i>et al.</i> (2015) Synder <i>et al.</i> (2006)	'Several of the participants referred to attending the group as an opportunity to learn more about dementia and strategies for coping, where you can 'ask questions' and 'get to understand what is happening'. Members were also able to offer their experience and understanding to help others.' (Mason <i>et al.</i> , 2005, participant and author comments, p. 98)  'Twenty percent of participants stated that verbal sharing or learning was the best part of the group. One participant replied, "When we can share things and then that way we might be able to help each other'. (Synder <i>et al.</i> , 2006, participant comment, p.17
Selfhood	Positioning Active role Personhood Sense of self	Mason <i>et al.</i> (2005) Hedman <i>et al.</i> (2014)	'Predominantly, participants affirmed each other's first-order positioning, and thus strengthened their sense of self. This was done by showing each other interest, listening, encouraging, asking questions, and

	Affirming self	Offord <i>et al.</i> (2006) Semple <i>et al.</i> (2015)	expressing agreement and appreciation'. (Hedman <i>et al.</i> , 2014 author comment, p. 17). 'The groups observed here can also be seen as a facilitative context for members' stories about the past and seemingly inconsequential 'chat' about the present, thus enabling the talk through which members' social selves are established and held' (Mason <i>et al</i> , 2005, author comment, p.106 )
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### **3.9.2 Chains of Inference**

The next stage in theory development was to consider how these concepts may link to form explanations of how and why memory cafés may be working. From the seven overarching concepts, five chains of inference were developed. 'A chain of inference is a connection that can be made across articles based on the themes identified' (Rycroft-Malone *et al.*, 2015, p.7), to formulate an explanatory picture of a programme (Rycroft-Malone *et al.*, 2015). To construct the chains of inference the data for each concept were examined to see how they may link to develop a programme theory. Notes were made on the excel spreadsheets, and lines drawn between the extracts where there was a possible connection. The data selected were based on credibility and trustworthiness; their association to the focus of the realist review and their relevance to generating theory. The next section outlines the five chains of inference, showing which concepts have formed that chain. Each chain of inference is discussed with extracted data from both author and participant. Realist reviews utilise significant portions of extracted data to evidence the inferences made (Pawson, 2006a).

#### **Chain of Inference 1**

Facilitator approach – social connectedness – psychological connections

This chain of inference links the concepts of facilitator, social connectedness and psychological connections. It looks at the role of the facilitator and how it might affect how the café is structured, and how guests may interact with one

another and perceive their roles. Eight studies (Halley *et al.*, 2005; Hedman *et al.*, 2014; Kjallman Alm, Hellzen & Norbergh, 2014; Kritz, 2016; Mason, Clare & Pistrang, 2005; Offord *et al.*, 2006; Semple, Willis & de Waal, 2015; Ward *et al.*, 2012) included the role of facilitators, with some commentary around the use of professional or lay facilitators. The evidence is limited and of a qualitative nature, from small evaluations and reflective reports, with only one study by Halley *et al.* (2005) specifically related to memory cafés. This limited evidence is highlighted by Ward *et al.* (2012):

*What is distinctive about the limited but emerging literature on peer support and dementia is that the role of the practitioner appears to have been whitewashed from the picture, with very little consideration given to the particular skills that facilitating such groups may require (p.300).*

The characteristics of the volunteers have the potential to shape the experiences of attendees (Semple, Willis & de Waal, 2015) and their interactions (Mason, Clare & Pistrang, 2005). The facilitators (volunteers) can also bring a group together and foster a sense of cohesiveness:

*Facilitators appeared to function for these participants as an anchor in the group, able to facilitate coherence both of speech and experience and offer a sense of stability against a background of threat and change (Mason, Clare & Pistrang, 2005, p.107).*

However, this sense of being an anchor may lead to them being viewed as in charge with the risk of attendees adopting a passive patient role:

*In some of the groups we observed there were still indicators of a more traditional helper model, with the facilitators making and serving tea, taking decisions over the timings of the group and the introduction of activities and assessing people to discern their suitability for the group (Ward *et al.*, 2012, p.298).*

A memory café that adopts a helper approach, where attendees are viewed as 'looked after' and the structure set out by the volunteers, may therefore inhibit the interactions that occur between attendees. Furthermore, such an approach may lead to attendees seeing the facilitators as being in charge, 'the people running it' or 'who might 'stop it', (Mason, Clare & Pistrang, 2005, p.100-101). To ensure the people who attend are treated as equals (Capus, 2005), facilitators need to 'stand back' (Ward *et al.*, 2012), to 'support rather than lead' (Ward *et al.*, 2012).

Regardless of whether there are professional or lay facilitators, there was consensus on the need for dementia specific training. Volunteers may not have had personal or professional experience of working with people with dementia (Halley *et al.*, 2005) or conversely have worked in dementia care or have a loved one that attended a memory café (Minnema, 2008). Knowledge on how to support people with dementia is important as volunteers are needed to coordinate interaction and conversation between group members (Hedman *et al.*, 2014). The role of a group champion was discussed by Tarrant *et al.* (2016), where someone with personal experience of the condition acts as a coordinator, welcoming new members. Where such a role is fostered, this may enable a shift from seeing the volunteers as being in charge to a more equitable approach to ownership of the memory cafés. Facilitators and volunteers of memory cafés potentially have the power to shape how it is structured and delivered and the experiences and outcomes of the people with dementia and their carers.

## Chain of Inference 2

Social connectedness – psychological connections – selfhood

The second chain of inference links the concepts of social connectedness, psychological connections and selfhood. It captures how being in a group, provides an opportunity for people to share experiences and stories and how this may strengthen a person's sense of self. In the initial mapping exercise, how memory cafés may enable those that attend to express their sense of self was not considered. Four papers (Hedman *et al.*, 2014; Kjallman Alm, Hellzen & Norbergh, 2014; Mason, Clare & Pistrang, 2005; Offord *et al.*, 2006) highlighted the importance of expressing a sense of self and affirmation of self in qualitative analysis of group discussions for people with dementia. A fifth paper, focusing on a social return on investment (Semple, Willis & de Waal, 2015) refers to the term personhood and how it can be promoted by how attendees are welcomed and treated in the group. None of the papers relating to this chain of inference are specifically about memory cafés but instead focus on other group contexts for people with dementia and their carers. Inferences have been drawn, however, as these might provide some insights into what happens at memory cafés. Memory cafés bring people with dementia together and can provide a platform in which they can share experiences and stories. This sharing of information can be more than:

*...a mere exchange by providing a possibility for an individual to experience his or her own awareness of self when sharing experiences (Kjallman Alm, Hellzen & Norbergh, 2014, p.295).*

This sense of self can be strengthened by the responses of others, which can range from non-verbal interaction (nods and smiles) to verbal interaction

(encouragement, expressing agreement and reflections) (Hedman *et al.*, 2014; Offord *et al.*, 2006). As a result, the relationships between members are reciprocal:

*If there's any sort of problem I've got or might get - I'm quite sure there's somebody there who would want to help me if I told them. I get that feeling. So that's a comfort in itself' (Mason, Clare & Pistrang, 2005, p.102).*

Bringing people with dementia together in a group setting, affirmative interactions can be provided which strengthen each other's sense of self (Hedman *et al.*, 2014). Attending a group can also give a person focus, something to look forward to, and get ready for (Semple, Willis & de Waal, 2015).

Another study, a randomised control trial on self-management groups for people with dementia and their carers (Laakkonen *et al.*, 2016), concluded that the friendships between participants was probably the main factor contributing to self-management skills. The authors also state that a focus on what a person can still do can enhance their sense of self. This focus on still intact abilities and skills was also highlighted by (Offord *et al.*, 2006, p.185) but additionally they also found that participants frequently used 'self-deprecating' language and 'joked about themselves'. It is possible that an environment such as a memory café can evoke humour about the difficulties people experience with others that understand.

Reminiscence can provide a means in which people with dementia can converse with more ease, due to the nature of how the disease process affects short and long-term memory.

*I can tell you past things, but I can't tell you what day it is (Mason, Clare & Pistrang, 2005, p.100).*

Therefore, if conversations and activities at memory cafés utilise reminiscence, this may help group cohesiveness and individuals' selfhood. Reminiscence can provide a means by which people with dementia are able to converse with more 'confidence' (Mason, Clare & Pistrang, 2005).

This sense of understanding is highlighted by (Kritz, 2016), who found that a woman with dementia could hold a doll and this behaviour is accepted by others. However, people with dementia are not always understanding of the behaviour of others with dementia:

*I'm not too old to suffer - you know when someone is talking nonsense...they repeat the same thing three times...it's irritating (Mason, Clare & Pistrang, 2005, p.99).*

Other factors may also impact group dynamics and cohesiveness. For example, other participants may also find it difficult to join in and talk (Kjallman Alm, Hellzen & Norbergh, 2014). Also, the ratio of male to female participants, may add another difficulty for individuals feeling like they belong or not. Ward *et al.* (2012) discussed how a mainly male group had females join but then leave due to feeling that they didn't fit in. Homogeneity of group members may aid with group cohesiveness (Bender & Constance, 2005; Earle, 2006). Memory cafés are generally a mix of males and females, generally of varying ages (Minnema, 2008) and support individuals with varying degrees of cognitive decline. Providing a service that meets the needs of a wide range of individuals may be challenging to memory café volunteers.

### Chain of Inference 3

Environment – social connectedness – psychological connections

This chain of inference links the concepts of environment, social connectedness and psychological connections. As memory cafés are run in various locations such as community halls, church halls and day centres; the environment in which they are held, therefore, has to be adapted to run a memory café.

Environment considers the physical space such as access, set up of room, activities and refreshments. Seven studies Bender and Constance (2005); Capus (2005); Halley *et al.* (2005); Kritz (2016); Minnema (2008); Semple, Willis and de Waal (2015); Tarrant *et al.* (2016) discussed environmental factors when running groups for people with dementia. Studies by these authors Bender and Constance (2005); Capus (2005); Halley *et al.* (2005); Kritz (2016); Minnema (2008) were all in relation to memory cafés. They highlight the need for memory cafés to provide a safe-environment (Minnema, 2008), be held in a non-stigmatising setting (Bender & Constance, 2005), and not linked to statutory organisations (Minnema, 2008) or institutional settings (Kritz, 2016) and be a place where people can meet as equals (Capus, 2005). The memory café that Minnema (2008) discusses was held in a building that provides social activities for people aged 55 and over. They found that people with dementia and their carers did not want the café held in a local day centre, due to the stigma they felt was associated with it. The café was held on a Saturday, at the request of carers, due to the lack of services available at the weekend. They also changed the name from dementia café to memory café, as they thought it was a more inclusive term. This wish to not be associated with statutory services may be a

contributing factor to the growth of memory cafés. People with dementia and their carers can attend without the need to complete formalised assessments and measures:

*I think it's almost an attitude because the people who come here are not coming here to be serviced, they come here because they add something (Semple, Willis & de Waal, 2015, p.14).*

There is also a need for locally based services, especially if people with dementia are no longer able to drive or have difficulties using public transport (Kritz, 2016). Rural communities in particular are geographically dispersed and just getting from one village to the next can be problematic. Memory cafés can be facilitated in small villages if there is a suitable location and sufficient volunteers to facilitate them. They may also be viewed as more acceptable than attending a day centre (Halley *et al.*, 2005). A common feature with all memory, dementia and Alzheimer cafés is creating a 'café' style environment. Such as table clothes on the tables, flowers to decorate the room, music and the provision of refreshments and food:

*The creation of a café-style environment is felt to be crucial to the success of the project. The café is held in a modern church hall the appearance of which is transformed by the addition of flowers on the table, table cloths, and pictures on the walls painted especially for the café by local school children. As the hall is used by other organisations, these have to be set out and taken away each month'... 'All the food is 'finger food', which is more manageable and helps to create a more informal atmosphere (Halley *et al.*, 2005, p.592-593).*

Cafés are a prominent feature in most Western countries, providing an environment where people can meet, chat and enjoy food and a drink. In many ways memory cafés are providing an environment that mimics this, particularly if a person with dementia and their carer no longer feel they can visit public cafés:

*The café style atmosphere also means that people with dementia can walk around freely'. This is valued by people caring for someone who is unable to sit down in a conventional restaurant or café for any length of time (Halley et al., 2005, p.593).*

Carers can talk freely whilst their loved one is occupied in a safe environment (Minnema, 2008). Furthermore, it provides a normalised environment:

*The common element seems to be creating a space where people can connect socially and experience a 'normal' get-together with friends (Kritz, 2016, p.8).*

The ability to conduct everyday conversation, not just around specific problems (Halley et al., 2005), can provide a break from routine. Normal aspects of social interaction such as humour (Mason, Clare & Pistrang, 2005) teasing, joking, wanting to know more, and even flirting and flattery (Offord et al., 2006) are important, especially when people may no longer be able to socialise with previous social groups (Ward et al., 2012).

Memory cafés provide an on-going service, offering a wide range of activities including reminiscence, music, yoga and visiting dogs (Minnema, 2008). They may also personalise activities such as singing happy birthday to guests or having a welcome song (Kritz, 2016). Singing is gaining increasing attention for people with dementia and other health conditions (Tarrant et al., 2016). Whilst not specifically about memory cafés, Semple, Willis and de Waal (2015) comment that by providing a service for both people with dementia and their carers, people with dementia can be engaged in an activity, giving time for carers to talk with other carers. The complexity of providing a service for two separate but inter-related groups is that the focus may be more on providing activities or respite for carers (Halley et al., 2005). Cafés might evolve to meet

the needs of the local area and personal preferences, so may be more focused on carers, or on people with dementia. As such identifying and recognising the benefits for people with dementia may not be immediately clear (Capus, 2005).

#### **Chain of Inference 4**

Social connectedness – information and support – psychological connections

The fourth chain of inference links the concepts of social connectedness, information and support and psychological connections. It includes the different types of support that a group setting may provide and how this may contribute to the formation of relationships/friendships between members. A common thread throughout the majority of the included studies, is the importance of forming social connections with others, through the sharing of information and support (Bender & Constance, 2005; Capus, 2005; Earle, 2006; Halley *et al.*, 2005; Hedman *et al.*, 2014; Kjallman Alm, Hellzen & Norbergh, 2014; Laakkonen *et al.*, 2016; Mason, Clare & Pistrang, 2005; Minnema, 2008; Offord *et al.*, 2006; Semple, Willis & de Waal, 2015; Snyder, Jenkins & Joosten, 2007; Tarrant *et al.*, 2016; Ward *et al.*, 2012). Cuijpers, Hosman and Munnichs (1996) detail four different types of support that can occur in support group settings, informative (such as receiving information about dementia), counselling (looking at how to handle problems), normative (confirmation of choices and actions), and emotional (talking about problems and emotions). Interestingly whilst memory cafés are included in Toms *et al.* (2015) a systematic review on support groups for people with dementia, Kritz (2016) states that they are not considered a formal support groups. This lack of clarity on their role and

function of memory cafés, complicates understandings of their purpose and how they benefit people with dementia and their carers.

Memory cafés provide an opportunity where people with dementia and carers can meet others that are in a similar situation (Capus, 2005; Kritz, 2016), which can help normalise their situation (Capus, 2005). This shared health condition can be unifying in bring people together and helping psychological connections (Tarrant *et al.*, 2016). Relationships may form due in part to shared experiences not only in relation to dementia, but also to life experiences and hobbies and interests (Ward *et al.*, 2012) and feeling understood by 'likewise kin' (Laakkonen *et al.*, 2016). These regular meetings with others can develop into deeper connections, such as a collective relationship (Mason, Clare & Pistrang, 2005) or even friendships with particular individuals or a group (Offord *et al.*, 2006):

*The café has also led to the establishment of many supportive friendships among people with dementia and their carers. Most importantly they no longer feel on their own (Halley et al., 2005, p.594).*

Ward *et al.* (2012) refer to this forming of friendships as facilitated, as people are brought together due to a shared diagnosis and the groups are supported by a facilitator. This sharing of experiences can help bond people together (Ward *et al.*, 2012) and create a sense that 'members' are a team (Earle, 2006). For people with dementia and their carers that attend memory cafés, these friendships may be ongoing (Minnema, 2008) and continue outside of the café (Bender & Constance, 2005; Earle, 2006), creating a new social network (Capus, 2005) when others might have been lost (Ward *et al.*, 2012).

Carers are able to learn from others about varying issues, from the caring role, to services available, legal issues and long-term planning (Earle, 2006), and

therefore contribute to self-management skills (Laakkonen *et al.*, 2016) and combat negative feelings (Halley *et al.*, 2005). The memory café can act as an access point to find out about what is available to people with dementia and their carers through resources or speaking with a health professional that may attend. Combining psychosocial support and education is likely to be more effective (Toms *et al.*, 2015), with friendship/socialisation and education cited as the key factors for attending a support group (Snyder, Jenkins & Joosten, 2007). Due to the relaxed, informal style, memory cafés may also act as gateway to using other services:

*Eventually, as they build up a relationship of trust, they become more willing to accept another form of help. In this way, the café can act as an entry point into other services (Halley et al., 2005, p.594).*

The sharing of information and support can extend beyond verbal exchanges to practical support. Semple, Willis and de Waal (2015) highlight how people with dementia can provide practical support to each other, which they may not be able to do in other settings:

*I watch some people with dementia helping someone else, being fed, making sure they have a drink...and that's just wonderful because in any other setting they might have thought 'oh I can't do that...' (Semple, Willis & de Waal, 2015, p.14).*

This can be empowering for people with dementia who may feel they have limited opportunities to be of help to others.

## **Chain of Inference 5**

Environment – psychological connections - memory

The final chain links the concepts of environment, psychological connections and memory and discusses how attending groups may have an impact on memory, even when this might not necessarily be the focus of the group. Studies by Bender and Constance (2005); Kjallman Alm, Hellzen and Norbergh (2014); Mason, Clare and Pistrang (2005); Offord *et al.* (2006); Semple, Willis and de Waal (2015) highlight the varying ways groups can play a part in memory: from peoples' memory being underestimated (Bender & Constance, 2005), to forming implicit memory of other members (Offord *et al.*, 2006). Also, reported (Semple, Willis & de Waal, 2015) and measured (Laakkonen *et al.*, 2016) improvements in cognitive functioning and having an emotional memory of attending (Mason, Clare & Pistrang, 2005; Semple, Willis & de Waal, 2015).

People with dementia, despite having difficulties in remembering names or specific events, can still form 'implicit' memories of one another over time and the group and give their thoughts about the group (Offord *et al.*, 2006). As memory cafés are ongoing, this enables people to see the same people at regular intervals. Often memory abilities may be underestimated (Bender & Constance, 2005) and working as a group, focusing on positive events and reducing anxiety are felt to be beneficial in aiding memory (Bender & Constance, 2005). Findings from a randomised controlled trial by Laakkonen *et al.*, (2016) suggest that the socialising in groups may have contributed to an improvement in cognitive functioning for people with dementia. Whilst this was the only included paper that used outcome measures, another paper highlighted how carers felt taking part in memory stimulating activities, had been beneficial for cognition (Semple, Willis & de Waal, 2015):

*What is interesting is that she will talk more in the car on the way home. But not on the way in...I think she is just generally more relaxed, a bit happier, got back into the routine of making conversations (Semple, Willis & de Waal, 2015, p.13).*

Individuals may also seek out a group that they feel will help with memory stimulation (Snyder, Jenkins & Joosten, 2007).

An enabling approach, where the focus is on what a person can still do and contribute to the group, may improve quality of life outcome measures (Laakkonen *et al.*, 2016):

*Elements supporting self-management skills such as encouraging participants control over implementation of the group program, enhancing their empowerment, feelings of self-efficacy, and peer support may be the dimensions that improved their HRQoL (Laakkonen *et al.*, 2016, p.795).*

Just by the nature of contact with others, conversation and discussion may contribute to mental stimulation (Ward *et al.*, 2012). These positive experiences of attending a group may have a wider reach through a person with dementia retaining an emotional memory of the session:

*'...by the time you get out you don't know what was said, but you're calmer' (Mason, Clare & Pistrang, 2005, p.103).*

This suggests that people with dementia don't need to recall specific details to gain a benefit from attending. Memory cafés generally provide a wide range of activities that are meaningful to people that attend and, whilst not having specific outcome measures, they may help emotional well-being and memory.

### **3.9.3 Programme theories**

The final step operationalised the five chains of inference into five programme theories. In line with a realist approach the programme theories are presented as context-mechanism-outcome configurations (Pawson & Tilley, 1997). These are detailed in Table 3.3. The first column shows the chain of inference and the second and third column detail context – mechanism – outcome statements.

The programme theories are read across the table.

**Table 3.3: Five programme theories developed from five chains of inference**

Chain of inference	Context	Mechanism and outcome
1.Facilitator – social connectedness – psychological connections	If volunteers at memory cafés adopt a co-productive approach, encouraging people with dementia and their carers to shape how sessions are facilitated	Then this fosters equitable relationships (m) and a sense of ownership (m) leading to increased guest to guest interactions (o) as volunteers are not viewed as in charge (o)
2.Social connectedness – psychological connections – selfhood	If people with dementia and their carers are able to share experiences with others in a similar situation	Then this creates reciprocal relationships between guests (m) through a shared understanding (m) thus strengthening individuals sense of self (o) by being able to help and value each other (o)
3.Environment – social connectedness – psychological connections	If cafés provide a range of activities in a safe, non-statutory linked setting	Then this creates a relaxed environment (m) and a sense of normalcy (m) thus facilitating reconnection between people with dementia and their carers (o) as the focus is on a break from their usual routine (o)
4.Social connectedness – information and support – psychological connections	If information and support is shared between volunteers and guests and between guests	Then this can foster a sense of belonging (m) and not feeling alone (m) which leads to the facilitating of friendships between guests (o) that might extend outside the memory café (o)
5.Environment – psychological connections – memory	If people with dementia are mentally and/or physically stimulated through activities at a memory café	Then this creates meaningful experiences (m) that lead to positive feelings (m) that are stored as emotional memories after the café session has finished (o) or perceived benefits to cognition from the person with dementia or their carers (o)

### **3.9.4 Summary of programme theories**

This realist review of 17 papers identified seven overarching concepts; psychological connections, social connectedness, facilitator, environment, information and support, memory and selfhood. Chains of inference were developed showing linkages of these concepts across the papers. These five chains of inference were then operationalised into programme theories, providing plausible explanations for how and why memory cafés may be working. Programme theory one looks at how the approach of the facilitator/volunteers who run the café may affect how the café is structured and delivered. If the volunteers adopt a partnership approach to running the memory café, where people with dementia and their carers feel equal, interactions between members may increase, due to them feeling involved and having ownership of the café. Conversely a hierarchical approach may lead to members viewing the volunteers as in charge, the ones that make the decisions about what will happen, with interactions filtered through the facilitators. Programme theory two highlights how bringing people with dementia and their carers together to share stories and experiences, may result in the development of reciprocal relationships through a shared understanding, helping each other and strengthening a person's sense of self. Programme theory three considers how the memory café environment that is relaxed and non-institutional can create a sense of normalcy, as members are not attending to be formally assessed, where the focus is on creating connections between the person with dementia and their carers and providing a break from routine. Programme theory four shows how memory cafés can enable the sharing of information and support, where members feel like they belong and are not on their own,

facilitating friendships between members that might continue outside the café. Finally, programme five looked at how providing meaningful experiences can create positive feelings that is stored as emotional memory or perceived benefits in cognition.

### **3.10 Discussion**

This review adds to the evidence base related to groups provided for people with dementia and their carers. Current policy, including the National Dementia Strategy (Department of Health, 2009) and Prime Minister's Challenge on Dementia (Department of Health, 2015), outlines the need for access to post-diagnostic services, information and peer support. This realist review finds that memory cafés can contribute to these aims, for not only people with dementia but their carers too, however, certain contexts may affect how users experience the café and the benefits they gain from attending.

The first programme theory considers the role of the facilitator. Memory cafés are typically run by volunteers and there is little published research looking at their role in dementia services. The use of professional or lay/peer facilitation can foster different group structures and dynamics (Clare, Rowlands & Quin, 2008). A move towards people with dementia being recognised as active citizens, rather than passive receivers of care and services (Bartlett & O'Connor, 2010), has led to initiatives such as The Dementia Engagement and Empowerment Project (DEEP) (DEEP, 2015), which seeks to involve people with dementia in creating dementia friendly communities. Services may adopt a person-centred or citizenship approach (Kelly & Innes, 2014), however, from

this review it is unclear whether memory cafés align to these approaches or they vary.

The second programme theory explores how meeting with others in a similar situation, to share experiences and stories can strengthen an individual's sense of self. Research suggests that positive social interactions and supportive relationships can reduce the potentially negative experiences of dementia (Macrae, 2011) and that the social benefits of being in a group contribute more to enhancing quality of life (Haslam *et al.*, 2010; Spector, Gardner & Orrell, 2011) than a specific individual activity or therapy. Memory cafés can provide an opportunity for individuals to talk without the focus of sessions being about dementia. The importance of having the opportunity to talk about everyday things was highlighted by Mason, Clare and Pistrang (2005).

The third programme theory looked at how memory cafés create an environment that provides a break for people with dementia and their carers, from their usual routine. A recent publication looking specifically at memory cafés, explored the experiences of 11 carers, attending five different memory cafés (Greenwood *et al.*, 2017). They identified four key themes: being able to switch off from being a carer, normalising the experience of being a carer, peer support, and developing networks and reducing isolation. Memory cafés can provide a safe, relaxed environment where people can be themselves giving the opportunity for carers to have a break from caring, whilst also engaging them and the person they support in a range of activities (Greenwood *et al.*, 2017).

The fourth programme theory explored the different types of support that may be available at a memory café, from education about living with dementia,

signposting about other services to providing emotional support. Social isolation can occur if people feel they are no longer able to partake in previous activities. Memory cafés can provide an opportunity to develop new social networks and be a source of information (Greenwood *et al.*, 2017). A review on psychosocial intervention for carers (Dickinson *et al.*, 2017) concluded that interventions should be multi-component, including an educational and therapeutic component and delivered in real-world settings. However, two other reviews (one of which was included in this review) that explored psychosocial interventions for people with dementia, suggested that group support should provide psycho-education components (Leung, Orrell & Orgeta, 2015; Toms *et al.*, 2015) but concluded that, based on the current evidence it is not possible to determine how beneficial they are in promoting psychosocial outcomes for people with dementia.

The fifth programme theory discusses how, for people with dementia, attending memory cafés, engaging in cognitive based activities may help memory and that people may retain an emotional memory of attending, even though they have forgotten specific details about the session. There is now good evidence that group-based cognitive stimulation can improve cognitive functions, social interaction and quality of life (McDermott *et al.*, 2018). This review did not determine in detail the types of activities memory cafés provide but, by inference, it is possible that they may offer activities that provide cognitive stimulation. Another benefit of attending a memory café is the recalling the emotional aspects of an experience rather than specific facts, due to emotional memories being controlled by the amygdala area of the brain which is less affected by the dementia disease process (Alzheimer's Society, 2015).

Therefore, people with dementia that attend memory cafés may retain an emotional memory of attending, even though they are unable to recall specific information about the session.

Kitwood's ground breaking work, in 'Dementia Reconsidered' (Kitwood, 1997), outlined the main psychological needs for people with dementia as love, comfort, identity, occupation, inclusion and attachment. The importance of psychosocial support for people with dementia and their carers is widely recognised in the literature (McDermott *et al.*, 2018). The programme theories generated from this realist review suggest that memory cafés can provide psychosocial-educational support for both people living with dementia and their carers.

### **3.10.1 Strengths of this review**

This realist review provides a timely contribution to evidencing the growing phenomenon of memory cafés to help explain how and why they may be working. Utilising a realist approach enabled the consideration of relatable programmes, and fragments of information from varied sources. Using the initial folk theories as the unit of analysis, rather than the intervention, has enabled the exploration and development of five testable programme theories. They suggest that memory cafés are multi-functional including; providing a space where people can meet and talk to others in a similar situation, engage in activities, receive and provide information and support and have a break from their usual routine. The programme theories required further testing, and this was undertaken through, a realist evaluation of memory cafés in Cornwall. Understanding the theoretical basis of an intervention is important, both for evaluation of that intervention and for future developments (Medical Research

Council, 2006). This review clearly highlighted the need for further research in this area of support for people with dementia and their carers.

### **3.10.2 Limitations of this review**

A number of the papers included were reflective accounts, and these were included with caution. Whilst having methodological limitations, they provided insights on contexts, mechanisms and outcomes that were lacking from more methodologically rigorous papers and thus were considered relevant to the review. The lack of grey literature available on memory cafés was also surprising. There were subjective reports of what people gained from them but little to explain the how and why. Furthermore, there were limited research studies that focus on both people with dementia and their carers, and only one found (Semple, Willis & de Waal, 2015) that considered the role of volunteers as well. Having multiple groups within a group setting is complex and the perceptions and experiences of each group may be different. It is likely that there are multiple interlinking chains of context-mechanism-outcome configurations that are beyond the scope of this review due to resource and time constraints. There was limited information on mid-range theories with only three papers outlined a theoretical framework for their paper; Cuijpers, Hosman and Munnichs (1996) Stress and coping theory (Lazarus, 1981), Hedman *et al.* (2014) Harré's theory of self (1998) and positioning theory (Davies and Harré, 1990) and Tarrant *et al.* (2016) Social Identity Theory (Tajfel and Turner, 1979). Two other papers refer to a model, Laakkonen *et al.* (2016) outlines that their intervention is based on a psychosocial rehabilitation model and Ward *et al.* (2012) mention a peer support model (no reference provided) when discussing their findings. Due to the limited information it was problematic to apply these as

part of the explanations at this stage. Theories and models are explored further in the second stage of the project following primary data collection and analysis, see chapter five & six.

### **3.11 Chapter summary**

This review has developed plausible explanations of how and why memory cafés work have been developed, through the process of synthesising the literature and programme theory development. The review detailed how the five programme theories were formed, from chains of inference, based on the overarching concepts from the papers. The review found that memory cafés are complex and multi-faceted, providing a number of important functions. These range from providing a safe setting where people can meet that are in a similar situation to sharing stories and information, and the formation of relationships. It was possible to identify how the focus of the café, the approach of the volunteers and the types of activities provided may affect the experiences of people with dementia and their carers. Furthermore, due to memory cafés bringing together the three inter-related groups (people with dementia, their carers and the volunteers that run the café), expectations and outcomes may be different for each group. There is need for further research that examines why a memory café starts, the demographics of people that attend and what makes them stay. Furthermore, there is currently a paucity of research that examines the views of each group and the reported benefits, as well as identifying the philosophies that structure and inform how memory cafés are run. The next

chapter, chapter four details the memory cafés (cases) used for the primary data collection.

## **4 Chapter 4: Case studies – setting the context**

### **4.1 Introduction**

This chapter details the four case studies (memory cafés) that were used for the realist evaluation part of this study; including descriptions of their location, physical layout, session format, activities provided and attendees. As previously discussed in chapter two, a realist perspective embraces complexity in interventions for understanding how and why they work. The circumstances in which an intervention runs, the context, is a source of complexity (Pawson, 2013). Complex interventions are situated within complex social systems, therefore, are never formed and enacted in the same way. These descriptions of the memory cafés provide the contextual details of how they are different and how they are similar. Furthermore, it provides the conditions in which the programme theories are situated. The chapter concludes with a section on reflexivity and outlines the inferences that have been drawn from the observations of the memory cafés, as such some of the section (4.8) is written in the first person.

### **4.2 Memory cafés in Cornwall**

As of 20/4/2019, there were forty-two cafés covering the whole of Cornwall, with another two not listed (Wheal Martyn and West Cornwall Hospital) on the Cornwall Memory Café website (Cornwall Memory Cafés, 2018). The first cafés opened in 2007 and have steadily increased, with another four cafés opening in 2018. Most are free to attend but some charge a small fee of £1. Table 4.1 details the cafés in Cornwall and the year they opened.

**Table 4.1: List of cafés in Cornwall and their year of opening**

<b>Café Location</b>	<b>Year of opening</b>
Launceston	2007
Liskeard	2007
Camborne	2008
Camborne College	2008
Redruth	2008
Polperro	2008
Wadebridge	2008
Helston	2009
Mullion	2009
Penzance	2009
Downderry	2010
Falmouth	2010
Lostwithiel	2010
Padstow	2010
St Austell	2010
St Columb Major	2010
St Columb Minor	2010
St Ives & Carbis Bay	2010
Bude	2011
Perranporth	2011
Roseland	2011
Callington	2012

Fowey	2012
Isles of Scilly	2012
Perranwell	2012
Probus	2012
St Just	2012
Truro	2012
Bodmin	2013
Pensilva	2013
Penzance Hospital	2013
Carnon Downs	2014
Crantock	2014
Camelford	2015
Penryn	2015
Saltash	2015
St Agnes	2015
Wheal Martyn	2015
Looe	2016
Pelynt	2017
Hayle	2018
Mevagissey	2018
Millbrook	2018
Newquay Day Centre	2018

Figure 4.1, shows on a map where the memory cafés are located in Cornwall.



**Figure 4.1: Map showing the locations of memory cafés in Cornwall**

### **4.3 Data collection periods**

Table 4.2 outlines the number of visits and hours of data collection. All the café sessions were run on specific days at specific times, meaning visits to collect data could only happen during these periods

The cafes included as case studies in this study were selected using both purposive and theoretical sampling. This was to ensure geographical variation, difference in how long the cafes had been running, independently run or

national charity and size. It was important that the cafes were reflective of these factors in order to aid the exploration of what works for whom and in what situation.

**Table 4.2: Number of visits and hours of data collection**

Café	Number of visits	Hours of data collection
A	12	42
B	9	31.5
C	11	38.5
D	8	28

As outlined in section 2.9.7, different types of data were collected to inform the development of the programme theories. Observation sheets detailed what happened at each café session and the field notes contained what was observed, as well as what was told by the participants included in the study. The full field notes, which were typed up at the end of each café session, incorporated the data collected from both the observation sheets and participants. At the end of each café session, a reflective diary was also completed, which detailed thoughts on what was been observed and reported in light of the programme theories from the review. It was also a way of detailing patterns and differences, and what questions to ask at the next café session.

## **4.4 Café A**

### **4.4.1 Location**

The first case study was situated in a seaside resort town, and a popular holiday destination. The beaches were within easy access to the town, offering plenty of places to walk including the coastal paths. The population was just over 4,000 (UK Census Data, 2012), with around 27% being people of pensionable age. This was a larger proportion than usually seen across Cornwall and the Isles of Scilly of around 24.3% (Cornwall Rural Community Council, 2009), and nationally of just over 18% (ONS, 2017). It was estimated that there were just under 300 pensioners living alone (Cornwall Rural Community Council, 2009). Furthermore, around 16% of people reported themselves as having a long-term illness, again higher than the average of 13.5% across Cornwall and the Isles of Scilly but lower than the national average of around 22% (Department of Health, 2012). The population mix in this town was predominantly white British (97%). In terms of health services, the nearest hospital was 10 miles away and there was one GP surgery serving the whole town.

The memory café that forms this case study has been running for over five years and was established as a result of collaboration between the Rotary Club and the local church. There are a number of cafés throughout Cornwall where the Rotary Club have initiated their development. The rotary club is a humanitarian service organisation, with 1.2million members in over 200 countries (Rotary Club, 2019). It has an established relationship with approximately 60 memory cafés, throughout the UK, with varying degrees of involvement. The organisation has developed a guide on how to set up and run a memory café (REPod, 2015).

The café received a grant from the Cornwall Rural Community Council (CRCC), which is one of 38 rural community councils across England. The CRCC is a not for profit charity that supports and guides individuals, communities and businesses across Cornwall. The CRCC enables memory cafés and dementia support groups to apply for up to £1000 towards running costs and activities (Cornwall Rural Community Council, 2019). The café was free to attend but there was a donation tin available.

The café was also part of the Cornwall Memory Café Network Forum, a board of elected and honorary members who provide support to the memory cafés across Cornwall. The memory cafés in Cornwall can also opt to be under a group insurance scheme which includes a constitution. Café A has a steering committee comprised of a Chair, Deputy Chair, Secretary and Treasurer.

#### **4.4.2 Physical layout**

The café was held in the church hall, which was a few minutes' walk from the town centre. There was limited parking available adjacent to the building, with further parking on the road outside. The hall was accessible for wheelchair users, and has toilet facilities within the building. The hall was used for a variety of activities that were detailed on the noticeboard, including church related and community groups. Consequently, this required the room to be set up and packed away for each café session, which were held on specific days, for two hours twice a month. There was also safeguarding information available on the noticeboard. The hall was a reasonable size with windows on two sides, providing a good amount of natural light into the room. The room was set up for the café with two rows of tables on each long side of the room, either set separately so all sides of the table were available or pushed together to form

continuous rows. The layout of the tables were determined by the activities being provided for the session. Chairs were placed on the available sides of the tables or depending on the activity being provided. Sometimes this meant there were chairs back to back, which restricted people from easily conversing with others sat on the table behind them (see figure 4.2).



**Figure 4.2: Layout of café A**

All tables had wipe-clean table cloths placed on them and the 'Weekly Sparkle' in preparation for the arrival of guests. The Weekly Sparkle is a reminiscence newspaper containing a range of stories and activities, such as 'the way we were', quizzes, evocative images and a letters column. It is also available as a daily option. The Daily and Weekly Sparkle are produced in Devon and, for a fee, are available to community groups, care homes and hospitals. Care notes

are provided with each article to give further background information to the featured articles and support reminiscence interaction (<https://dailysparkle.co.uk>). There was a table just inside the entry door way, where a volunteer sat and signed everyone into the book and handed out name badges, to all attendees, volunteers and guests. People attending the café were referred to as guests, which appears to be the preferred term used by the Cornwall Memory Café Network Forum. Everyone wore a badge with just their name on it, there was no differentiation between people with dementia, their caregivers or volunteers. This role was generally done by the same few volunteers each time and they spent time talking to people as they arrived. At the front of the room a microphone was used by the volunteers to speak to everyone and facilitate the activities. The hall was quite large and had poor acoustics, so conversations between groups of people reverberated around the room, making it quite noisy. The use of a microphone helped the volunteers speak at a louder volume, so everyone could hear. To one side of the room was the kitchen. Drinks were made in the kitchen and brought out to guests when they arrived, with more drinks provided midway through the session when food was also handed out. The café had risk assessments for the room and also completed one if there was a trip out. There was also safeguarding information on the wall.

#### **4.4.3 Session format**

Each memory café session followed a similar format:

1. Guests arrived, signed in and collected badges
2. Guests sat down and drinks were provided

3. Introduction by café leader using the microphone (announcements of what was going on in the session, updates on other cafés members for example if someone had been unwell)
4. Activity
5. Midway break, next round of drinks and food also provided
6. Activity
7. Closed by group leader, again using the microphone (details of next café, offers of support) generally lasted for 10 minutes

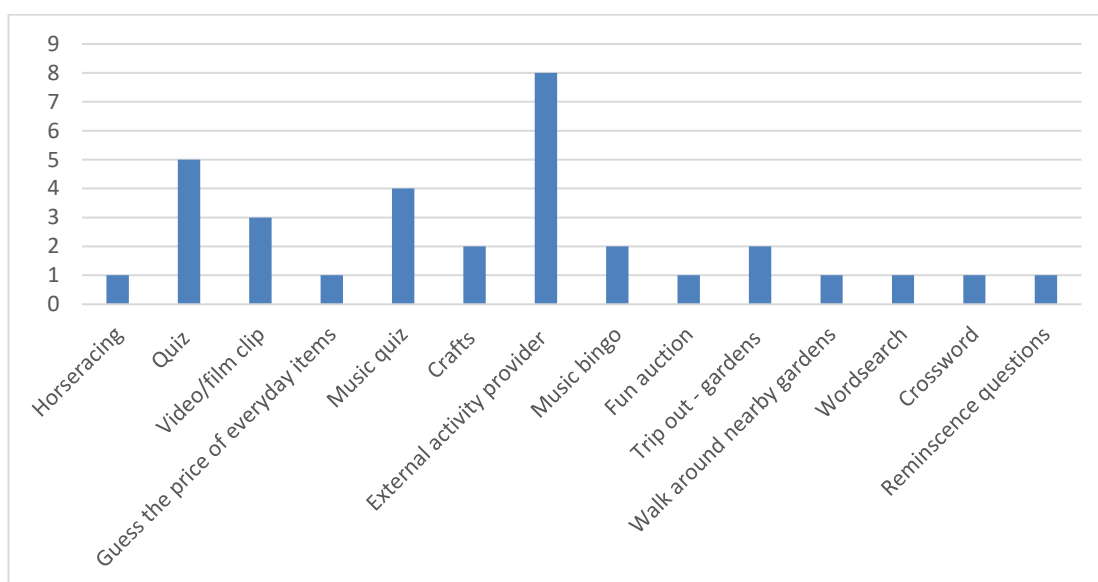
On arrival there was little interaction amongst guests and they went straight to one of the tables to sit down. Throughout the session, guests mainly remained in their seats and stayed with the people they had sat with on arrival. There were some instances of guests getting up from their seats and moving around but this was usually due to the activity being provided.

Refreshments and food were provided. The food often tied in with the theme of the day for the café; generally this consisted of sandwiches, pancakes and a variety of cakes. The guests were waited upon, with drinks and food being brought around to them at their tables. Whilst not explicit, volunteers appeared to generally adopt the same role at each café with some being responsible for introducing and coordinating the activities, others at the welcome table and the rest providing drinks and food and collecting cups.

#### **4.4.4 Activities**

During the period of data collection (12 café sessions), there were a wide range of activities provided (See figure 4.3), sometimes with multiple activities at one café session. In total there were 33 different activities in 12 sessions. The most common activity involved external entertainers, who were generally music orientated. There were eight external entertainers who presented; singing for

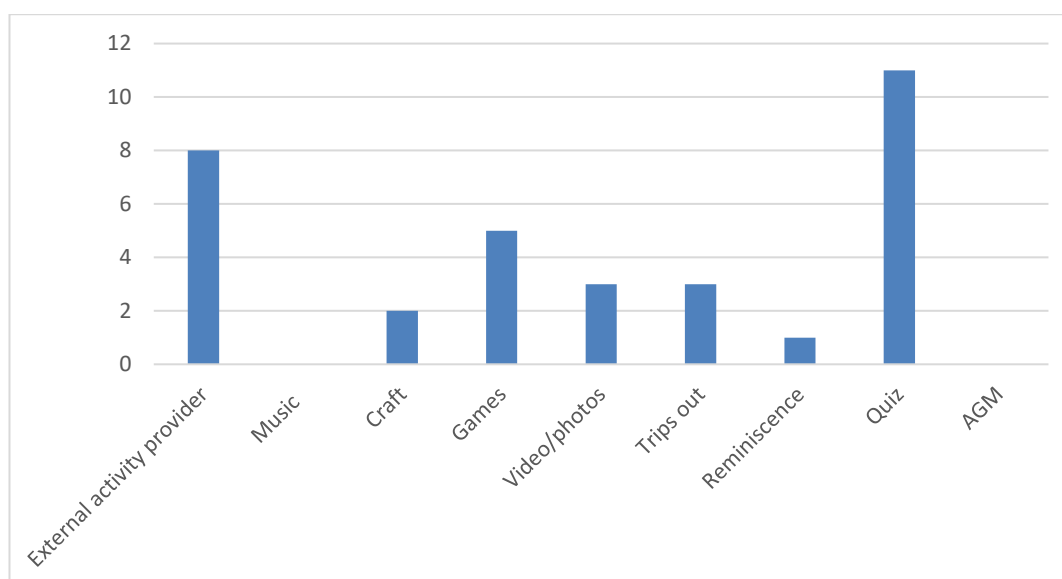
the brain, sculptor, talks and other forms of music. Quizzes were also another regular activity, with some type of quiz being provided at each café session. The quizzes involved general knowledge type questions, music questions, word searches and crosswords. Other activities included; mock horseracing, bingo, auction, video clips and reminiscence questions. The activities appeared to have been planned a few sessions in advance and took into account any particular events, such as Valentine's Day and Easter. For example at the café session, closest to Easter, guests decorated eggs and the quiz questions written by the volunteers, were related to Easter. The art based activities, usually involved guests making something that guests could take home. Some were also shown to the rest of the group. Events such as guest's birthdays were celebrated with the wider group and a card provided. At the end of each café session, guests were informed of what was happening at the next café.



**Figure 4.3: Activities provided at café A**

For this café, there were two trips out to local attractions during the observation period; one trip was quite some distance away and therefore, was for a longer time frame than the usual two hours for the café. The trips out involved additional planning, including organising transport and ensuring enough support from volunteers and caregivers.

To aid with comparison across the cafés (A, B, C and D), figure 4.4 shows the activities grouped together; external activity provider, music, craft, games, video/photos, trips out, quizzes and annual general meeting.

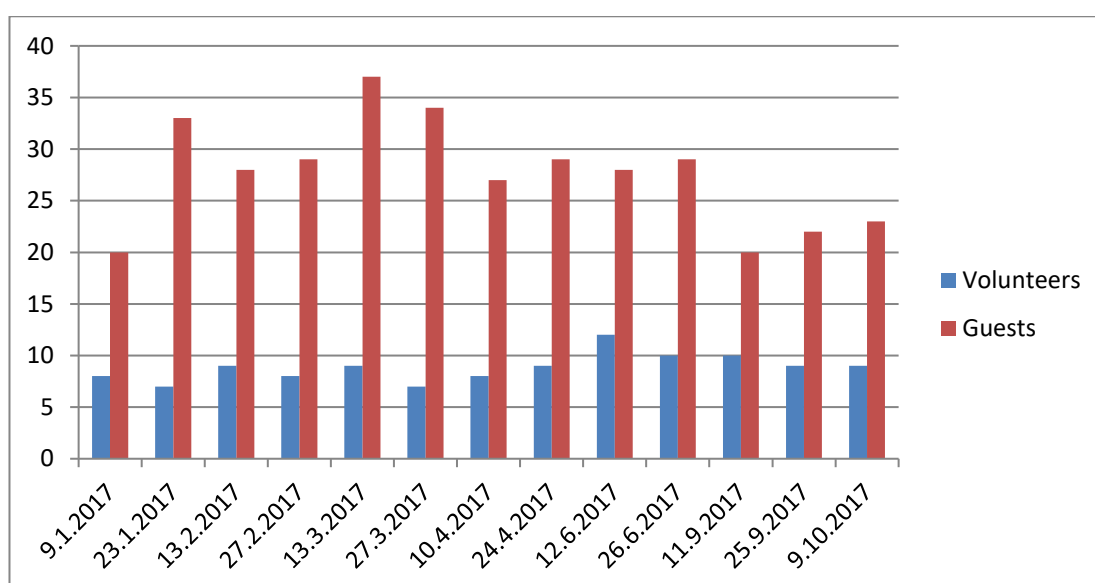


**Figure 4.4: Activities grouped together (café A)**

#### **4.4.5 Café attendees**

Figure 4.5 outlines the volunteer and guest numbers at each café during the data collection period. There was no differentiation between people with dementia and their caregivers in the signing-in book, with all just listed as guests. Therefore, in the figure, guests include people with dementia and their

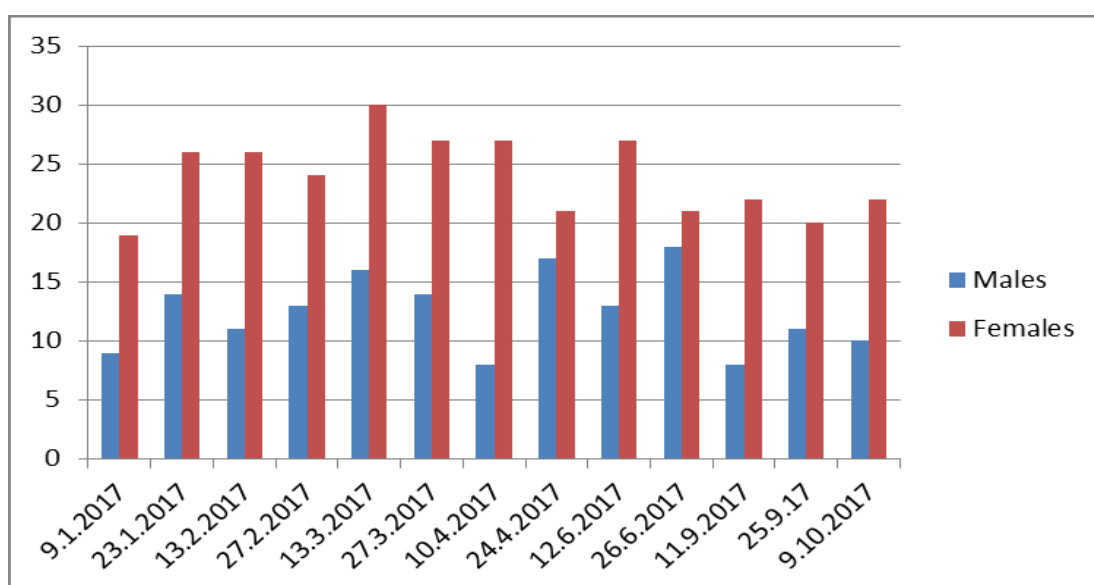
carers. The café had a mixed group; people that attended on their own, people with dementia and their caregivers, and caregivers whose loved one had died or moved into long-term care and were now too unwell to attend. At café A the number of volunteers ranged from seven to 12, with the average number across the sessions as 9 (rounded up). The number of guests ranged from 20 to 37, with the average number as 28 (rounded up).



**Figure 4.5: Guest and volunteer numbers at café A**

The volunteer group remained constant throughout the period of data collection. The volunteers were a group of retired individuals, consisting of mainly women. Some of the volunteers lived in the town with others living in nearby villages. At this café volunteers were referred to as helpers, with some being involved in the church where the café is held. Guests were informed of other events that were provided by the church, such as coffee mornings.

There were a higher number of females to males both for guests and volunteers, consistently throughout the data collection period (see figure 4.6). The age ranges of guests were from people in the 60s to their 90s, all would be classed as of pensionable age.



**Figure 4.6: Number of female and male guests and volunteers at café A**

The majority of the guests lived in the town or surrounding village, however, some guests travelling from further afield. Some guests also lived in local care homes and they were accompanied to the café by staff from the care home.

## 4.5 Café B

### 4.5.1 Location

Café B was situated in a historic market town in Cornwall, where the surrounding area has a rich cultural history and open countryside. The parish population was around 9, 000 (UK Census Data, 2012), with around 20% of

people of pensionable age, lower than the Cornwall and Isle of Scilly average of 24.3% (Cornwall Rural Community Council, 2009). In this area, approximately 500 people of pensionable age live alone, and were vulnerable to low income (Cornwall Rural Community Council, 2009). Based on the Index of Multiple Deprivation, around 16% of the total population in the area were income deprived (Cornwall Rural Community Council, 2009). Around 12% self-classified as having a long-term illness (Cornwall Rural Community Council, 2009) which is slightly lower than across Cornwall and the Isles of Scilly. The majority of the population (around 97%) classified themselves as White British (Cornwall Community Council, 2009). There is one GP surgery serving the whole town, plus a community hospital providing community health services. The closest tertiary hospital is over 25 miles away.

Café B was also part of the Cornwall Memory Café Network Forum. The café had a steering committee comprised of a chair, deputy chair, secretary and treasurer. The café was actively involved in community events and fundraising for the running of the café.

#### **4.5.2 Physical layout**

This memory café was held in a church hall, situated near the town centre.

There was no direct parking available, other than on the street outside and two small car parks nearby. There was a small step leading into the grounds but there was an alternative access for wheelchairs, plus a small ramp into the building. There was a banner outside attached to the railings, informing people that the café was on. It was a large building, with two hall areas. The sessions used to be held in the smaller hall but moved to the larger hall when café numbers grew. There were a number of toilet facilities situated within the

building, plus a kitchen adjacent to the large hall. The church hall was used for a number of community and religious based events, including coffee mornings and a toddlers group. Therefore, the room had to be set up and packed away for each café session which was held on the same day, twice a month for two hours. There were limited windows, so not much natural light but bright and colourful displays adorned the walls, showing events that had happened in the church hall. The hall was a large size allowing a number of tables to be grouped together and laid at different angles around the room. The layout remained the same for all the café sessions, as there was still plenty of free space for people to move around. Chairs were set out on either side of the tables, so some people did have their backs to each other (See figure 4.7). However, there was a lot of movement with volunteers and guests regularly getting up and moving around to speak to each other.



**Figure 4.7: Layout of café B**

All tables had wipe clean cloths placed on them, and plates of food were laid out ready before the start of the session. On arrival there was the signing in table where a nominated volunteer, signs everyone into the book and hands out their name badges. Guests were generally recorded separately; as client, carer or visitor but the badges just stated the person's name. Next to the signing in table there were a range of quizzes, puzzles and colouring in sheets that guests could take if they wished. Then there was a display board with photos showing the various trips out and activities, plus local fundraising events for the memory café. On the next two tables was the food, for the food share. Reduced food from one of the local supermarkets was donated to the memory café, such as bread, cakes and fruits and vegetables. Guests could take items for a monetary

donation of their choice, to the memory café. To one side of the room was the kitchen with two large hatches that remained open throughout the session.

#### **4.5.3 Session format**

The session format at café B followed a loose structure:

1. Guests arrived, signed in and collected badges
2. Guests sat down and drinks were provided, food was already laid out on table (biscuits, cakes and fruit)
3. Time for guests and volunteers to talk
4. Introduction by café leader (announcements of what was going on in the session, updates of people that had been unwell and events planned)
5. Food share
6. Activity for those who wanted to partake
7. Drinks provided again midway through the session
8. Activity/conversation continued
9. Close – guests leaving
10. Following guests leaving, the volunteers got together to reflect on the session

During the observation period it was noted that on arrival there was considerable time for everyone to greet and talk to each other. This included hugs, kisses, conversing and laughing. The guests generally sat in the same seats and with the same group of people, however, individuals did get up and move around. Carers in particular moved to speak to each other, when their loved one with dementia, was engaged in an activity or speaking with a volunteer. There were long periods of time for people to sit and chat.

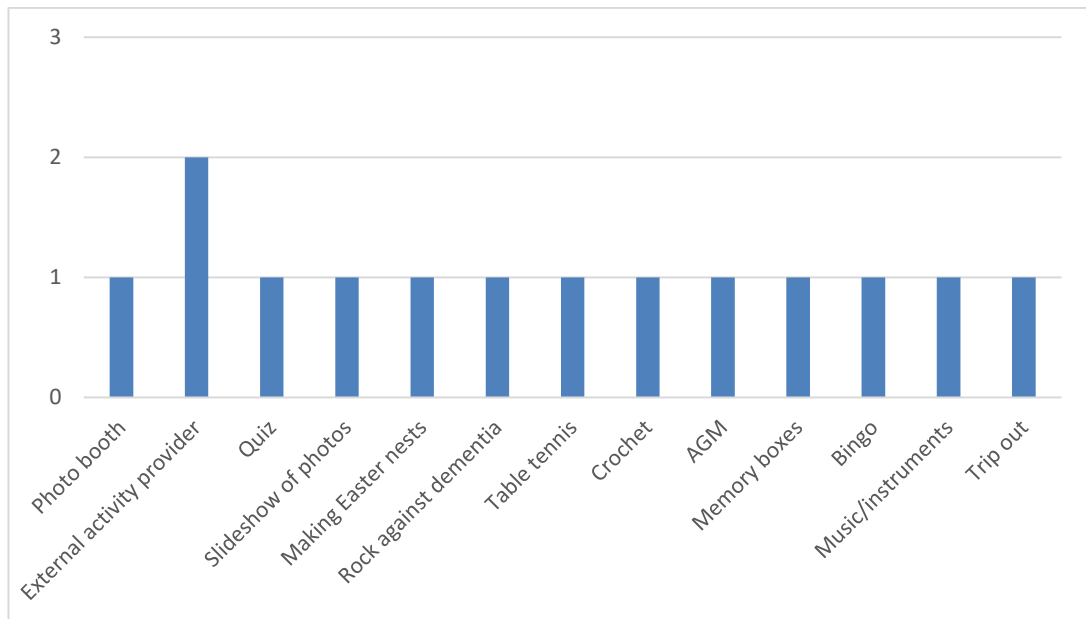
Refreshments and food were provided at each café including, a variation of biscuits and cakes but also a range of fruit. The guests were generally waited upon, with drinks being brought out and empty cups collected. Guests also went

up to the hatch themselves to request a drink and have a chat with the volunteers making the drinks. The volunteers generally took on the same role at each café, with a nominated person doing the signing in, others serving drinks and the rest speaking to guests and helping with the activities. A couple of volunteers focused on administration, such as collecting names for the carers lunches and the accounts.

At the end of each café, the volunteers met to discuss how the session went, including numbers, the activity and any concerns about any of the guests. They also looked at plans for the next sessions and which volunteers will be there.

#### **4.5.4 Activities**

During the period of data collection (11 café sessions), there were a variety of activities (Figure 4.8). Usually there was one activity per session, allowing plenty of time for guests and volunteers to talk. Some of the guests chose not to join in with the activities, preferring to remain either at their tables or talking with others.

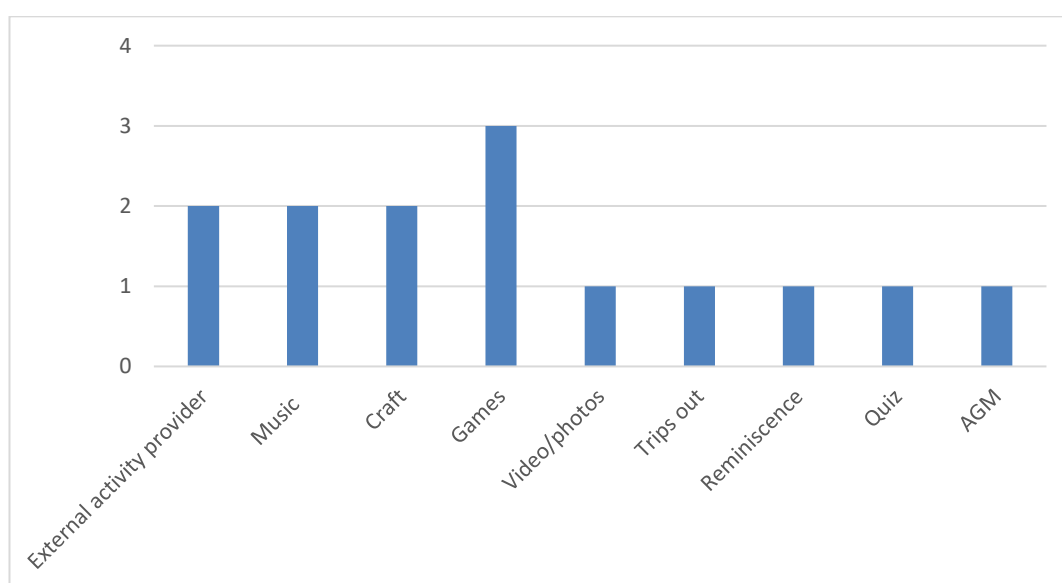


**Figure 4.8: Activities provided at café B**

The most common activity was an external entertainer such as a singer and bell ringers. There was also table tennis, a quiz, photo slideshow, photo booth, crochet, music and instruments. The slide show of photographs was of previous café sessions and was shown at the yearly anniversary of the café starting, where members of the community that supported the memory café were invited to attend and a buffet was provided. The photo booth had props for people to put on, such as big glasses and hats, and then they had instant photographs taken. The rock against dementia session was music and dance in support of a worldwide awareness raising event on dementia. There was also the Annual General Meeting, a formal process where the members of the committee were reaffirmed and the expenditure for the year checked. There was one trip out to a local attraction for all the café guests. In addition to this the café volunteers also arranged quarterly meet ups for just the carers, outside of the normal café

session times, usually a meal out. The craft sessions, making Easter nests and crochet, provided guests an opportunity to make something they could take home.

Figure 4.9 shows the activities grouped together. The most common activity were games, followed by external activity provider, music and craft.

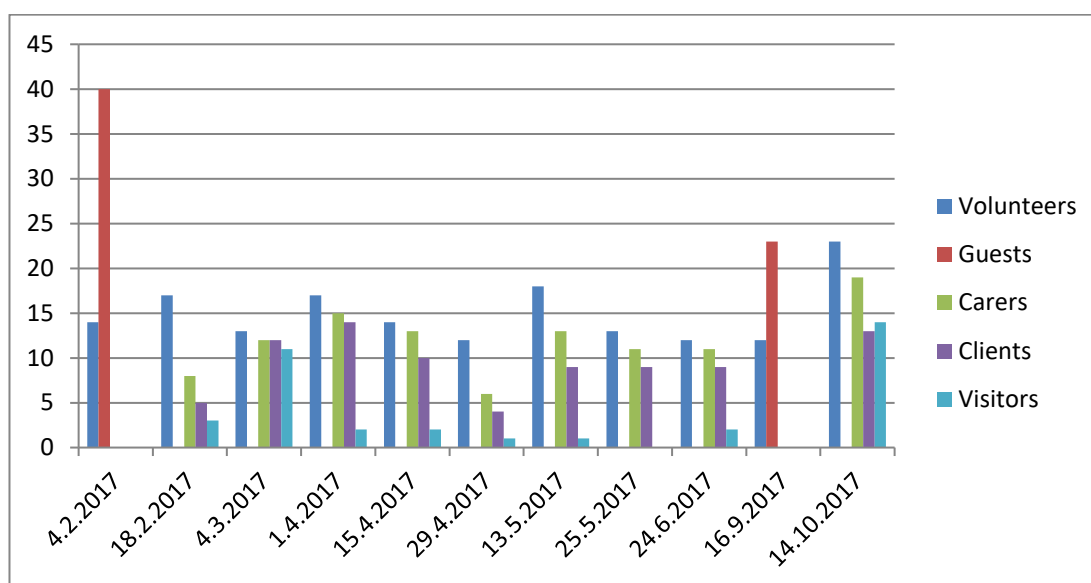


**Figure 4.9: Activities grouped together (café B)**

#### **4.5.5 Café attendees**

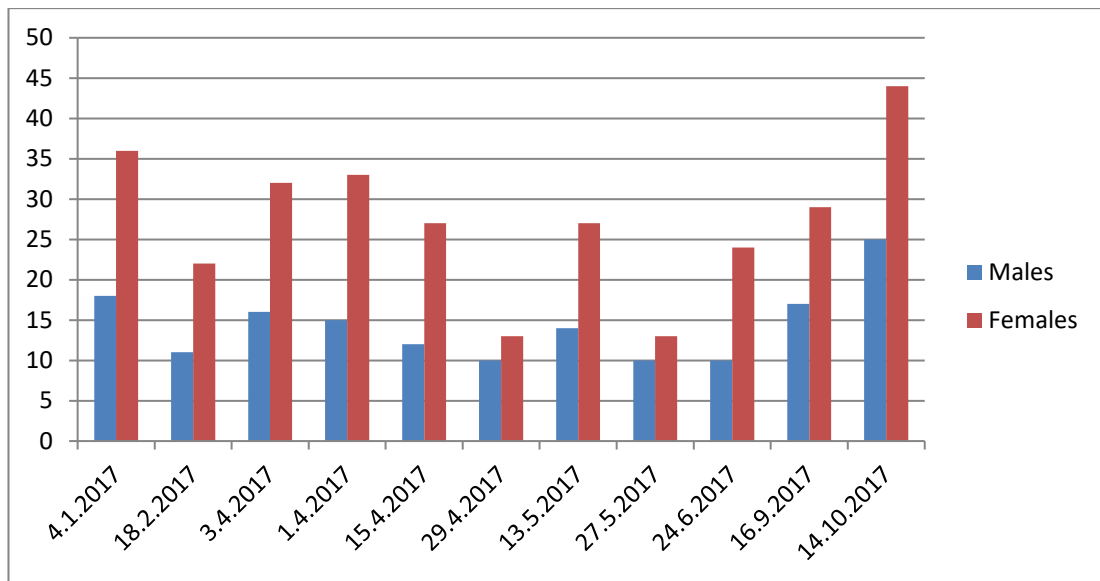
As previously mentioned, at café B, the numbers of people with dementia and carers are recorded separately, however, on two occasions this did not happen, the trip out and the first visit to the café, where a manual headcount was completed. Visitors to the café were also recorded separately. There were some slight fluctuations in the café numbers, with one occasion, 29/4/2017 having considerably lower numbers, interestingly this was when the café leader was away (See figure 4.10). Guests at some of the café sessions, also included

people that lived in a local care home. The number of volunteers ranged from 12 to 23, with an average of 15 across the sessions. The number of guests ranged from ten to 40, with the average number of guests being 23. For visitors the range was one to 14, with the average across the sessions as five (rounded up).



**Figure 4.10: Guest, volunteer and visitor numbers at café B**

The volunteer group remained constant throughout the period of data collection, with a number being involved since the start of the café. The volunteers were mainly a group of retired females, however, there were also a number of younger volunteers and male volunteers. The volunteers lived in the town where the memory café was held and got involved in local town events to raise awareness and fundraise for the memory café. There were visitors at several of the cafés, usually people that wanted to see what happened at the memory café and people interested in being volunteers.



**Figure 4.11: Number of female and male guests and volunteers at café B**

There were a higher number of females to males for both guests and volunteers (See figure 4.11), with a higher number of female carers with male spouses, with dementia. The age range of guests was from people in their 60s to their 90s. There were also some younger guests that were related to another couple and a younger guest with a learning disability.

## 4.6 Café C

### 4.6.1 Location

The location of café C was in a historic mining town with a population of just under 21, 000 (ONS, 2011). An industrial heartland; mining and other industries, helped transform the area into a town, resulting in it being one of the richest mining areas in the world. The last mine closed in 1998 and the subsequent decline in industry and revenue, meant the area is now classified as deprived

with the highest number of neighbourhoods in the 20% most deprived areas in England (Indices of Multiple Deprivation, 2015). There was a higher than average number of people who self-reported as having a long term illness, 16% and 13.5% respectively. Around 22% of the population were of pensionable age which was slightly lower than the average of 24.3% across Cornwall and the Isles of Scilly, with just under 3000 pensioners living alone and vulnerable to exclusion (Cornwall Rural Community Council, 2009). The majority of the population (over 97%) classified themselves as white British. No household was further than 8km away from a GP surgery and there was a small community hospital with a minor injuries unit. The main hospital was less than 15 miles away.

#### **4.6.2 Physical layout**

Café C was one of three cafés run by the Alzheimer's Society in Cornwall. The Alzheimer's Society provides a wide range of support services to people living with dementia and their families including face-to-face, telephone, online and community based support. The café was held twice a month for two hours in a church community centre that provides a venue for various local groups, meetings and parties. It was situated off a main road with a regular bus route. There was limited parking available, directly outside but there was further free parking on the road in front, and on the nearby residential areas. There was a sign placed outside advertising that the memory café was on. Access to the building was via a wheelchair friendly ramp, situated at the front. The main hall where the memory café was held is on the left-hand side as you entered. There was also an office for the community centre staff, a full kitchen and seating area, toilet facilities and some smaller meeting rooms. The walls were full of

displays and posters, informing visitors about local groups, social events, meetings and fundraisers. As the room was widely used by the local community, the room had to be set up for the memory café and packed away once it had finished. The tables were laid out in two rows, down the long sides of the room. Chairs were laid out on both sides, so some guests had their backs to each other. Furthermore, as the tables were joined closely together, there was little room for people to get out and they had to ask others to move in order to do so (See figure 4.12).



**Figure 4.12: Layout of café C**

All the tables had wipe clean tablecloths on them. The Weekly Sparkle (as discussed in café A), quizzes and pens were laid out ready for guests' arrival. On entering the room there was a small table where a volunteer recorded

names in a book, under the headings volunteers, visitors, carers and clients (people with memory problems or dementia) and wrote out labels for name badges. There was no differentiation between people with dementia, carers and volunteers. Guests could also buy raffle tickets, for a raffle that was held during the café session, with the money raised used for trips out. This role was generally done by the same volunteer, who spent time greeting and talking to people as they arrived.

There was little natural light with one main window at the front of the room. A corridor ran the length of the hall, with windows that let further light in from the windows to outside. The acoustics of the room whilst being of benefit to singers, meant conversations between people reverberated and it could become very noisy. At the back of the room there was a smaller area where the chairs were stored and a table for the drinks to be placed on, after being made in the kitchen situated behind the hall.

#### **4.6.3 Session format**

The session followed a structured format:

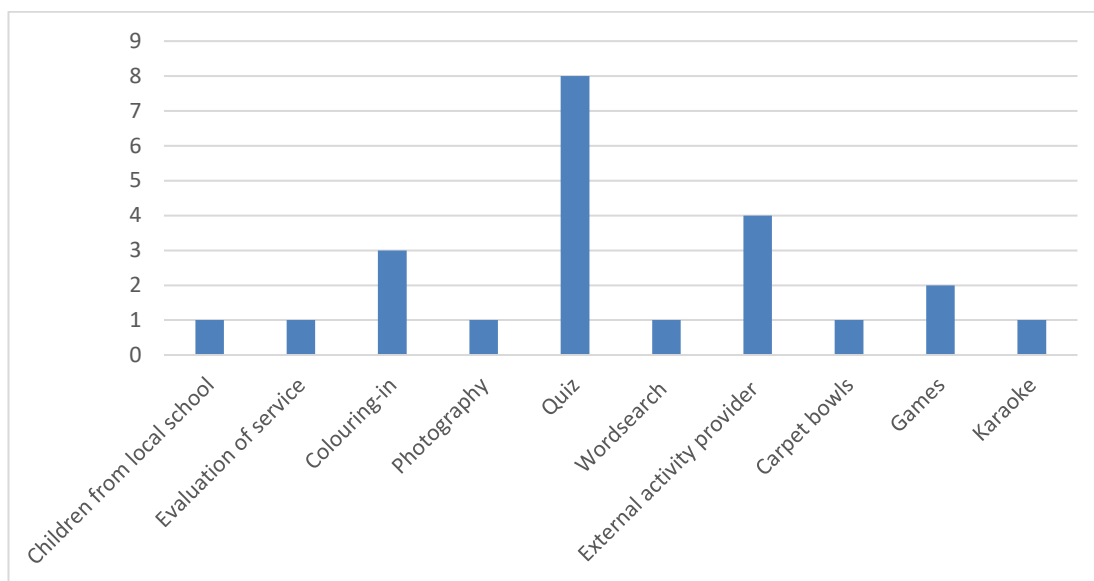
1. Guests arrived and signed in, name labels completed
2. Guests sat at tables
3. Introduction by café leader (names of volunteers present, allocation of volunteer roles – fire marshal, first aid and activities planned)
4. Activity
5. Tea break – tea and biscuits/snack bars
6. Carers group during tea break
7. Raffle
8. Activity/going through quiz answers

On arrival there was a short time for guests to greet and talk to each other and the volunteers. Guests usually sat in the same seats and stayed with the same group of people. The room shape and layout made it difficult for people to move around once they were sat down. During the tea break, some guests did get up to speak to other guests and volunteers. Some of the volunteers also moved around to speak to guests. During the tea break there was an opportunity for carers to get together if they wished, in the seating area linked to the kitchen. A volunteer sat with them, to provide support whilst they shared experiences and difficulties. Drinks were provided at the beginning with further drinks and biscuits or small chocolate bars provided at the midway point of the café session. The drinks were made in the kitchen and brought out by volunteers to the guests. The guests did not go into the kitchen area.

#### **4.6.4 Activities**

Over the period of data collection (10 sessions) there was a different main activity at each session (See figure 4.13). In addition there was some type of quiz or word search at most of the sessions. The quizzes were made available from the start and many guests would start working on them straight away, often with others sat next to them at the tables. There were a variety of quizzes provided, including question and answer, filling in missing words and identifying names beginning with a particular letter, for example girls names beginning with c, flowers beginning with c. The answers were read out at the end of session and chocolates given as a prize to the winners. The quizzes provided an opportunity for guests to talk and work together. The other most frequent activity was visiting singers. The external activity providers also included a session on

poetry. The activities were planned a year in advance and detailed on a card that was provided to all guests, so they know what is going on at each session.

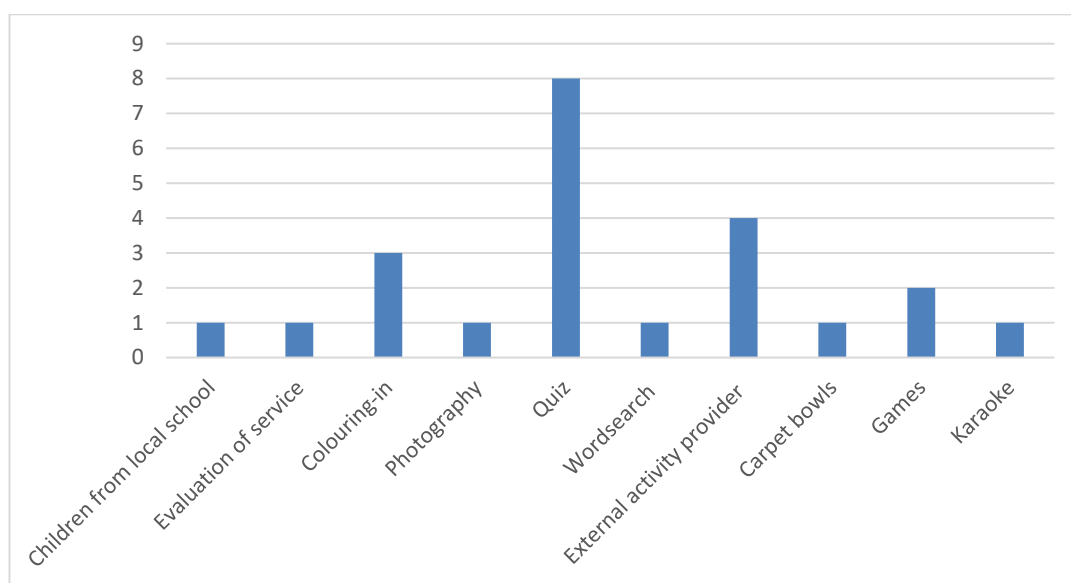


**Figure 4.13: Activities provided at café C**

The other activities included; slide shows of photographs, carpet bowls, games, colouring-in and karaoke. The photography session was facilitated by a person with dementia and a carer that have a particular interest in photography. They showed their photographs to the group and talked about the images. There was also a visit from children from the local primary school, where they sang songs and then spent time with guests talking and doing activities such as colouring-in. The café had an established relationship with this school and a group of children visited the café every year. One of the sessions involved an evaluation of service, where a manager attended from the Alzheimer's Society and guests were invited to complete an evaluation form, followed by questions to the group about how the memory café was run. There was no trip out during the period of data collection but there was generally a trip or lunch, arranged for guests each

year. Important events for guests such as a birthday or wedding anniversary were acknowledged. A birthday involved the wider group singing 'happy birthday'.

Figure 4.14 shows the activities grouped together. The most common type of activity were quizzes and then activities facilitated by an outside provider.

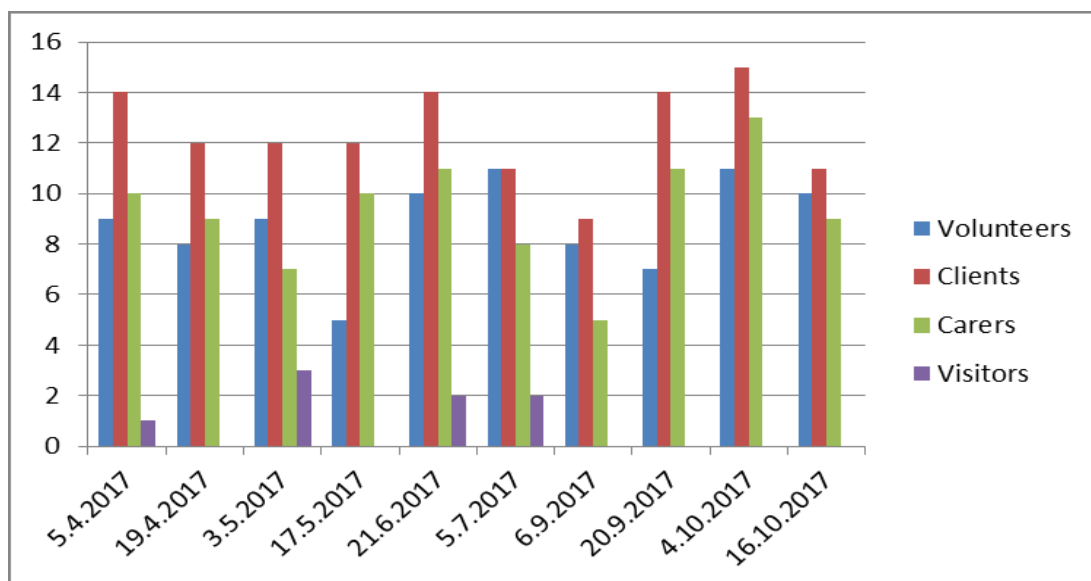


**Figure 4.14: Activities grouped together (café C)**

#### **4.6.5 Café attendees**

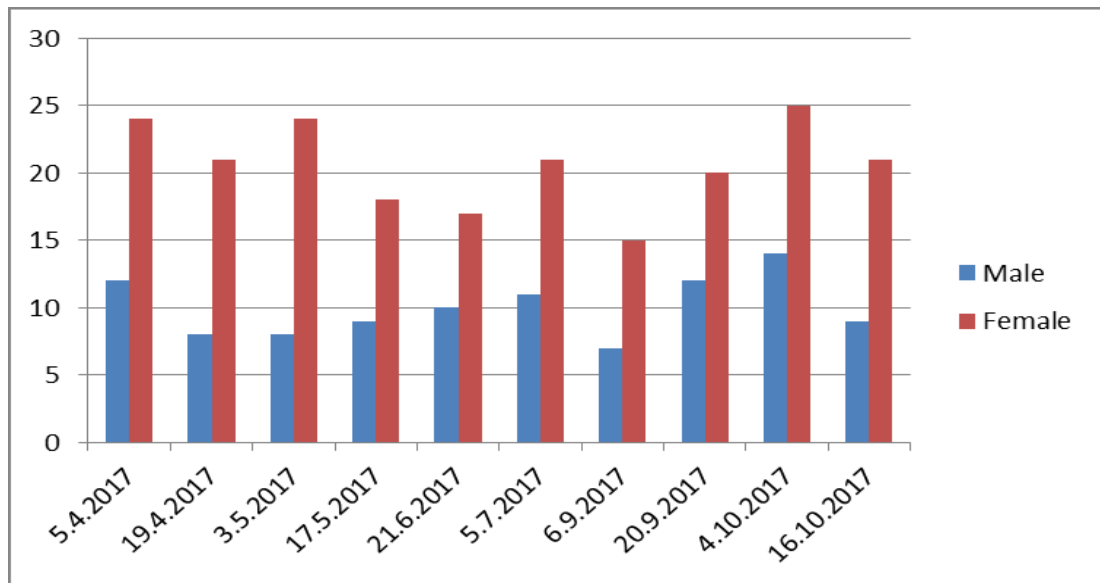
At café C, like café B, the numbers of people with dementia and carers are recorded separately (See figure 4.15). There were some fluctuations in numbers attending the café, particularly on the 6/9/2017; this was when poetry was the main activity. There were also a higher number of people with dementia and memory problems than carers, as several people lived independently. The number of volunteers ranged from five to 11, with the average number being 9 (rounded up). The number of guests ranged from 14 to 28, with the average

number across the sessions as 22 (rounded up). There was also an average of two visitors across the sessions.



**Figure 4.15: Guest, volunteer and visitor numbers at café C**

The volunteer group remained constant, ranging from eight to 11 volunteers at each session. The volunteers were mainly a group of retired females and one male. The volunteers lived locally to where the memory café was held and some were involved in other Alzheimer Society activities. The volunteers had allocated roles at each café, such as fire marshal and first aider. Others took charge of making drinks and collecting cups and mainly stayed in the kitchen area.



**Figure 4.16: Number of female and male guests and volunteers at café C**

Throughout the period of data collection, there were a higher number of female guests and volunteers than males at café C. There was a higher number of female carers with spouses or relatives with dementia or memory problems. The age ranges of guests were between 60 and 90 years of age.

## **4.7 Café D**

### **4.7.1 Location**

The location of café D was a well-known old mining town. However, the area's history is much older than its associations with industrial development. There were a number of places nearby to walk, both in the countryside and on the coast. The population is around 2,000 (ONS, 2011), with around 24% of people being of pensionable age, which was a slighter smaller proportion of the population than across Cornwall and the Isles of Scilly (Cornwall Rural

Community Council, 2009). Of those, around 200 pensioners were reported to live alone and vulnerable to exclusion (Cornwall rural community council, 2009). Around 21% of the total population was classified as income deprived, and around 15% of the population classified themselves as having a limiting long-term illness which was higher than the 13.5% average across Cornwall and Isles of Scilly (Cornwall Rural Community Council, 2009). The majority of the population was classified as white British. There was one GP surgery serving the whole town and there was a general hospital just under ten miles away.

Café D was part of the Cornwall Memory Café Network forum which provided the insurance and constitution. Café D had a steering committee comprised of a chair, secretary and treasurer. A grant for running costs was obtained through the Cornwall Rural Community Council and donations from guests and the local community provided additional funds.

#### **4.7.2 Physical layout**

The memory café that forms this case study was established by volunteers that run other cafés in the nearby towns. It was held in a community building situated near the town centre, on the same day of the week, twice a month for two hours. Prior to this location, the café was held in another building in the town but had to relocate due to the building having a change of purpose. The community building had parking for a couple of cars, enabling people to be dropped off and collected. There was an additional car park and plenty of streets to park on, nearby. The building was a modern structure with wheelchair access. It was small, comprising one room with toilets, a kitchen area and a storage room. The area could hold around 15 -20 people. The hall was used for other community groups and events. There was a display board informing of

future and past town activities. As such the room had to be set up and packed away at the end of each café session. The café facilitator had to bring all the items required for the session each time. There were a number of different sizes of tables which were set up accordingly to the activity being provided, sometimes as one big table or several small tables (See figure 4.17).



**Figure 4.17: Layout of café D**

Once the tables were set up there is very limited space for people to move around, so guests talked with whom they were sat with. When the café had a small number of guests attending, they would all sit around one big table together, however, this filled most of the room. On arrival there was a table with the signing in book and a donation pot for the café. There were also leaflets on

services available, not all specifically relating to living with dementia. All guests and volunteers wore badges that were made by one of the guests. There was no differentiation between people with dementia, carers and volunteers. There was good natural light due to doors that open out to a patio area. Due to the hall being small it could get quite noisy when people were talking. Also, particular activities such as music with instruments could become very loud. A risk assessment had been completed for using the room and additional risk assessments were completed if there was a trip out.

#### **4.7.3 Session format**

The session format at café D had a simple structure:

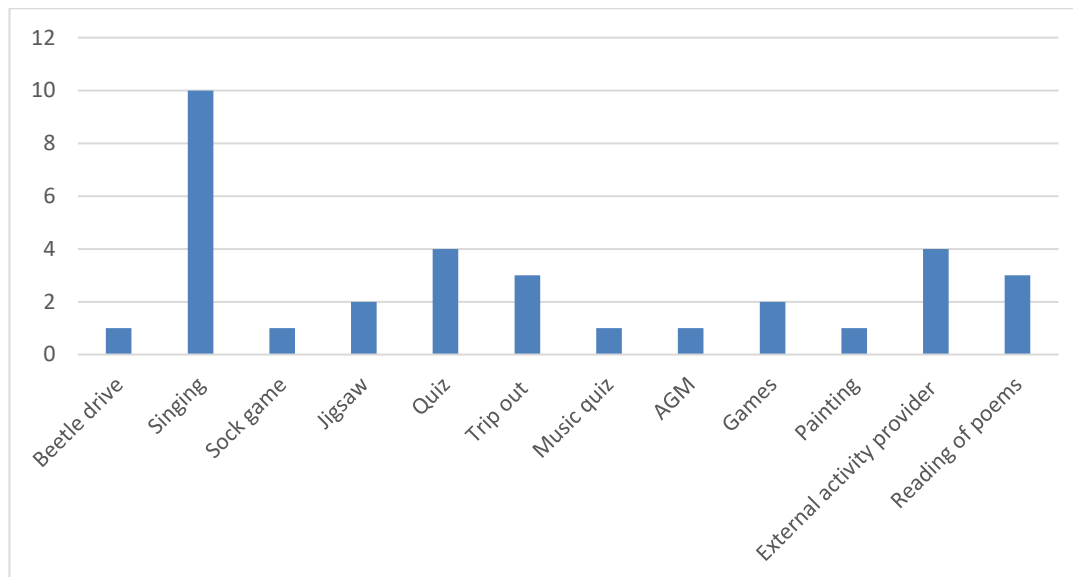
1. Guests arrived, sign in and collect badges
2. Time to talk and activity
3. Drinks and biscuits
4. Sing café song
5. Time to talk and activity
6. Close – guests leave

Some guests were dropped off and collected by family members and others arrived alone. On arrival there was plenty of time for people to talk to each other. There were some individuals that usually sat together but generally people just sat where there was an empty seat. Due to the café being small, guests all seemed to know each other well. There was no drink provided on arrival at this café, just at the midway point where biscuits/small chocolate bars were also provided. The guests were waited upon, with drinks being brought out and used cups collected and washed. There were usually only three volunteers at each café session, with the café leader facilitating the activity and quizzes and the other volunteers helping with setting up, packing away and the

refreshments. During the drink break, guests and volunteers sang their café song. It has been pre-recorded onto a cd that was played and the printed words were handed out, to help people with joining in.

#### 4.7.4 Activities

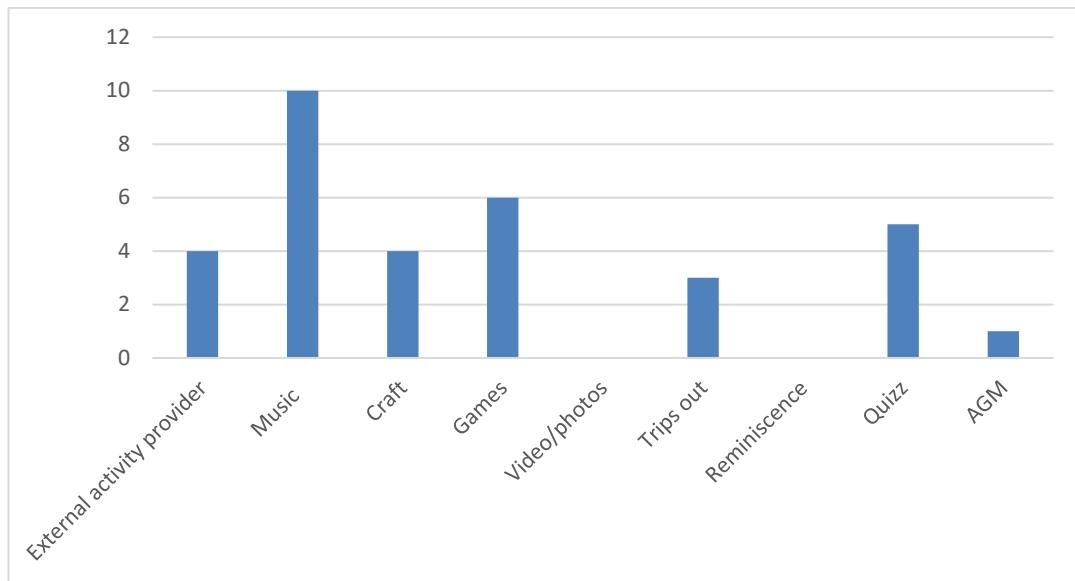
Over the period of data collection (10 sessions) there was a different main activity at each session. In addition, there were quizzes, and singing occurred at each session (See figure 4.18). The quizzes involved the café leader reading out questions to the group, rather than sheets to fill out. Some of the sessions involved grouped activities such as jigsaws and painting, set up on different tables. Games included card games and board games. The sock game was played with two teams, where objects have to be found in a sock, just by touch. The local library was utilised to source some of the jigsaws and games.



**Figure 4.18: Activities provided at café D**

As previously mentioned the most common activity was singing which occurred at each session during the data collection period. Quizzes and external provider/entertainer were the next most common activity. The external providers included; a clay sculptor, artist, pets as therapy and a musician. All the guests joined in with the activities and there was also plenty of time to talk in between and at times during the activity. There were three trips out during the data collection period; a garden party at one of the guests house, visit to a garden centre and to a café. For all the trips out, information detailing what was happening was provided to guests or their carer when they were collected. The trips out involved additional organising for the café leader, as guests that lived out of the immediate area were collected and dropped off at different points along the way. If the trip out was some miles away the session was also longer than the usual two hours. The garden party at one of the guest's house was an annual event which was held outside, food and drinks were provided and there was plenty of singing, along with a guitar player. Events such guest's birthdays were celebrated with a card and the singing of 'happy birthday'.

Figure 4.19, shows the activities grouped together.

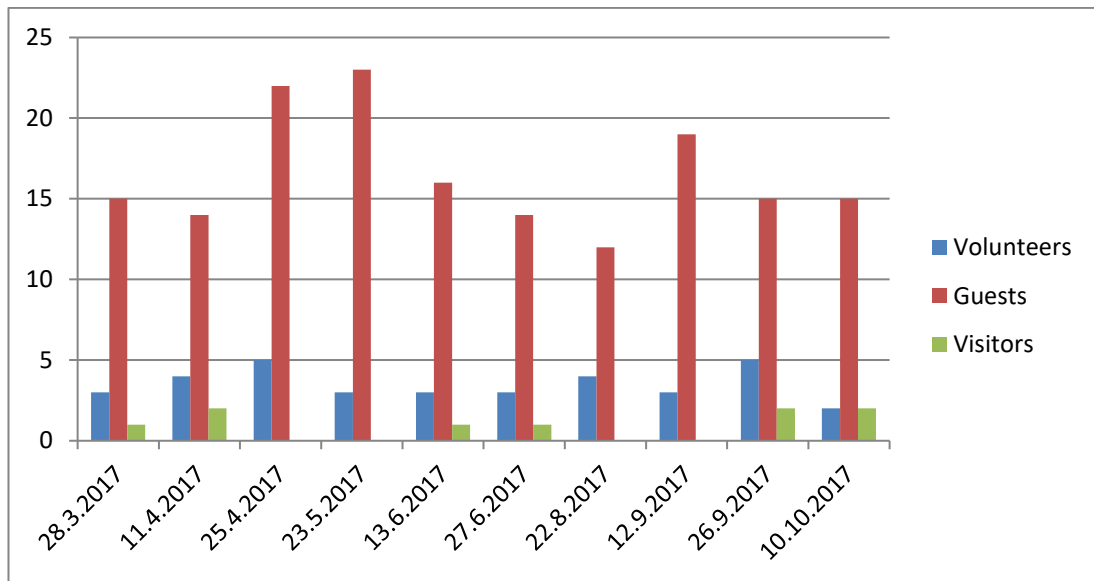


**Figure 4.19: Activities grouped together (café D)**

The most common activity during the data collection period was music, followed by activities facilitated by an external provider and quizzes. Guests were informed at the end of each café session what was happening at the next one and also about other groups and events in the area.

#### **4.7.5 Café attendees**

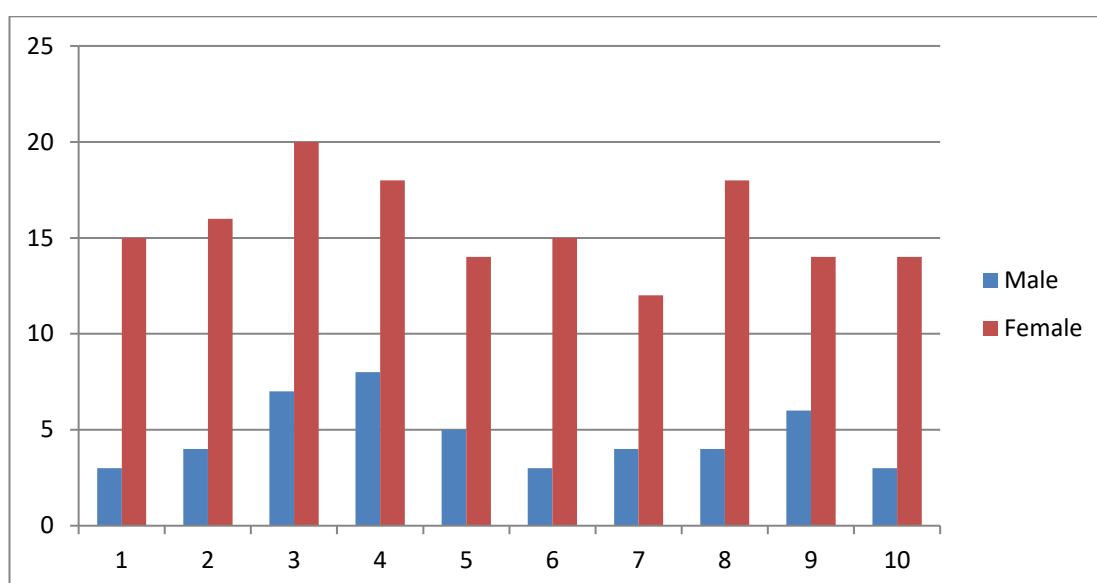
At café D, the majority of guests were people living with dementia and memory problems or people that lived alone. Very few carers stayed for the whole session. Guests, volunteer and visitor names were recorded in the signing in book, in one long list. Therefore, in figure 4.20, guests included people living with dementia/living alone and carers. Visitors were also recorded but not separately, so were counted by the researcher at each café session. The number of volunteers ranged from 2 to 5, given an average of 5 (rounded up). The number of guests ranged from 12 to 23, with the average across the sessions as 17 (rounded up). The average number of visitors was 2 (rounded up).



**Figure 4.20: Guest, volunteer and visitor numbers at café D**

There were more volunteers when there were trips out. The café leader was present at each café session, and they were supported by four other volunteers, who attended at different times or for only part of the session. The volunteers were retired individuals that were also involved in other groups and activities in the town, sometimes to help raise awareness and funds for the memory café. There were visitors at several of the cafés; the primary care dementia practitioner and a person with learning disabilities that lived in the area. Primary care dementia practitioners (PCDPs) are registered health professionals employed by the local community and mental trust to support people with dementia and their carers across most of Cornwall. They work closely with GPs to assess people's needs from diagnosis to end of life care. Some of the guests that attended the café were on the primary care dementia practitioner's caseload.

The guest numbers also increased when there were trips out, as the café leader would open them up to other family members and friends, and members of Age Concern. Towards the end of the data collection period there was some talk of moving to a bigger hall, to accommodate everyone more comfortably.



**Figure 4.21: Number of female and male guests and volunteers at café D**

As with the other cafés, there were a higher number of males than females for both guests and volunteers. The age range of guests was people in their 50s through to their 90s. All were retired individuals.

## 4.8 Summary of reflections

The following section provides reflections on the similarities and differences between the case studies. Observations on the layout, structure, activities and numbers were collected throughout the data collection periods and once it was agreed by all café attendees they were happy for the research to take place.

#### **4.8.1 Café A**

The café sessions were very structured in how they ran. On arrival guests signed in and collected their badge. Guests were greeted by the volunteers at the signing in table, and there was little interaction from other volunteers unless they passed the guests on the way to their seats. Guests also spoke to each other as they waited at the signing in table and then went onto sit down at the tables in small groups. Guests generally sat at the same table with the same people. The sessions usually had one activity after another, with every gap, other than the break for refreshments and food filled with an activity. Therefore, there was often very little time for guests to converse, other than when it was required for the activity. Guests were encouraged to take part in activities but some chose to sit and observe, particularly the singing for the brain sessions. Activities such as quizzes provided some interaction across the tables, with one of the café volunteers reading out answers and facilitating discussion between guests. The room provided enough space for a range of activities but the way the tables were laid out was not always conducive to promoting interaction amongst guests, often people had their backs each other.

As previously mentioned, the volunteers adopted duties and roles which they maintained at each café. Some of the volunteers appeared more comfortable with roles that were task focused, such as bringing out tea and collecting cups. Their interactions with guests were based on that task, for example 'Would you like a cup of tea' and 'have you finished with your cup'. Other volunteers spent time facilitating the activities or sitting at time with guests.

Some of the volunteers were also involved with the church where the café was held. Whilst there were no overt religious activities, there were comments when

talking about other guests that were unwell, of 'keeping them in your prayers'. There was a general sense of providing something for the community and being there for anyone that felt they would benefit from attending. Even though it was called a memory café, it was not specifically aimed at people with dementia and their carers but open to other older people that may be socially isolated. The term 'helper' used for the volunteers also seemed to encompass this sense of 'doing for' and the altruistic nature of providing a service to the community. This was also reflected in the amount of food provided for guests at each session given that it was the middle of the afternoon. There were also offers of support to guests outside of the café times, such as help with shopping and keeping in contact with people that were unwell. The café leader also kept guests up to date with news about guests that had been unwell.

People at the café were welcoming in their manner to me and the posters I had sent to the café leader, were laid out on the tables. The first visit gave me an opportunity to introduce myself, explain the study and speak with all the guests. Some of the volunteers were a little unsure of my role as a researcher, giving me jobs to do such as sitting and keeping one of the guests occupied. However, I was invited to attend both the trips out where costs for my attendance were covered as a 'volunteer'. In one way, I was very much accepted as part of the group during my time there but there were certain aspects that I was not openly invited to, such as the café planning meetings, however, I did not explicitly request if I could attend. These meetings were to decide upon and organise future activities.

#### **4.8.2 Café B**

Café B was less focused on providing activities and there was considerable time for guests to move around and talk to each other. Often the introduction and announcement from the café leader did not start until half an hour into the café session, with the activity available after that. The café sessions were always active with lots of conversations and laughter, however, there was a 'go-with-the-flow' approach where guests could join in with the activity if they wished or just spend the time talking to each other. The large hall was conducive for interactions between guests, and between volunteers and guests whilst an activity was facilitated at the front of the room.

The café leader seemed to be much liked and respected by the guests, with many greeting her with hugs, and wanting time to talk. The café leader kept everyone informed of the well-being of guests who had not attended for a while. Carers were encouraged to ring the café leader if they had any particular problems. During the café sessions, some of the volunteers had specific roles but most would move around and spend time sitting and talking with guests or providing drinks. Food was laid out from the start enabling guests to help themselves throughout the session. In addition to cakes and biscuits, there was fruit provided, something the café leader felt was important to ensure a healthier option.

The café was set up by the current café leader, following a visit to another memory café, and was one of the earliest cafes to be set up in Cornwall. The café initially had people with dementia and carers in separate groups but as the café grew and moved to the larger hall, everyone was now together. There seemed to be a particular focus on carers, with additional social events where

carers met up with volunteers outside the memory café session. The additional events meant carers had more regular contact with each other and the volunteers. A number of guests were carers whose loved one now lived in long-term care or had passed away. The café has established strong links with the community, to ensure it was known and well supported, such as the food share and fund raising events. The annual party was open to the community and was well attended.

I was welcomed as part of the memory café right from the start. The first visit gave me an opportunity to introduce myself and the study and spend time talking to all guests and volunteers. Everyone understood my role as a researcher, with the guests and volunteers keen for me to see what happened at their café. There was a general sense that the café was an important part of the community and provided much needed support. I was included in all aspects of the memory café, including attending the debrief at the end of each memory café session. The café leader was keen for me to see all aspects of what was involved, including the trip out, and see what was provided not just during the memory café sessions but outside these times too. I was also invited to contribute my views on how the café sessions went.

#### **4.8.3 Café C**

Café C is run by a national charity and as such there were certain processes that they had to follow. The café was initially open only to people diagnosed with dementia but then expanded to include people with a mild cognitive impairment. New guests have a form that is given out on their first visit for them to complete which includes their diagnosis. On arrival guests were greeted by a volunteer at the signing in table and then they went to sit down. Guests sat in

the same seats and with the same people at each café session. There was some interaction amongst guests and volunteers whilst people made their way to their seats. The sessions started promptly, with a welcome, information on the activity and introduction of the volunteers. The sessions were structured with a main activity, plus quizzes at each session. There was little free time for guests to converse other than during the break or when working on a quiz together. The memory café was referred to as an activity club by some of the volunteers which may explain the focus on activities. The tables were laid out pushed together in two rows on either side of the room, with chairs on the inside against the walls; meaning that if they wanted to get out, guests would need to get other people to move. The chairs on the outside were then back to back with a narrow open space between, making some activities such as the carpet bowls difficult with the restricted space.

Part way through the data collection period a carers group was introduced and held during the break. This separate time for carers to meet was introduced at the request of the carers that attended the café, as they felt it wasn't easy to talk with each other. Due to chairs being situated very close together, it was difficult to have any kind of private conversation or carers that wanted to talk without their loved one with dementia/memory problems from over hearing. The volunteers had to complete a range of training provided by the charity to fulfil their roles, which took place outside the café sessions, and as such the volunteer group seemed close. Volunteers were given identified duties such as fire marshal and first aider as part of the processes required for running the café. The majority of the volunteers stayed amongst the guests during the café session, with one or two remaining in the kitchen to sort out the drinks.

As previously discussed in chapter 2, to include a café run by the Alzheimer's Society a research partnership had to be applied for and agreed before I could attend the café. I was given a contact within the Alzheimer's Society who acted as a gatekeeper and at my first visit it was evident that the volunteers were informed of who I was and the purpose of the research. This first visit enabled me to spend time with guests too and explain what I was doing. I was made to feel welcome and included in conversations about the memory café. The café leader was keen for me to understand how the café was run in accordance with guidelines of the charity, and the other services that were available to guests.

#### **4.8.4 Café D**

Café D also had a main activity at each session usually for only part of the session, allowing plenty of time for guests and volunteers to talk. On arrival guests were greeted by the café leader and it was evident how much they were liked by the guests. Very few carers/family members stayed for the café session and would drop off and collect their loved one. However, on trips out carers/family members did attend to provide additional support to the volunteers. It was evident that the guests all knew each other well, likely helped by the fact it was a small group where everyone could sit together in a close environment. The café has been running for over five years with some guests attending since the start.

As this was a smaller café there were fewer volunteers, with the café leader facilitating the session and other one or two volunteers there for all or part of the session to help set up, pack away and provide drinks. This café was also well supported by the primary care dementia practitioner for the area, who joined in with the activities and spent time talking to guests. Guests were involved in the

running of the sessions and were often asked what they wanted to do next or what they would like at future cafés. Some of the guests also supported other guests with completing an activity. Even during the set activities there was lots of conversation and banter amongst guests that often included the person facilitating the activity. Quiz questions were also asked to the group which facilitated discussion and laughter. There was a strong sense of identity with the café having its own song that was sung whole heartily at each session, including on any trips out. There was a 'go-with-the-flow' approach to the café sessions, with the constant being a break at the midway point to have a drink and biscuits.

The group welcomed me from start and the fact that it was a much smaller group enabled relationships with guests and volunteers to be established quickly. The initial visit enabled me to spend time talking with guests about who I was and answer questions about the research. Guests were keen to tell me how much they enjoyed attending the memory café. I was very much included in all aspects of the café, including the trips out where costs were covered as a member of the café. I was often referred to as one of the group.

#### **4.8.5 Similarities and differences between the memory cafés**

All the cafés followed a similar format for when they were held; on the same day, twice a month for two hours. Three of the cafés; A, B and C were run in church halls, despite them not being directly run by the church. There are numerous churches with halls situated in towns and villages in Cornwall, making them an ideal location for memory cafés. The churches are often

situated in a central location, thus aiding with accessibility. However, many guests arrived by car or walked if they lived nearby, as public transport is limited. Café A and C were more activity focused which is evident from figures (4.2 and 4.10) in comparison to café B and D (See figures 4.6 and 4.14) which provided more time for guests to just sit and talk. All cafés provided refreshments and snacks but the amount and types of food varied.

The most common activities across the cafés were; external activity providers, quizzes, games and music (See figures 4.3, 4.7, 4.11 and 4.17). The outside providers were often music related where they would sing, encourage guests to join in or have instruments that guests could play. The quizzes were varied and included word searches, filling in missing words, music related and finding categories of words beginning with a certain letter. Café A and C would have quizzes available on the tables for guests to work through during the café session, with answers read out at the end or guests shouting out their answers. At café D the café leader would read questions to the group for guests to answer.

All the cafés experienced fluctuations in numbers throughout the data collection period (See figures 4.4, 4.8, 4.12 and 4.16). The open nature of the cafés means guests are free to attend as they wish. The drops in numbers often occurred during the summer months, June to July, likely caused by holidays or having family visiting. Café B also had a marked drop in one of the April café sessions, this was when the café leader was away. All the cafés plan the activities in advance, café B and café C for the year ahead, whilst café A and café D plan a few months ahead. Guests were kept informed at café B and C on

the activities coming up, by printing the details on a leaflet. All cafés informed guests at the end of each café what was happening next time, therefore, guests were able to choose if they don't want to attend a particular session if the activity was something they felt they would not enjoy. Café B also used digital platforms to show what was happening at the memory cafés.

All the cafés had a group of volunteers that were consistent throughout the period of data collection. The larger cafés: A, B and C had a larger number of volunteers. There was also a café leader for all the cafés with this role more evident at café B and D, where guests were obviously drawn to the characteristics of those individuals. Across the cafés the volunteers were mainly retired females, some with caring or healthcare experience. There were also some volunteers that were retired men. Only café B had younger volunteers. Across all the cafés there were a higher number of females than males for both visitors and guests.

## **4.9 Chapter summary**

This chapter has provided a detailed description of the cases (memory cafés) that were involved in the primary data collection, outlining their structure, numbers and the activities provided. By highlighting the similarities and differences between the memory cafés, and through reflexivity, inferences about the memory café have been presented. Understanding the circumstances in which an intervention runs is important for developing and refining programme theories on how and why it works. The next chapter, chapter five focuses on data analysis with the refinement of the programme theories that were generated from the realist review and the development of new programme theories.

## **5 Chapter 5: Programme theories**

### **5.1 Introduction**

This chapter presents the data collected from interviewing and observing participants at the four memory cafés. The first part is presented under the five programme theories that were developed from the realist review. For each programme theory, the related accounts from participants and researcher observations are outlined to provide evidence relating to that programme theory. As previously stated in section 2.9.7, notes were transformed into natural language, however, they have not been changed if grammatically incorrect, to ensure the actual words of participants are shown. The letters A, B, C and D relate to the cafés, the letter P indicates a person with dementia/memory problems or person living alone, the letter C for carers and the letter V for volunteer. As discussed in chapter two, participant's mental processes are not directly accessible, so inferences have been drawn based on their accounts and other evidence (Maxwell, 2012). As a starting point, the programme theories developed from the review are outlined in table 5.1. Each of these programme theories are then presented (detailing the context, mechanism and outcome), and then discussed and refined where necessary in light of the data collected. In the last part of the chapter the new programme theories are presented and discussed. These new programme theories have been developed from the data collected that did not align to the programme theories from the review.

Collectively the programme theories provide insights into how and why memory cafés work.

**Table 5.1: Programme theories developed from the realist review**

Context	Mechanism (m) and outcome (o)
If volunteers at memory cafés adopt a co-productive approach, encouraging people with dementia and their carers to shape how sessions are facilitated	Then this fosters equitable relationships (m) and a sense of ownership (m) leading to increased guest to guest interactions (o) as volunteers are not viewed as in charge (o)
If people with dementia and their carers are able to share experiences with others in a similar situation	Then this creates reciprocal relationships between guests (m) through a shared understanding (m) thus strengthening individual sense of self (o) by being able to help and value each other (o)
If cafés provide a range of activities in a safe, non-statutory linked setting	Then this creates a relaxed environment (m) and a sense of normalcy (m) thus facilitating reconnection between people with dementia and their carers (o) as the focus is on a break from their usual routine (o)
If information and support is shared between volunteers and guests, and between guests	Then this can foster a sense of belonging (m) and not feeling alone (m) which leads to the facilitating of friendships between guests (o) that might extend outside the memory café (o)
If people with dementia are mentally and/ or physically stimulated through at a memory café	Then this creates meaningful experiences (m) that lead to positive feelings (m) that are stored as emotional memories after the café session has finished (o) or perceived benefits to cognition from the person with dementia or their carers (o)

## 5.2 Programme theory 1

If volunteers at memory cafés adopt a co-productive approach, encouraging people with dementia and their carers to shape how sessions are facilitated (c), then this fosters equitable relationships (m) and a sense of ownership (m) leading to increased guest to guest interactions (o) as volunteers are not viewed as in charge (o).

This programme theory looks at the focus of memory cafés and how the sessions were structured and facilitated by the volunteers. Whilst there are some guides available, there is currently no structured or commissioned framework on how memory cafés should be delivered; this results in volunteers not having, a clear position on café role or function. This was evident from comments from all four cafés.

*The café is mainly for people with dementia and their carers but if people are lonely they can attend too – there are just as many people lonely as there are with dementia (AV3).*

*The focus of the café is support for carers – it's paramount to what we do – if we keep them happy, everyone else is happy (BV2).*

*The café is open to all that feel they can benefit from it (DV1).*

*The focus is on the person with dementia and the carers (CV1).*

*The café focuses on people with dementia (CV2).*

Two of the cafés, A and D had a broader remit than just supporting people living with and affected by dementia. Café A had opened to the wider community, encompassing individuals that were experiencing isolation and loneliness. Café

D was also flexible about who could attend the café, seeing it as being there for anyone that felt they would benefit from attending. Café C, which was run by the Alzheimer's Society, initially only accepted individuals with a confirmed diagnosis of dementia or Alzheimer's disease, but then expanded their inclusion criteria to enable individuals with memory difficulties to attend. However, volunteers had differing perceptions of their focus of support, even within the same café. One of the volunteers at café C viewed their role as mainly supporting people with dementia, whereas another volunteer viewed it as supporting both the individual and their carer. For café B volunteers, their focus was on the carers and viewed their role as primarily providing support to carers, as this in turn would help them in their caring role. Two of the cafés had chosen to support the wider community, possibly highlighting the lack of other support services available, since volunteers from both cafés had commented that they felt that this was the case.

The focus on who the memory café was for appeared to be reflected in the types of activity being offered and how the sessions were structured. Café A had much more structured time, with activity after activity being delivered, resulting in very little unstructured time being available for people to just interact with each other. The approach was also volunteer led, with volunteers standing at the front to deliver the activities.

*We are going to do this now (AV3).*

*Can everyone take part? You will enjoy it (AV3).*

As a result there was minimal physical movement by the guests, with them remaining in their seats for the duration of the session. The lack of time for

guests to freely engage with one another appeared to inhibit the development relationships between guests, since the interactions were facilitated via the volunteers delivering the activity. The impact of this was evident during a trip out; 'AP3 commented to AC4 and AP5 that they hadn't met them before', despite the fact they had attended the café on several occasions. Similarly, it was noted that café C had a strong activity focus, resulting in scenarios where guests didn't move around to talk to each other. This was possibly exacerbated by the layout of the room, with tables in long rows.

*People sit on one side or the other, people don't mix. The layout of the room makes it difficult to mix. Their side, our side (CP1).*

Café C had changed focus a number of years ago to include more activities, rather than their previous focus on educational sessions, where professionals would come in and talk to the café guests about different aspects of living with dementia. They had changed the name to activities group but memory café had stuck.

*We are now an activities group, not an education group. Feedback from clients and carers was that they didn't like the education side but liked the activities (CV2).*

A sense of doing tasks appeared to help volunteers to adopt a role and purpose whilst at the café. A traditional coordinator/helper role often associated with service delivery appeared to feel more comfortable for volunteers. It may be that just sitting and talking to guests was perceived by volunteers as helping guests in the same way as, for example, ensuring they have had enough to eat and drink.

In contrast to Cafés A and C, at Café B there was more unstructured time allowing people to talk, with carers moving around to chat to each other, whilst knowing that volunteers were there to look after individuals with dementia. Volunteers highlighted the importance of the café being informal. Café D, a much smaller café, did things differently again. It had more guests with dementia/memory problems or who lived alone, than carers. These guests sat together, around one big table along with the volunteers. With cafés B and D, there was much more a sense of ‘going-with-the-flow’ and having a more guest led approach to the sessions. This type of approach however requires volunteers to feel comfortable with this more relaxed way of working. Creating a structured format at café A and C may have helped volunteers mitigate unpredictability but resulted in the removal of a sense of freedom and choice from café guests, particularly in terms of how the sessions should run.

Contrasting perceptions of the effect of more structured and less formal approaches were noted; for example, at café A, where there appeared to be a sense of ‘doing’ for the guests and volunteers were referred to as helpers, participants AP1 and AC2 commented about how they liked ‘Being made a fuss of’. There was also more food provided, constituting a small meal, rather than just a piece of cake or biscuit.

*We don't eat before we come due to the amount of food (AC3).*

*We are well-fed here – we won't need tea tonight (AC5).*

Despite this more prescribed approach to how the café was structured and delivered, guests saw this as being focused on themselves, and consequently they seemed to appreciate being looked after. There was no pressure on guests

to be involved in the running of the café, and even during the breaks, food and drinks were brought out and collected, which the guests appeared to like.

The structure and content of Cafés B, C and D had been developed in response to the wishes of guests. For example, in café B, guests BC3 and BC4 talked about how they had been attending for a number of years and that initially people with dementia and their carers met in separate groups. Following an increase in numbers at café B, and at the requests of the guests of the café, both groups moved into a bigger room where they could enjoy time together. Café C introduced a carers' group, where carers could meet in a separate room, with one of the volunteers. This was at the request of CC2, as she thought it would be beneficial to meet separately, as she was finding it difficult to get time to talk to other carers.

CV1 said she wanted to ensure carers were supported and they were aware they wanted their own group.

*It is good the users are asking for what they want (CV1).*

*Hopefully members feel we have listened (CV2).*

Café D also considered the wishes of guests when particular activities required that they worked in smaller groups, rather than one big group around a table. DP1 proposed that they thought the café worked well when they all sat together or having part of the session in small groups and then back to the big group. This approach was discussed as a group together and then agreed amongst all guests.

*It's good that you feel able to speak out about the sessions. I thought that it had gone well (DV1).*

DV1 planned activities with the group and talked about listening to the guests and commented 'If we don't like it, we don't do it again'. The use of the term 'we' seemed to relate to the fact that DP1 viewed everyone as equal. However, this highlighted how volunteers may perceive what is happening differently to the guests and the importance in having open discussions.

The volunteers at all the cafés were predominantly women of retirement age; due in part to the cafés being held during the week, which made it difficult for people of working age to volunteer. Some cafés did run on a Saturday, as with café B, where it was felt that there was less support available for people in the week. This enabled younger volunteers to assist at café B. BV2 highlighted the mutual benefit of having younger volunteers, enabling them to develop skills and also provide a different perspective for guests. Across the four cafés, some of the volunteers had previous health care experience, such as nursing or had provided care for someone with dementia.

*Some of the volunteers have been carers (CV2).*

*Some of the volunteers used to be nurses (CV1).*

BV1 had previous care experience but had not worked with people with dementia before. BV4 had no previous dementia experience but had a family member with Parkinson's disease. AV1 talked about her personal experience of caring for someone with dementia, which was the trigger for her volunteering at the café.

*Dementia is my passion. You do something good – well you hope you do something good – you see it in their faces (AV1).*

CV1 talked about wanting to do something after her mother had died.

*I have past experience of caring for someone with dementia'. 'I want to help people that are in a similar situation (CV1).*

For café A, which was held in a church, some of the volunteers were also involved in other activities related to the church.

*Some of the volunteers are involved in the church and some are not (AV3).*

This was also noted by some of the guests (AP1, AC2 and AC5), who thought the café was directly associated with the church. The catalyst for the formation of most of the memory cafés in Cornwall was other charitable organisations such as the Rotary club or steering groups of one café, helping set up a new café in a different area.

At all the cafés, guests and volunteers wore badges that only stated their name. This approach prevented any clear differentiation between volunteers and guests. However, in café B volunteers wore polo shirts with the name of the memory café on them. Whilst the café had an atmosphere of togetherness, the uniforms provided a very visual representation of separation between volunteers and guests. A sense of separation or distinction was also evident from the behaviours of the volunteers at the cafés. It appeared that some preferred to undertake tasks, for example working in the kitchen, preparing drinks and food, whereas others would sit at tables interacting with the guests. This was more apparent during trips out. AV1, during a trip out at a local

attraction, stayed inside with guests, whereas AV2 and AV3 sat outside with a group of volunteers. At most of the café sessions, AV1 was observed to stay at the back of the room. Another example came from Café B on a trip out, BV2 kept moving around talking to everyone, whereas BV1, BV3 and BV4 sat at a table with other volunteers for a long period. It was possible that this approach of sitting away from guests provided them the freedom to enjoy the attractions, and the volunteers just being there if needed.

Annual General Meetings (AGMs) were held at each café during the data collection period. These were all held within the café hours, enabling the guests to take part and contribute their thoughts on how the café was running. AGMs form part of the cafés' constitutions and are a requirement of membership with the Cornwall Memory Café Network forum (Cornwall Memory Cafés, 2018); they are also good practice. It was noted that these AGMs followed a structured format, facilitated by the chairperson/leader of the café. Apart from at café D, there was little involvement from guests, other than confirming whether or not they were happy with how the café sessions were run. It is possible that the environment of an open forum made it difficult for guests to talk or contribute in front of all other café members. Cafés B and C also had debriefing sessions at the end of each café, and café A had a committee meeting every month, however these were for volunteers only, as they discussed their perceptions on how well the café session had gone and if they had any concerns about guests.

*We have a committee meeting every month to discuss what works – we are aware that people have different likes, for example if we have drums, I know some people won't attend (AV3).*

In contrast, Café D guests were able to talk openly in front of the café leader, possibly helped by the café being much smaller in size and all guests knowing each other. Other than at café D, and one session at café C, where carers showed photographs, there was little evidence of the cafés having peer-led aspects, where some of the guests facilitated the activities.

- **Theory refinement**

This programme theory states 'If volunteers at memory cafés adopt a co-productive approach, encouraging people with dementia and their carers to shape how sessions are facilitated (c), then this fosters equitable relationships (m) and a sense of ownership (m) leading to increased guest to guest interactions (o) as volunteers are not viewed as in charge (o)'. Despite no overt criticisms on how the cafés were run, in relation to the programme theory there was little evidence, other than from café D, of a co-productive way of working. The cafés that were more activity focused had less time for people to interact beyond their immediate table groupings in which they sat. Therefore, there were limited opportunities for guests to get up and move around and talk to others. At cafés A, B and C people tended to sit in the same area at each café week after week, possibly as it felt more comfortable for them. So, for the bigger cafés there were signs of the overall group being made up of smaller groups of guests. There was also evidence of volunteer led or instructive ways of working, which resulted in behaviours of 'providing for' or 'doing for' for guests. However, some guests said they liked being made a fuss of and waited on, as would occur in a public café. There were little data to support this theory but it highlighted different ways of working. Two of the cafés had a more volunteer led, structured approach whereas the other two cafés had a more guest led,

unstructured approach. The cafés that were more unstructured had more periods of time for guests to interact.

### 5.3 Programme theory 2

If people with dementia and their carers are able to share experiences with others in a similar situation (c), then this creates reciprocal relationships between members (m) through a shared understanding (m) thus strengthening individuals sense of self (o) by being able to help and value each other (o).

Programme theory two explores the relationships formed by guests and volunteers at the memory cafés and the social networks created. Moreover, it focuses on being in a group with people experiencing a similar situation and the reciprocity between café members. Some participants talked about how the café had helped them with feeling that they were not alone, and the importance of having someone to talk to that understands their situation.

*You learn to become more sociable. You feel that you are not alone and in the same boat (DP2).*

*Its respite, I look forward to talking to other carers and having people that will listen (CC1).*

*It's the people. It's important to go somewhere people understand (AP1).*

*I like the people, nobody is criticising. We see the funny side here. It's a lovely atmosphere (DP1).*

*I meet different people which I enjoy (AP7).*

However, for some, this did not happen straight away and was not always easy, as reflected in these quotes:

*I didn't like the memory café at first, not many people attended but then it moved venues and it got bigger. I didn't know anyone to start with but I have got to know people since attending (DP1).*

*I find it hard talking to other carers, I can't just get up and sit next to someone else, as others are listening. The room layout makes it difficult to move around (CC1).*

This quote from a carer at café C supported the observations in section 4.1 in that, at café C, the tables were placed together around the edge of the room, which made it difficult for people sitting on the inside to get up and move. This is further evidence that the variations noted in the way the tables and chairs were set out for guests impacted on how guests could interact with each other. Separate tables encouraged guests to sit with others in small groups and work on activities, with such activities enabling guests to work together and share their skills, as illustrated below:

*DP3 was observed helping another guest with how to do a water colour. She shared her knowledge and skills and gave positive encouragement.*

*AC1 was observed encouraging and helping another guest with a clay sculpture. Having a banter with them and laughing about what they were making.*

*DP1 observed helping another guest play snap. Also assisted another guests who was hard of hearing.*

Reminiscence based activities that are used to evoke memories from the past, were highlighted by the realist review as an activity that can help people with

dementia to converse with more confidence. However, observations from the cafés revealed that they rarely utilised reminiscence-based activities. This was acknowledged by one of the volunteers at café C.

*Getting people to share who they are and what they have done, we don't do enough of but not everyone would want to do it (CV1).*

Remembering the past was noted at one of the cafés, café D, where at one of the sessions, one of the guests with dementia shared memories from her life to the whole group. Everyone sat around, listened attentively and laughed at the stories told. It was apparent that this was something the group enjoyed as well as being of benefit to DP1 who became animated when reliving these experiences.

*DP1 observed to become emotional when sharing memories of her life, commented to the group, stating - It's me.*

*DP3 approached DP1 at the end of her reading her memories to say that she had enjoyed it and to say thank you - It's important to talk about what you have done.*

One of the most prominent features across all the cafés were the sounds of laughter between guests, and guests and volunteers. Gentle banter, playfulness and humour were often noted in relation to the activity or the behaviour of certain guests and volunteers.

*DP1 and DP2 observed to be laughing and singing the songs together.*

*BC1 and BC2 observed laughing and joking together.*

Another example was conversations heard between a volunteer and guests at café D. DV1 and DP2 during the session facilitated by a sculptor, where guests made clay sculptures of Prince Charles' face, had the following exchange::

*I need to blow my nose. DV1. Which nose do you want (in reference to the sculptures) (DP3).*

Another conversation between DV1 and DP1 occurred after the singing of the song 'Lipstick on your collar' during the memory café session:

*When DP1 left the bathroom she commented that she had looked in the mirror and stated 'I have no lipstick on' to which DV1 replied 'None on your collar'. DP1 laughed and started to dance.*

For some guests, humour was related to difficulties with memory problems, as captured by the following:

*CC2 commented - join the club, when the song 'Up around the bend' played.*

*DP1 and DP2 observed to use self-deprecating language, mocking their memory difficulties but in a humorous way.*

*Can't tell who are the inmates and who are the helpers. We are all nutty here (DP1).*

As discussed in chapter 4, the data reflected that the cafés varied in how much free time there was available for guests and volunteers to converse with each other. The importance of having time just to talk with each other was highlighted by some of the guests and volunteers:

*I like talking to people (AP3).*

*It's a chance to get things off your chest. We may not see each other outside the café, so we like to catch up. There is not much social opportunities outside memory café related events (BC1).*

*You feel better when you have company (AC5).*

*All they want to do is chat (BV4).*

These periods of interaction enabled guests, particularly those that were carers, to talk about their lives, share experiences and provide support. This reciprocity was evident during a conversation between guests at café A (AC1, AP3 and AC5), when two carers were talking about their loved ones deteriorating health. AC1 and AC5 spoke about their relatives being unwell and needing more support. AC1 hadn't attended the café for a while as their spouse had recently moved into long-term care and they spoke about how they were struggling with the decision. They commented.

*It's lonely on your own, I haven't been to the café for a while and I wanted to see people, I need to keep busy (AC1).*

AC5 came to the café for a break whilst their spouse was currently in hospital. There were supportive interactions between these three the guests such as:

*Look after yourself, it might sound silly but I hope he is okay (AP3 to AC5).*

At café D an another example to illustrate this programme theory was the ongoing topic of conversation between DP1 and DP2 that was noted across a number of the café sessions. This was in relation to DP1 asking DP2 about her daughter, who had been unwell. The sharing of personal information appeared to strengthen the relationships amongst some of the guests at the cafés. In particular there were carers in cafés A, B and D who continued to attend the

sessions after their loved one had moved into long-term care or had died. They would often sit together during the café sessions.

At café B, one of the carers whose spouse had died, talked about how his role had changed now that he was no longer bringing his spouse to the café. He had taken a break from attending initially but returned to the café as he felt it would be of benefit to him. He sat with another carer whose spouse had also passed away and he commented on their change in roles:

*We are no longer carers (BC4).*

The independent cafés (A, B and D) had no restrictions on attendance and there were carers that continued to attend for months and even years after their loved ones had passed away. At café C, run by the Alzheimer's Society, carers could only stay for a few months after their loved one no longer attended the café. This reflects that some cafés are part of a larger organisation and may have more rules. Therefore, carers that have formed relationships with other carers through shared understandings, may lose the connection when no longer able to attend the café.

This support also extended to individuals who attended the cafés and yet were not either living with dementia or a carer. At both Café B and Café D there were younger individuals that attended who had learning disabilities. They were warmly welcomed as guests of the café, with all the guests being largely accepting of individuals with different needs. However, it was noted that one of the individuals with a learning disability made repeated vocalisations and there was an instance at café D where DP1 was observed to become irritated by the repetitive behaviour of another guest, rolled their eyes and tried to avoid them.

Thus highlighting that guests may not always connect with others because they may be in a similar situation.

- **Theory refinement**

This programme theory states 'If people with dementia and their carers are able to share experiences with others in a similar situation (c), then this creates reciprocal relationships between members (m) through a shared understanding (m) thus strengthening individuals sense of self (o) by being able to help and value each other (o). The data collected from interviewing and observing participants supported the programme theory about the importance of being able to share experiences with others that are in a similar situation. Strong relationships had formed through the reciprocal nature of having conversations about the experiences of living with dementia or caring with someone with the condition. Whilst there was a little activity based around reminiscence, where people could share stories from the past, the majority of the conversations were situated in the here and now. Both carers and people living with dementia were able to help and value each other and share skills. Furthermore, the cafés provided ongoing support for carers whose loved ones had moved into care or passed away. Whilst their roles as a carer may have changed, they were able to continue the relationships they had formed with other guests and the cafés.

## 5.4 Programme theory 3

If cafés provide a range of activities in a safe, non-statutory linked setting (c) then this creates a relaxed environment (m) and a sense of normalcy (m), this facilitates connection between people with dementia and their carers (o) as the focus is on a break from their usual routine (o).

Programme theory three looks at the environments in which the cafés were held, the activities and why people attend. It also considers what people get from them and what activities they enjoy. Chapter four outlined the range of activities provided in the four cafés. All the cafés had some type of activity at each session that guests were able to join in with if they wished. Guests across the cafés appeared to enjoy music-based activities, particularly songs from musicals or songs that were local to Cornwall. However, music from particular genres did not always meet everyone's preferences.

*The first time I attended there was musical instruments – I really like the music (CP1).*

*I really enjoyed the music, it brought back memories, my wife was Cornish (CP1).*

*The music doesn't cover always cover all the ages here (AC3).*

The volunteers felt it was important to provide a range of activities and spent considerable time planning in advance what would take place at each session. Café B and C provided guests with a leaflet listing the activities that were

scheduled during the year, whereas café A and D, informed guests at the end of each session what would be happening at the next one:

*I like that it is informal. The guests can do an activity if they want to. There is always something to do (BV3).*

*We have a range of activities from singing, quizzes and games. It's about having fun (CV1).*

*We look at guests during the activities to see how engaged they are – make sure they don't look glazed (BV2).*

The difficulty with providing activities that met everyone's preferences was discussed at all the cafés, as was the challenge of ensuring there was a varied programme throughout the year, so the sessions did not become repetitive. For example, at café C, CP2 said how much he enjoyed the session on poetry. However, the café numbers were much smaller that day which CV1 felt was due to the activity.

*You get lost in the poems (CP2).*

*Some of the guests said it wasn't their thing and others have said they didn't enjoy the poetry (CV1).*

As memory cafés are open to a wide range of people, all with different interests, it can be difficult to provide activities that meet everyone's likes which is evident in the comments below.

*It's hard to meet everyone's likes, some people have physical limitations (BV1).*

*Some guests like the production of something, such as a card. It's difficult to please everyone (CV1).*

*It's difficult to cater for a range of people with dementia (CP2).*

*It's social, hopefully they enjoy it. Hopefully members feel we have listened about what they like (CV2).*

*There are always new people and there are mixed abilities (BC4).*

When guests were informed in advance of what was happening at the cafés, it enabled them to choose which sessions they wanted to attend. The Annual general Meetings at café A, B and D and the evaluation meeting at café C provided a formal platform for guests to feedback on the café sessions including what they liked and didn't like. Some of the activities were popular, such as the quizzes and craft activities, as they enabled people to work together. This was particularly evident at café C where there were quizzes at each café session. Guests would sit and chat about what answers they had got and there was even some competition around who got the most correct answers. However, some guests talked about not liking a particular activity, but they still joined in. Some acknowledged that the important thing was getting out and being with others:

*Karaoke is not my kind of thing. I prefer it when we can all sing. Difficult to get something for everyone. I appreciate the planning, it's about getting out (CC2).*

*AP1 and AC2 commented that they didn't really enjoy the 'Singing for the Brain' session but joined in – It's not our kind of thing.*

*AP5 and AC4 talked about not liking singing for the brain but still joined in.*

There were also some guests who talked about the joy of anticipation, of the not knowing about what was going to happen at each session:

*We never know what is going to happen (AP1 and AC2).*

*It's a surprise not knowing what you are going to do (AP1).*

*You do stuff that you wouldn't do at home (CP1).*

Or that there was something to look forward to, outside of usual routines.

*They get quality time together – out of normal routine (CV2).*

*We look forward to it. We have something to talk about after – the things and activities they have done (CC1).*

*You get stir-crazy, need to get out. Being cut off, easy to slip into a ruckus (CP1).*

*It's good to get out, it is encouraging and supporting here (AC1).*

*It gives meaning, something to look forward to (CC2).*

*It's something to do every couple of weeks (AC3).*

*It's important to get out. Beats staring at four walls (AP3).*

At cafés A and B there were individuals that preferred to not engage with the activities and just sit and watch. Guests were encouraged to join in but wishes were respected.

*I like to sit and watch (AP3).*

*BC3 and BC4 never joined in with activities, preferring to sit and talk with each other on a table at the back of the hall. (Observation)*

At café B, BV3 talked about how she liked that the group was informal: 'Guests can do activity if they want to'. At café D, DV1 commented on the how she felt it was important that the memory cafés were voluntary:

*I like the fact it is voluntary, I wouldn't want it to be regulated, as it would lose what it's all about (DV1).*

For people diagnosed with dementia and their families, there can be numerous forms to complete and regular assessment measures undertaken. However, at memory cafés, no formal assessments or monitoring are carried out as part of attending, beyond an initial form to capture contact details. The amount of forms had been commented on by guests

*They say, no more forms (CV2).*

Attending the café also provided carers with the opportunity to talk to other carers or volunteers whilst knowing their loved ones were occupied and in a safe place.

*The volunteers sit with my husband and talk to him, so I can attend the carers group (CC2).*

*The carers have time to relax and it gives them a break from their routine (AV2).*

The activities and time away from normal routines also provided time for couples to connect.

*AP1 and AC2 were observed singing to each other during one of the music activities.*

This connection wasn't necessarily through the medium of an activity but the memory café provided a place where couples could both attend. At café A, AC5 talked about her husband not being social but that he liked to sit and watch. She liked the fact that there was somewhere they could go together.

- **Theory refinement**

This programme theory states 'If cafés provide a range of activities in a safe, non-statutory linked setting (c) then this creates a relaxed environment (m) and a sense of normalcy (m), this facilitates connection between people with dementia and their carers (o) as the focus is on a break from their usual routine (o)'. The cafés provided a wide range of activities and there was considerable planning involved to ensure a varied programme. It was recognised that catering for a wide range of people, all with different likes and preferences that not everyone would like each session. Guests were informed of the activities in advance, enabling them to make a choice about which sessions they attended. However, some also liked the fact they did not know what was going to happen, with the most important aspect being a break from their usual routine. All the cafés created a relaxed environment, where guests could join in if they wished. The activities also enabled people living with dementia to do an activity with their carer or with each other, either by joining in or sitting and watching others.

## **5.5 Programme theory 4**

If information and support is shared between volunteers and guests, and between guests (c) then this can foster a sense of belonging (m) and not feeling alone (m), which leads to the facilitating of friendships between members (o) that might extend outside the memory café (o).

This programme theory explores how memory cafés bring together people who are in a similar situation, enabling connections with other people in their communities. Also, it reflects how the cafés can create environments where relationships and friendships can develop between guests, and between guests and volunteers. Guests talked about how the memory cafés were a place that they were made to feel welcome and everyone was friendly.

*I didn't know anyone when I first attended but I was made to feel very welcome, so I came back (DP3).*

*Everyone is so friendly (AP3).*

*You get a warm welcome (CP1).*

The volunteers also ensured events such as guests' birthdays were acknowledged and celebrated with a card and the whole café singing 'Happy Birthday'.

*It's important to celebrate events together (CV2).*

Some of the guests talked about how the memory cafés had given them a place to go when they no longer felt able to attend their previous groups, either due to the behaviour of others or feeling they could no longer contribute.

*We lost friends when he was diagnosed with dementia. People didn't understand and we didn't feel welcome at our previous clubs (BC6).*

*I stopped attending the Rotary Club, as I felt I could no longer contribute (CP1).*

One of the guests at café C also felt unable to tell another group he attended about his dementia diagnosis.

*I don't feel comfortable telling my bridge group about my dementia diagnosis (CP2).*

The cafés enabled new connections to be created. Some of the guests spoke fondly of the people they had been able to meet through attending the café.

*It's important to have someone to listen to you, it's about communicating (DP1).*

*It's about getting out and meeting others, puts a different spin on things. I've developed friendships from attending (CP1).*

*It's about the friendships (AP1 & AC2).*

*Friendships have formed at the café. We speak (referring to BC2) on the phone outside the café, both our husbands live in long-term care (BC1).*

*Memory cafés are social, they get people out of their ruts. It's about human companionship. I met another person with dementia at the memory café and we know go to other memory cafés together (CP2).*

These friendships were between carers, people with dementia/memory problems and couples. At café D, DP2 and DP3 had met whilst travelling on the bus to the memory café. They spent each café session together, talking and, laughing and joking. At café C, CP1 recognised another person when they first attended the memory café; this reconnection resulted in them always sitting together and CP1 being provided with a lift to attend, rather than relying on public transport. At café B, BC3 and BC4 had attended the café for many years. They always sat together and were constantly talking with each other. Both had cared for spouses with dementia who they used to bring to the café, and after they had died, they continued to attend. Whilst neither were explicit about their friendship, there was an obvious strong bond between them reflected in caring and sharing. BC4 usually gave BC3 a lift to and from the memory café sessions

and were observed sharing advice in relation to a health issue. At café A, AP1 and AC2, and AP4 and AC5, also sat together when they were all at the café and spent the sessions talking to each other.

BC6, who had lost friends following her husband's diagnosis of dementia and felt longer welcome at their previous groups, spoke of how the memory café had enabled them to develop new friendships.

*We have been attending for years. Didn't know anyone when we first attended. We haven't looked back, as we made friends with others at the café (BC6).*

Carers, in particular, emphasised the importance of being able to talk with other carers.

*Carers can share resources (BV1).*

*I've been attending for a few months. I felt left after husband's diagnosis, there was no regular support. We have formed a friendship with another couple that attend. I find it useful speaking with other carers, sharing experiences about what might happen (CC2).*

*It's important to talk to other carers...You go home to an empty house. People underestimate how that makes you feel. Coming here is a change from looking at the wallpaper (BC4).*

*The carers share how things are going, support each other. The carers like to get together to talk, it is different support than from the volunteers. If I can support anyone then I will do and if they can support me they will, that's what it is about. Volunteers not all, don't know the practical side of living it 24/7 (BC6).*

These connections weren't just contained within the memory café sessions but extended outside, with guests reporting speaking to each other on the phone or meeting up. Some guests commented that they saw people from the memory cafés by accident when out and providing an opportunity for a conversation.

*I bump into people when out that I know through the memory café (CP1).*

*The area is friendly. I met another guest from the memory café when out walking the other day and we stopped to chat (AP2).*

DP2 and DP3, who had met on the bus to the memory café, spoke of regularly phoning and meeting each other in their local community. BC4 and BC2 did not know each other until meeting at the memory café, and their conversations had led to BC4 taking BC2 to visit their spouse in hospital, as they could not drive. BC4, along with BV2, visited BC3 when they were unwell in hospital for several weeks. At café A, AP2 said that the area was supportive and that he regularly saw guests from the memory café when out in the town and they would stop and talk. At café D, they had a “pets as therapy” dog visit for one of the sessions and DP2 took a photo of DP1 holding the dog. At the next café session she brought in a printed copy of the photo for DP1 that she could keep. DP1 responded with a thank you and a smile and showed others the photos.

The cafés were also a source of information on other services for people with dementia and their carers. Cafés B and D had leaflets available for guests to take away, whilst volunteers across all the cafés would provide information on what else was available in the area if needed and benefits they may be entitled to.

*You can get information on other services, I wanted to find out about a local vicar and they helped me with that (CP1).*

*I didn't know about my council tax entitlement until I attended the memory café. It's saved me money (CP1).*

*There is information available. I found out about this café from going to another café (DP2).*

- **Theory refinement**

This programme theory states 'If information and support is shared between volunteers and guests and between guests (c) then this can foster a sense of belonging (m) and not feeling alone (m), which leads to the facilitating of friendships between members (o) that might extend outside the memory café (o). The memory cafés provided a warm and welcoming environment for guests, and a place to go when people with dementia and their carers felt unable to attend their previous groups. Carers in particular spoke of the importance of being able to talk with other carers and the volunteers. Being with others in a similar situation not only enabled new connections to be established but at time allowed much deeper friendships to form between guests. There was evidence of friendships extending outside the café sessions, including telephone calls, meeting up and providing assistance such as a lift. The volunteers at the cafés also provided information to guests on other services available.

## **5.6 Programme theory 5**

If people with dementia are mentally and/or physically stimulated through activities at a memory café (c) then this creates meaningful experiences (m) that lead to positive feelings (m) that are stored as emotional memories after the café session has finished (o) or perceived benefits to cognition for the person with dementia or their carers (o).

This programme theory explores how memory cafés can generate meaningful experiences and positive feelings for guests, as well as how guests perceive

these experiences and feelings to be of benefit to them. DP2 talked at length about the importance of attending the memory café. She said that others kept an eye on her and recognised traits when seeming unwell, such as not making an effort.

*I want to delay deterioration. I have learnt tricks and aids from other people to help with memory. I utilise positive self-talk and I do a Sudoku or crossword puzzle every day (DP2).*

She also spoke about the importance of routine and having something to get up for.

*It's not just about attending the group but getting ready to go. I like to keep busy (DP2).*

Finally, she spoke about how she felt it had helped her cognitively.

*Memory stimulation is important. I feel attending has helped with preventing deterioration. I frequently forgot where I was when out but this hasn't happened for a while. It's what you put into it (DP2).*

The impact on motivation of attending the café and joining in with the quiz- type activities was also highlighted by two guests at café C.

*The activities have helped. Getting your brain to do something. It has helped my memory and motivated me to do things at home (CP1).*

*I noticed difficulties at bridge. Keeping my brain active was advised by my psychiatrist. I go to two other memory cafés, in addition to this one. I feel my bridge has improved since attending. You have to put yourself out there (CP2).*

A focus on keeping the brain stimulated and active was also recognised by guests at café A;

*The crosswords get your brain working (AC5).*

*It's important to keep active and engaged (AP1 and AC2).*

*Coming here helps. You learn something. I do crosswords every day, keeps my mind active. It exercises the mind (AP3).*

*I enjoy the questions (AP5).*

As previously discussed, laughter and humour was evident at all the cafés. At times this was as a result of conversations between guests, guests and volunteers or the activities that acted as a catalyst for smiles and laughter. Guests spoke about the positive feelings they experienced at the memory cafés, including being cheered up and feeling better.

*I really enjoy singing for the brain. It helps you swallow and it helps you breathe (AP7)*

*I love it. I feel better for it. (AP7).*

*Cheers you up, makes you feel good. It stimulates you (AC5).*

*It lifts your spirits (CP1).*

*We have such a laugh (DP1).*

For the volunteers, they watched the guests for the engagement and responses to activities.

*You look for guests being focused on what they are doing and enjoyment in their faces (AV2).*

Some guests indicated they did not always want to attend the memory café but acknowledged that once they got there they enjoyed it and didn't regret attending.

*I don't want to come but I always feel better for it. We have such a laugh (DP1).*

*My husband doesn't always want to go, so I said 'I'm going and see what it is like', at the last minute he changed his mind, and he always enjoys it when he is here (CC2).*

*I always feel better for attending (DP3).*

Not all the experiences, however, were positive. At one karaoke session at café C, where guests could get up and sing if they wanted to, CP2 talked about not enjoying the music. He wanted to sing something that was more to his personal preference, however, the volunteers missed his cues indicating that he wanted to have a go. At the following memory café session he said he was disappointed that he wasn't able to sing. At café D, during the trip out, DP1 experienced some mobility difficulties. She spoke about how much this had upset her at the next memory café session, as it was in front of others, and she said that it had ruined the trip for her. Whilst the majority of experiences for people were positive and resulted in guests returning, negative experiences also had an emotional impact and remained after the event.

#### ▪ **Theory refinement**

This theory states 'If people with dementia are mentally and/or physically stimulated through activities at a memory café (c) then this creates meaningful experiences (m) that lead to positive feelings (m) that are stored as emotional memories after the café session has finished (o) or perceived benefits to cognition for the person with dementia or their carers (o). Many of the guests felt it was important to keep their brains active through cognitive based activities like quizzes. For some individuals living with dementia and memory problems,

they felt this had an impact more broadly on their day to day functioning. Whilst these self-reported improvements were not validated by an objective assessment measure, it is important to recognise the impact that self-perceived benefits had on an individual's experiences and well-being. Not all experiences were positive and, again, they had a wider and lasting impact than just around the actual event, with emotional memory remaining for subsequent sessions.

## 5.7 New programme theories

The additional data collected that did not fit with the programme theories developed from the realist review, were analysed and formulated into new programme theories, using the process of theory development described by Walker & Avant (2014). The data were analysed by first identifying concepts and then looking at the relationships between concepts to formulate theories. These new programme theories provide further explanation on how and why memory cafés work. Table 5.2 details the new programme theories.

**Table 5.2: New programme theories**

Context (c)	Mechanism (m) and outcome (o)
If memory cafés have volunteers with a range of characteristics (c)	then this will ensure guests are well supported (m) and continue to attend (m) due to having positive experiences (o).
If memory cafés are volunteer led (c)	then this may lead to volunteers putting in considerable work (m) and viewing their role more broadly (m) to provide additional support to guests (o).

If there are a number of memory cafés available for people with dementia and their carers (c)	then they are able to choose (m) which one they prefer (m) which best meets their needs and interests (o).
If memory cafés have clear information on what they provide (c)	then this will help ensure other services and the wider public are better informed (m), and be able to recommend it to people with dementia and their families (m) and maximise the inclusivity of the café as part of the community (o).

### 5.7.1 Programme theory 6 and 7

#### Programme theory 6

If memory cafés have volunteers with a range of characteristics (c), then this will ensure guests are well supported (m) and continue to attend (m) due to having positive experiences (o).

#### Programme theory 7

If memory cafés are volunteer led (c) then this may lead to volunteers putting in considerable work (m) and viewing their role more broadly (m) to provide additional support to guests (o).

As previously discussed, the memory cafés in Cornwall are all run by volunteers. These programme theories focus on the characteristics of the

volunteers and the volunteer structures in the memory cafés. At cafés A, B and D there were no specific role descriptions for the volunteers, other than a wish to support their local community and people living with dementia and their carers. Café C in contrast advertised when they required a volunteer for the memory café and had a clear role description. They also had to complete various training to meet the requirements of the role.

*The Alzheimer's Society advertises when they need volunteers, including for the cafés. They have to do a lot of training and we have a volunteers meeting every 3 months (CV2).*

At the independent cafés, there was training for volunteers available through the Cornwall memory café network forum. The majority of the volunteers at all the cafés had been there for a number of years and each café had a static volunteer group.

It was clear from the data that volunteers gave up their time freely and there were few criteria for the role, other than a desire to help. Café C was different in that this was run by the Alzheimer's Society, and did advertise for its volunteers; this approach was due to its national charitable status. All the cafés included in this research had a core group of volunteers who had been part of the cafés for a number of years, many since the inception of the cafés. The need for the right type of volunteers was highlighted by BV2.

*We need volunteers to have the right characteristics – sometimes they can take over – especially if they have worked in a role where they have been in charge (BV2).*

*It's not our café. We are here to facilitate, some of the volunteers are ex-managers and need reminding that it is not our café – there is no us and them (BV2).*

All the cafés appeared well supported by volunteers, with the volunteers remaining consistent throughout the period of data collection. Café D, being the smaller café, had a much smaller group of volunteers. DV1 talked about some of the difficulties in attracting new volunteers.

*We have had some people interested in being a volunteer, they just come once and don't return or just want to make a cup of tea (DV1).*

However, the current groups of volunteers at all the cafés appeared to get on well, with some being involved in activities together outside the café.

*The volunteers are very close and go out together socially (CV1).*

There was a range of characteristics observed amongst the volunteers; from those that were outgoing; laughing, smiling, joking and dancing, to those that preferred to stay in the background and complete tasks such as providing drinks, or those who would sit and have conversations with guests at the tables. The volunteers were viewed as integral to the memory café and the experiences of the guests.

*The approach of the volunteers is what makes the café (BC4).*

*The volunteers are great (CP1).*

*The volunteers put in a lot of hard work, they help me get my husband out of the car which means I am able to attend (AC5).*

*It's the personality of the volunteers (CP2).*

The characteristics of the volunteers also resulted in a negative experience for one carer at café B.

*The volunteer manner can affect how you feel, I was questioned by a volunteer, who is no longer here, when I first attended, I found her manner quite upsetting (BV6).*

All the cafés ran for two hours twice a month, with the volunteers spending time either side of the guests arriving and leaving, to help set up and pack away the room. One of the volunteers, at café C, expressed the challenge of trying to support so many guests during the session.

*It's difficult to speak to people. I hate not being able to give time to everyone (CV1).*

However, discussions with the volunteers revealed that some were also doing considerable work outside the café time. This involved preparation for the café, such as organising the activities and sorting out the finances.

*There is lots of work to do outside the café, including paperwork and sorting out the money (CV1).*

*I have lots to do outside the café from sorting out the food for the food share, to planning and sorting the activities. It's hard work but enjoyable (BV3).*

*The work involved is time consuming (DV1).*

Some volunteers would also provide support to guest outside the café sessions. At café A, a volunteer would ring what AV3 described as the 'vulnerable' guests on the morning of the café to remind them that the café was on. They would also contact guests they had not seen for a while to check they were okay. Furthermore, at each café session guests were informed they could contact the volunteers if they had any concerns or worries, or needed help with the collecting of shopping. Guests were also kept up to date with news on other

guests that had been unwell or passed away and reminded of events such as flu jabs.

*If you know someone that is unwell, let us know (AV3).*

*Don't forget flu jabs are available (AV3).*

Observations revealed that, at café B, BV2 provided support to carers outside of the memory café sessions, from phone calls to visits. When BC4 was unwell in hospital, BC2 went along with BC3 to visit them in hospital. She talked about the focus on supporting carers.

*It's about trust, people feel they can talk to me. Carers know they can ring me. I have been involved in sorting out various problems for guests (BV2).*

*Carers are paramount to what we do, if we keep them happy that keeps everyone else happy (BV2).*

This was confirmed by one of the carers.

*I talk to BV2 if I have any concerns (BC6).*

This level of support offered by the volunteers at the memory cafés, appeared to reflect the involvement of statutory organisations at each café. As previously discussed, in section 4.7.5, primary care dementia practitioners perform a role within secondary mental health services and linked to GP surgeries in Cornwall. However, the role provision is not uniform across the whole of the county, since it is just one geographical area that has this different model of service provision. Café B in particular had no input from statutory organisations, health or social care services. This was commented on by BV2, who felt their memory café was not supported and was concerned by the lack of services available to help

carers. However, she also felt that her involvement in supporting guests was not always well received.

*We are not supported by statutory services. I feel we can be seen as busy bodies when we get involved in helping guests (BV2).*

Café A experienced infrequent visits from the dementia care practitioner; however links did exist as reflected in comments by AV3 who said they would ring them if they had any concerns. However, the primary care dementia practitioner's focus was on those individuals who had a diagnosis of cognitive impairment or dementia, thereby limiting the scope of support. CV1 reported that the café had been previously well supported by the primary dementia care practitioner but, due to staff leaving and the time taken awaiting a new person to start, there had been a gap in support provision. Café C did not provide additional support to guests outside the café, as the Alzheimer's café had a separate helpline and telephone befriending service. However, CV1 commented that they would ring guests they had not seen for a while. In contrast at café D, the primary care dementia practitioner visited most of the café sessions where they would check on guests they supported at home. DV1 would also speak to the primary care dementia practitioner, to keep each other up date if there were any issues with the guests.

The motivations for volunteering at memory cafés has been discussed in programme theory one, with many citing previously working in health care or supporting someone close to them with dementia. Most of the volunteers, however, did not have any prior knowledge about memory cafés before becoming involved, possibly reflecting a lack of awareness about memory cafés, in general, and their provision across Cornwall.

*I had not heard about memory cafés before (CV1).*

*I didn't know about memory cafés, until I saw an advert about in in the local paper and came along to see what it was all about, I hadn't worked with people with dementia before (BV4).*

*I only went along to make cups of tea, I saw a local add requesting help, I wasn't sure what it was (DV1).*

*I have previous care experience but not worked with people with dementia before, it was recommended as a place to volunteer. I hadn't heard about memory cafés before (BV1).*

The three independent cafés had a chairperson and café C had a café leader. However, this role varied across the cafés. Also, the chair person was not necessarily the person who ran the sessions. At café A and café C, identification of the leader was not easily apparent. There seemed to be a group approach to running the café sessions, especially facilitating the activities. Café B had a clear leader, who was obviously well thought of by the guests, with them greeting her with hugs and kisses. She was passionate about the memory café, as well as appearing self-assured but acknowledged that she found it difficult to rely on other volunteers.

*I do something most days to do with the memory café. I can't delegate, I rather do things myself (BV2).*

She had grown up in the area, so knew local residents, and this appeared to have helped with encouraging some of the guests to attend.

*My husband had dementia and we knew BV2 outside the café, she suggested we attend, so we did because of her (BV6).*

*I was encouraged to attend by BV2, not allowed to say no (said jokingly) (BC2).*

*A lot of people know BV2 (BV3).*

*I didn't know anyone when I first attended but I knew BV2 (BC5).*

Café D also had a visible leader; it was the smallest café, and she ran all the café sessions with some input from other volunteers. She had a warm, jovial manner, was humorous and engaging and often mocked herself, stimulating a laugh.

*DV1 is key (DP2).*

*It's like a family. The person who runs it makes a difference. DV1 always has a smile on her face and that is so welcoming (DP3).*

*She is the life and the soul. She keeps it together (DP1).*

The impact of having one clear leader at café B and D was something they both had thought about, including what would happen if they were away. Café B ran successfully whilst BV2 was away, but the numbers of attendees dropped considerably. The leader at café D, who had a much smaller group of volunteers, worried what would happen if she was unable to be there. This highlighted some of the challenges faced by some of the smaller cafés that have less resources available.

#### ▪ **Programme theory development**

This programme theory has highlighted the integral role of the volunteers in the running of memory cafés. Volunteers put in considerable work outside the café sessions to ensure they ran successfully. Furthermore, some volunteers provided specific support to guests, including phone calls and visits, and viewed their role as wider than just within the café sessions. The characteristics of the

volunteers were also key in ensuring guests continued to attend and the experiences they gained from attending. These findings are presented as two separate programme theories.

### 5.7.2 Programme theory 8

If there are a number of memory cafés available for people with dementia and their carers (c) then they are able to choose (m) which one they prefer (m) which best meets their needs and interests (o).

As previously discussed in section 4.2, there are currently over forty cafés in Cornwall, with figure 4.1 showing the distribution. There are memory cafés that are now situated within a few miles of each other. This programme theory explores how this has enabled guests to have a choice over which cafés they attend. Discussions with carers and people with dementia revealed that some had chosen to go to a particular café based on the size, the mix of people present, the volunteers and the activities. DP2 and DP3 talked about attending another café but found it too big. DP3 also found the number of men present uncomfortable.

*I went to another café but it was very big with lots of men which I found quite dominating. I prefer this café as it is smaller (DP3).*

*I previously attended another café where I found out about this one. I prefer this café as it is a smaller group. I feel some of the bigger ones can be cliquey. I find it difficult due to my age as people assume I am a carer (DP2).*

At café B, BC2 had also chosen to attend the café after finding they preferred it compared to the one they had previously attended.

*I found out this café through BV2 who I met at the other café I previously attended. I really liked her, so I came to this café instead. I prefer this one. She encourages me to attend (BC2).*

The range or type of activities, as well as the size, was also an issue for AP5 and AC4, who had attended café A and another café nearby. AP5 preferred café A as it was bigger and they did more quizzes.

*We went to another café but AP5 prefers this café as it is bigger and he found it difficult being exposed in a smaller group (AC4).*

*I like more activities rather than just sitting and talking. I like to keep busy with quizzes which they do a lot of here (AP5).*

Another couple at café A, AP1 and AC2, had selected to come to this café, despite living a number of miles away, because it was held at a time that fitted in with their other commitments. Cafés being run on different days and different weeks of the months, particularly those situated near each other, provided choice to guests, so they could attend the that café best fitted around their other commitments or they could attend multiple cafés. This was evident at café C where there was a group of guests and carers that attended 2-3 cafés per month.

*I go to two other cafés as well as this one. I feel more comfortable at one of the other cafés as they do more quizzes but I like to attend all of them to keep busy (CP2).*

*I have been to two other cafés, each has different value. This one is noisier and chatty (CP1).*

*I take my family members to two other cafés, as they are on different days. One is quite similar to this one (CC1).*

*There is a group of us that go to a few cafés (CC1).*

Guests did not attend every session. The open and flexible nature meant they could dip in and out as they wished. The numbers at some of the cafés fell during the summer months, possibly due to family members visiting. The information from participants revealed that people with dementia and their carers are not homogenous in what they like and don't like about memory cafés. Having a number of memory cafés enables people to attend a particular café or attend multiple cafés to meet different preferences and provide opportunities to occupy their time.

- **Programme theory development**

People with dementia and their carers have different needs and preferences. The provision of services that are facilitated in a specific way, or follow a set format, may not be inclusive to the diversity of people living with dementia and their carers. The fact that the cafés vary in size, type of activity and format, provided choice for people with dementia and their carers. The availability of a variety of memory cafés, enabled them to be 'consumers' and select which café they preferred or had the option to attend multiple cafés.

### 5.7.3 Programme theory 9

If memory cafés have clear information on what they provide (c) then this will help ensure other services and the wider public are better informed (m), and be able to recommend it to people with dementia and their families (m) and maximise the inclusivity of the café as part of the community (o).

Programme theory nine focuses on memory cafés in the context of the wider communities and how guests found out about them. The provision of memory cafés across Cornwall and the contact numbers are available on the Cornwall Memory café Network Forum's website. However, only two of the guests, AC4 and AP5 (married couple), had found out about the memory café through looking online. The other guests had been informed about the memory cafés through other services or word of mouth.

*We started attending due to a friend that goes, they recommended it to us (AP4 and AC3).*

*I found out about the memory café through the cognitive stimulation group I attended with my husband (BC1).*

*I found out about the memory café through the local care home (AP3).*

*We found out about the memory café from the admiral nurse (AC2 and AP1).*

It was only at café C that guests had been advised to attend the memory café by a healthcare professional.

*The psychiatrist recommended I attend the memory café, I went with the primary care dementia practitioner the first time (CP1).*

*The memory assessment nurse told me about the memory café but it took me a while to go (CP2).*

Individuals with dementia and their families should, ideally, come into contact with a number of health professionals; these include psychiatrist, memory assessment nurse or, typically, their GP. These healthcare professionals are in an ideal position to inform people with memory problems or dementia of the services that are available, which they may find beneficial to them. It is possible that there is geographical variation across Cornwall in whether GP and secondary health services are informing people of the availability of memory cafés, possibly due to not knowing they are there or not feeling able to recommend them due to limited knowledge of what they do. Advice from a healthcare professional appears influential and it may be more likely to be taken, as shown by one of the guests at café C.

*After seeing the psychiatrist he recommended I should attend the memory café, so I felt it necessary to try it (CP2).*

Three of the cafés had a sign placed outside the building on the day the café was held to inform people in the community that the café was open, and the time of the session. This gave a very visible indicator when walking past that a memory café was held in that location. One of the volunteers at café D (DV1), talked about how she felt people may not attend the memory café due to the stigma associated with dementia. She spoke of collaborating with other voluntary services in the area such as Age Concern, to see if there were people who would also want to attend the memory café. Café B also spoke of involving

the café in community life and arranging trips for guests to attend events such as the pantomime.

*It is important that the café is part of the community (BV2).*

Café B and D encouraged the wider community to attend café events. This was evident at several of the sessions, where different individuals joined in with the café activities or provided lifts to events away from the café location. This may be due in part to the characteristics of the areas; where the communities comprise people who have lived there for most of their lives and formed relationships over a number of years due to a shared history. This was commented upon by one of the volunteers at café B.

*People know each other, connections have been made from living in the area for a long time (BV1).*

In contrast, one of the volunteers at café A viewed the café differently in context to the wider community.

*There is a sense of community, it creates a new community, a community within a community (AV3).*

In addition to the cafés being listed on the Cornwall Memory Café Network forum website and having signs outside the café locations, there appeared to be minimal advertising of what the cafés provide. One of the guests at café C, said he didn't feel posters were a good way of advertising what happens at the memory café and that a poster would not have attracted him to it. He also talked about the need for informing areas of the wider community about the memory café.

*There are lot of people that would benefit from it, like those in social housing (CP1).*

- **Programme theory refinement**

This programme theory has highlighted the importance of raising awareness about memory cafés for both health and social care services, and the wider public. Also, that information needs to be available through various platforms. Only a couple of the guests had found out about it online, with another guest commenting that a poster would not have attracted him to attending. There was some evidence of linking with the wider community and other charity organisations. Expanding these connections would increase recognition of memory cafés and what they provide.

## **5.8 Chapter summary**

This chapter has presented the exploration and refinement of the five programme theories from the review through analysis of primary data collected from the four case study cafés. In addition, four new programme theories were developed through this analysis to provide a more comprehensive picture of how and why memory cafés work. The next stage is the development of a conceptual platform that outlines the ‘internal’ or ‘necessary’ components of an intervention (Pawson, 2013, p.92). This is detailed in the following chapter.

## **6 Conceptual platform and discussion**

### **6.1 Introduction**

This chapter outlines the conceptual platform that has been formulated from the nine programme theories. A conceptual platform details the essential components (Pawson, 2013, p.92) or core set of processes (Pearson *et al.*, 2015, p.9) of how a programme works. As Pawson (2013) discusses, to be able to test programme theories and compare and contrast them, their essential components need to be identified. These essential components can be applied to relatable interventions and investigated again, to develop and test the programme theories. Evaluation of programmes often start from scratch, despite the ideas for programmes being 'begged, stolen and borrowed' from other programmes (Pawson, 2013, p.94). By identifying the essential components, the conceptual platform operates at a level of abstraction that can be transferred and applied to other programmes, thus, preventing evaluations starting from the beginning each time.

The core processes have been numbered 1-12 and will be discussed in relation to the broader literature and the related programme theories. Some of the core processes are looked at individually and others have been grouped together where they are related. The conceptual platform will also be considered in relation to a prominent discourse in dementia care, that of person-centred approaches. It proposes that there needs to be a shift towards, and greater focus on, relationship-centred approaches and a relational model of dementia care. This leads on to a discussion about the focus on measuring impact within dementia care and the different views of people with dementia, carers and

health professionals. This is followed by section on reflexivity, which will consider the researcher's thoughts on the research process and how their perceptions and understandings may have shaped what was observed, recorded and the account given. As such this section is written in the first person. The strengths and weaknesses of the research are then outlined, incorporating a discussion on the application of realist research and ethnography, exploring how realist methodology may potentially mitigate some of the challenges faced by ethnography as outlined by Hammersley (2018). Finally, it will conclude with how the thesis makes an original contribution to research and sets out recommendations for future research.

## **6.2 Conceptual platform on memory cafés**

This section outlines the conceptual platform comprising the core set of processes for how memory cafés appear to work. Memory cafés work by:

1. Establishing from guests what they like and don't like through formal and informal feedback methods.
2. Involving guests as much as they wish in the running of the memory café.
3. Creating opportunities for humour and laughter.
4. Providing guests with time just to talk with one another around the structured activities, creating opportunities for relationships to form.
5. By being a place of continuity for carers even after their carer role has ended and enabling the broadening of social networks.
6. Providing a range of activities such as music, quizzes, crafts and including an opportunity for guests to share their history and skills.
7. Volunteers having a range of characteristics and knowledge on how to support people with dementia and their carers.

8. Ensuring the environment is conducive for guests to interact with each other, such as how the tables are laid out and providing space for people to move around.
9. Having information on other services available for guests.
10. Promoting the work of cafés through various routes and being part of the wider community.
11. Being responsive to local communities and adaptive to changing guests.
12. Establishing strong links with statutory agencies.

The following table (6.1) shows the core processes and their related programme theories.

Context	Mechanism (m) and outcome (o)	Core processes
1.If volunteers at memory cafés adopt a co-productive approach, encouraging people with dementia and their carers to shape how sessions are facilitated	Then this fosters equitable relationships (m) and a sense of ownership (m) leading to increased guest to guest interactions (o) as volunteers are not viewed as in charge (o).	Establishing from guests what is important to them and what their preferences are through informal and formal feedback methods. Involving guests and much as they wish in the running of the memory café. Volunteers having a range of characteristics and knowledge on how to support people with dementia and their carers.
2.If people with dementia and their carers are able to share experiences with others in a similar situation	Then this creates reciprocal relationships between guests (m) through a shared understanding (m) thus strengthening individual sense of self (o) by being able to help and value each other (o).	Providing guests with time just to talk with one another around the structured activities, creating opportunities for relationships to form. By being a place of continuity for carers even after their carer role has ended and enabling the broadening of social networks. Creating opportunities for humour and laughter. Ensuring the environment is conducive for guests to interact with each other, such as how the tables are laid out and providing space for people to move around. Having information on other services available for guests.
3.If cafés provide a range of activities in a safe, non-statutory linked setting	Then this creates a relaxed environment (m) and a sense of normalcy (m) thus facilitating reconnection between people with dementia and their carers (o) as the focus is on a break from their usual routine (o).	Establishing from guests what is important to them and what their preferences are through informal and formal feedback methods. Involving guests and much as they wish in the running of the memory café. Providing guests with time just to talk with one another around the structured activities, creating opportunities for relationships to form.

		<p>By being a place of continuity for carers even after their carer role has ended and enabling the broadening of social networks.</p> <p>Providing a range of activities such as music, quizzes, crafts and including an opportunity for guests to share their history and skills.</p> <p>Being responsive to local communities and responsive and adaptive to changing guests.</p>
4.If information and support is shared between volunteers and guests, and between guests	Then this can foster a sense of belonging (m) and not feeling alone (m) which leads to the facilitating of friendships between guests (o) that might extend outside the memory café (o).	<p>Providing guests with time just to talk with one another around the structured activities, creating opportunities for relationships to form.</p> <p>By being a place of continuity for carers even after their carer role has ended and enabling the broadening of social networks.</p> <p>Ensuring the environment is conducive for guests to interact with each other, such as how the tables are laid out and providing space for people to move around.</p> <p>Having information on other services available for guests.</p> <p>Promoting the work of cafés through various routes and being part of the wider community.</p> <p>Establishing strong links with statutory agencies.</p>
5.If people with dementia are mentally and/ or physically stimulated through at a memory café	Then this creates meaningful experiences (m) that lead to positive feelings (m) that are stored as emotional memories after the café session has finished (o) or perceived benefits to cognition from the person with dementia or their carers (o).	<p>Creating opportunities for humour and laughter.</p> <p>Providing a range of activities such as music, quizzes, crafts and including an opportunity for guests to share their history and skills.</p>

6.If memory cafés have volunteers with a range of characteristics (c)	then this will ensure guests are well supported (m) and continue to attend (m) due to having positive experiences (o).	Volunteers having a range of characteristics and knowledge on how to support people with dementia and their carers.
7.If memory cafés are volunteer led (c)	then this may lead to volunteers putting in considerable work (m) and viewing their role more broadly (m) to provide additional support to guests (o).	Volunteers having a range of characteristics and knowledge on how to support people with dementia and their carers.
8.If there are a number of memory cafés available for people with dementia and their carers (c)	then they are able to choose (m) which one they prefer (m) which best meets their needs and interests (o).	Providing a range of activities such as music, quizzes, crafts and including an opportunity for guests to share their history and skills. Being responsive to local communities and responsive and adaptive to changing guests. Promoting the work of cafés through various routes and being part of the wider community. Establishing strong links with statutory agencies.
9.If memory cafés have clear information on what they provide (c)	then this will help ensure other services and the wider public are better informed (m), and be able to recommend it to people with dementia and their families (m) and maximise the inclusivity of the café as part of the community (o)	Promoting the work of cafés through various routes and being part of the wider community. Establishing strong links with statutory agencies.

**Table 6.1: Programme theories and corresponding core processes**

### **Core processes**

- **Establishing from guests what is important to them and what their preferences are through informal and formal feedback methods**
- **Involving guests and much as they wish in the running of the memory café**

These two core processes relate to programme theory 1 and programme 3.

They focus on the importance of involving people with dementia and their carers in the running of memory cafés and gaining feedback on how the memory cafés run. Involving service users in health and social care is important as this facilitates meeting their needs and preferences, and such an approach has gained increasing recognition as being fundamental to the development of services. At a statutory level, the Health and Social Care Act (2012) details the need for NHS England and the Clinical Commissioning Groups to involve people in their own health and social care. The guidance outlines that involving people in their own health and social care; improves health and well-being, improves care and quality, improves financial sustainability and enables the efficient allocation of resources (NHS England, 2017). Whilst this is a legal framework for NHS England and the Clinical Commissioning Groups, it states that it might be of interest to the voluntary community by providing information on how to run a service. According to the King's Fund (2014), this move towards service involvement is due to the rise of consumerism, the decline of traditional paternalism and the persistence of health charities and patient advocate groups. The Health and Social Care Act (2012) also separated patient and public involvement into two separate groups with separate duties for each. Similarly, in social care the involvement of service users has also been driven

by a number of factors; social inclusion, rights and citizenship (King's Fund, 2014).

Citizenship is about an individual's relationship with the state (Bartlett & O'Connor, 2007). Typically viewed from the perspective of an individual meeting the requirements of a state, citizenship is a status that is bestowed by the state, as defined by Marshall (1949/92, p.18). However, this traditional view has been criticised for focusing on the influence of the state on the individual, and not the individual on the state (Bartlett & O'Connor, 2010). The social model of disability has been influential in showing how society disables individuals and highlighting the inequalities faced by disabled people in achieving civil rights (Boyle, 2008). According to Bartlett and O'Connor (2010, p.31) the Marshallian view of citizenship presumes capacity and cognisance, thus people with dementia have been excluded the status and rights of citizenship (Boyle, 2008).

Viewing people with dementia through a social disability lens helps to identify how they can be disabled by society (Boyle, 2008), such as access to and use of everyday places. Bartlett and O'Connor (2010) rightly argue that citizenship has been given little attention for people living with dementia, or only in the context of receiving care. Social citizenship considers not just rights and responsibilities but involvement in all aspects of life, including the services that are provided.

At the memory cafés, there was a lack of clarity on their role and function, resulting in the cafés having very different ways of working. Kelly and Innes (2014, p.3) discuss how services designed to support people with dementia can have slightly different aims (such as information and signposting, peer support

or socialisation) and different philosophies (such as person-centred or citizenship based approaches). Whilst there were no overt criticisms from guests about the memory cafés, there was little evidence, other than at café D, of guests being involved in how the memory cafés were run. Of note is that some of the guests talked about liking being made a 'fuss of' and being 'waited on', as you would expect when visiting a public café.

Despite a growing recognition of social citizenship in dementia discourse, there is a need for carers and people with dementia to attend places where they feel comfortable and they can relax, without feeling they have to be involved in some way with how it is run. However, it is important that different ways of working at memory cafés are explored, as some guests may wish to be more involved than others and ideas of 'providing for' and 'doing for' should not be assumed. A study by Clare, Rowlands & Quinn (2008, p.10) showed how facilitator led groups can lead to guests adopting a passive role and becoming dependent on the facilitator, with facilitators adopting a 'dependency-support-script'. Thus people with dementia and their carers that attend memory cafés may adopt a passive role, whereby the volunteers are viewed as 'in charge' and as such feel unable to contribute to how they are run.

There were some similarities in the structure of the sessions across the cafés but flexibility in delivery and the activities. Unlike other structured, time limited groups where there is often a focus on ameliorating a particular symptom or problem such as carer burden, depression or maintaining cognition, memory cafés have no specified measurable outcomes. Phinney (2016) posits that whilst psychosocial interventions have emerged as an alternative to medical

treatments they are often aligned to a medicalised viewpoint of negative states. Outcome measures in dementia care have also been developed from a negative viewpoint, where well-being is inferred from a reduction or absence of negative states (Clarke, Wolverson & Moniz-Cook, 2016). What is meaningful to people living with dementia that attend the café, the outcomes, may not always be easy to demonstrate or measure. According to Phinney (2016):

*Subjective measures are often critiqued for being prone to 'bias', but what this fails to recognise is their potential to reveal the complexity and contextual richness that contributes to these kinds of evaluations (Phinney, 2016, p.72).*

It is important that the memory cafés facilitate a co-productive way of working, where guests are informed they can be involved in how the café operates and guests are supported to do so, if they wish. As such people living with and those affected by dementia should have input into, and shape what they want from the café sessions, so that the outcomes are relevant to them.

### **Core Processes**

- **Providing guests with time just to talk with one another around the structured activities, creating opportunities for relationships to form**
- **By being a place of continuity for carers even after their carer role has ended and enabling the broadening of social networks**

These two core processes focus on memory cafés as a means to provide social contact with others, and to broaden social networks. They encompass programme theories; 2, 3 and 4. People living with dementia are the biggest recipients of social care but worryingly those living with and affected by

dementia are not always receiving the support they need, and may have to pay for services (Alzheimer's Society, 2017). In addition to requiring increased support, people living with dementia may find themselves becoming increasingly isolated and separated from the world around them (Phinney, 2016). This can be due to changes in abilities but, more so, due to misunderstandings and the stigma (Goffman, 1968) of dementia (Alzheimer's Society, 2017; Phinney, 2016). These result in people living with dementia being at higher risk of social isolation than other social groups (Alzheimer's Society, 2018b).

Dementia sits at the intersection of ageing, disability and mental health (Ward & Sandberg, 2019) meaning people living with, and affected by, dementia can experience multiple discrimination. Society has become increasingly individualised (Ferguson, 2016; Hughes, 2014) and 'hypercognitive' (Post, 2000). Stephen Post, an American ethicist, described a hypercognitive society as where too much emphasis is placed on cognitive abilities. For people living with dementia and their families this can lead to them feeling excluded from society, which is further compounded by the high value placed on youthfulness (Brooker, 2004) and the narrative around the burden of dementia (Shakespeare, Zeilig & Mittler, 2019). This can lead to people living with dementia becoming increasingly socially isolated. Loneliness, the subjective experience of isolation (Ferguson, 2016; Sutin *et al.*, 2018), is also associated with increased risk for early mortality (Holt-Lunstad *et al.*, 2015). The Harvard Well-being study, which has been conducted over a 75 year period, has consistently shown that relationships and the quality of those relationships are a powerful factor in shaping physical and mental health, and cognitive function

(Mineo, 2017). Furthermore, a meta-analysis of over 200 studies found a strong association between the quality of social contacts and subjective well-being (Pinquart & Sörenson, 2000).

These assumptions about loss of capabilities and increased dependency means people living with dementia may no longer feel part of previous social groups. This was evident from some of the comments from guests who felt they were no longer able to attend their previous groups, either due to feeling they could no longer contribute or not feeling welcome anymore. Stigma rests on the belief that little can be done for people with dementia due to the fact it is a deteriorating condition (Moniz-Cook & Manthorpe, 2009). Therefore, as memory cafés provide a place for people in a similar situation, they are free of the stigma that people living with and affected by dementia may experience in other areas. Moniz-Cook and Manthorpe (2009) consider memory cafés as social inclusion interventions where there is a strong focus on meeting others and social engagement. What was apparent across the cafés is that they created a space where people felt safe and were seen as equals (Capus, 2005).

The impact of caring for someone with dementia has long been a focus of dementia research. Historically framed from a stress/burden paradigm (Keady & Nolan, 2003), more recent research has explored the nuances of caring for a loved one living with dementia and highlighted that it is not a universally negative experience. Hellström *et al.* (2007b) found that couples work actively to maintain their quality of life for as long as possible and worked together to sustain couplehood. Individuals living with dementia are also able to recognise the psychological needs of their carers/families as evidenced in Bryden's (2005)

account of living with dementia. Ablitt, Jones, & Muers (2009), found that people with mild to moderate dementia are aware of the psychological health of the family member who cares for them. This shared recognition and understanding of accessing support services can be difficult when interventions can be quite specific in who they support and what they provide. That's not to say that specific interventions are not required, but that it is important that there are places people living with and affected by dementia can go together. Research into art gallery interventions for people with dementia and their carers found that carers were still able to have a period of respite and receive support, even when their loved one with dementia was present (Camic, Baker & Tischler, 2016).

Whilst the cafés generally support people living with dementia and their carers/families together, all were flexible in some way in terms of who attended. Examples of this included individuals living with dementia that lived alone and carers whose loved ones had passed away. The number of people living alone with dementia will double over the next 20 years (Alzheimer's Society, 2019a), so having somewhere that they can attend and be with others is vital to reduce isolation and loneliness. For carers whose loved ones had passed away, the memory cafés provided a place of continuity (Greenwood *et al.*, 2017). This recognition of a loss of role was significant to some of the carers, and being able to continue attending the memory café enabled the connections they had developed with others to be maintained.

The peer support model is well established in mental health and the disability movement and is now recognised as a popular way of providing support to people with dementia and their carers (Department of Health, 2009). A study by

Keyes *et al.* (2014) exploring peer support for people living with dementia found that it had a positive and social impact due to them being able to identify with others, commonality of experience and reciprocal support. However, a randomised controlled trial by Charlesworth *et al.* (2016) found no evidence that it improved quality of life. It is possible that the scales used may not have captured the subjective experience of participants (people living with dementia and their carers). These subjective experiences of the benefits of peer support have been highlighted by groups such as the Scottish Dementia Working Group (2019). Ward *et al.* (2012) define peer support groups as:

*Peer support groups involve the creation of a space that might not otherwise exist in the lives of those who attend, both a physical space and a space for collaborative meaning-making about dementia, away from the imposition of medicalised definitions of the condition characterised by an emphasis on deficit (Ward et al., 2012, p299-300)*

Despite not explicitly being called peer support groups, it could be argued from this definition that memory cafés fulfil this role as a peer support group for people with dementia and their carers. However, in some instances, the findings revealed that this shared understanding between guests had developed into something deeper and friendships had formed. These friendships are facilitated by the context of the cafés; furthermore, the volunteers that help run the cafés also bring people together (Ward *et al.*, 2012). The cafés acted as a 'Third place' (Oldenburg, 1999), which are places that are not home, or work, and provide a space in which connections are made (Ferguson, 2016, p. 28). The guests identified the importance of being with people that are in a similar situation, where they felt understood and were able to develop new connections

and friendships, highlighting how memory cafés can help facilitate social networks in later life.

### **Core Process**

- **Creating opportunities for humour and laughter**

Humour and laughter are generally associated with positive experiences (Bennett & Lenggacher, 2006), and are considered a fundamental aspect of being human (Clarke & Irwin, 2016). This core process relates to programmes 2 and 5.

Humour relates to what causes amusement, a stimulus that causes a psycho-physiological response of smiling and/or laughter (Bennet & Lengaughier, 2006; Clarke & Irwin, 2016). It is both cognitive and emotional, with mirth the positive emotion as a result of humour, considered to be a desirable state of being (Martin, 2007). Humour and laughter can be relational, however, they are not synonymous. Laughter can occur without humour and laughter may not be due to a humorous situation (Clarke & Irwin, 2016). Furthermore, what stimulates humour is not universal and it has different meanings for different people. In addition to being associated with a positive experience, humour and laughter are viewed as being beneficial to both physical and mental health (Clarke & Irwin, 2016).

Laughter is often called the best medicine. Laughter activates the reward centre in the limbic system (Martin, 2007), and has been found to be beneficial for pain management, reducing cortisol (stress hormone) and enhancing the immune system (Spitzer, 2011). Despite the widely accepted viewpoint that laughter is good for our health, further research is required to understand the mechanisms

of these claims (Bennett & Lengacher, 2006, Bennett *et al.*, 2014; Yoshikawa *et al.*, 2018). Gelotology, the study of the effects of laughter on the human body, has given rise to laughter therapy and studies examining its effects. A study by Yoshikawa and colleagues (2018) looked at the impact of stand-up comedy as laughter therapy, performed once a week to 17 older people. They concluded that the therapy had beneficial impacts such as reducing heart rate and systolic blood pressure. However, due to the small sample size and lack of control group the results should be interpreted with some caution. Another study by Kuru and Kublay (2014), used a quasi-experimental design to examine laughter therapy for older people living in long-term care. They used a self-assessment scale to measure quality of life related to health and also concluded that the therapy had a positive effect ( $p < 0.01$ ), on mean general quality of life scores. The therapy session included laughing yoga, which uses a mixture of breathing techniques and exercises to feign laughter.

Historically, there has been some reluctance to look at humour in the context of dementia due to concerns that people living with dementia may become the object of jokes or due to the pervasive medical model that focuses on cognitive decline and losses. Kitwood and Bredin (1992), in their paper proposing a theory of dementia care, outlined how humour was important for a person living with dementia to achieve relative well-being. The recent rise in publications by those living with dementia and those affected by it, often attest to the importance of humour and laughter in dealing with everyday challenges (Grierson, 2008; Scottish Dementia Working Group, 2011).

Across the memory cafés there were numerous episodes of humour and laughter between the people that attended. This was at times due to the activities; jokes and stories told by the visiting entertainers, shared moments amongst the guests or due to situations created by volunteers. This included a range of behaviours from playfulness, telling jokes, facial gestures and gentle mocking or teasing. Play is detailed by Kitwood (1997) in his positive person work. He describes play as having no goal outside of the actual activity, creating an experience that has value in itself. Humour is inherently social and can act as tension reliever. Martin and colleagues (2003) outline four styles of humour:

- Affiliative humour – where individuals use humour positively by telling jokes, witty banter, and even self-deprecating comments to facilitate interactions and relationships with others
- Self-enhancing humour – individuals have a humorous approach to life, even in the face of stress and adversity and is used as a defence or coping mechanism
- Aggressive humour – where individuals use humour in a negative manner to mock, tease and criticise others
- Self-defeating humour – involves individuals using humour to amuse others at their own expense, possibly to deal with negative feelings or as a means to gain approval

Using these definitions, the most common types of humour observed at the café sessions were affiliative and self-enhancing humour. There were also some incidences of guests joking about dementia-related symptoms, such as memory and behaviour. This could be viewed as self-defeating type humour. However, such an approach where people with dementia and their carers laugh at their own difficulties, may be a meaning-based coping strategy, helping to maintain positive well-being (Clarke & Irwin, 2016) by taking 'ownership' of dementia

stereotypes (Hickman, Clarke & Wolverson, 2018). Whilst there was no aggressive humour observed at the cafés, it is important that volunteers are able to recognise that not all guests will experience humour in the same way, with some potentially finding it upsetting.

This recognition of the importance of humour and laughter in people living with and affected by dementia has become a recent area of research (Clarke & Irwin, 2016). Liptak *et al.* (2014) held four focus groups with people with dementia and their caregivers following attendance at an art engagement activity. They reported that humour and laughter were recorded at all focus groups, and included silliness, sarcasm and the difficulties of dementia. The authors suggest that humour and laughter played a significant role in creating a safe and supportive environment. A recent qualitative study by Hickman, Clarke & Wolverson (2018) explored how people with dementia and their care-partners use and draw meaning from humour in the context of dementia and their relationship. The authors identify three themes; humour has always been there (and always will be), withstanding dementia and renewing the value of humour. They concluded that humour in its various forms strengthened relationships and wellbeing by being a buffer against the stressors associated with dementia.

Memory cafés can provide a context in which humorous situations are created, not only between a person living with dementia and the person they attend with but also amongst others that are in a similar situation. Humour is often used to enhance group norms (Martin, 2007) and it can help maintain and enhance relationships (Clarke & Irwin, 2008). Attending the memory cafés, enables the

guests to form connections and relationships with others and provides opportunities for humour and laughter.

In addition to 'in the moment' humour and laughter, there is now recognition that, due to the way the disease process affects the brain in individuals with Alzheimer's disease, they may forget specific details about an event but the emotions, and feelings around it, will remain for a period of time after the event. Andrews (2015, p.93) describes this as an 'emotional hangover'. The amygdala, in conjunction with the hippocampus, forms the limbic system of the brain and deals with emotions. It is affected later than the hippocampus, which controls memories, so an individual may recall the emotional aspects of something even if they cannot recall the factual content (Alzheimer's Society, 2015). Some of the guests talked about the positive feelings that remained after attending the memory café; therefore creating opportunities for humour and laughter is not only beneficial at the time of it happening but also for longer term well-being.

### **Core Processes**

- **Providing a range of activities such as music, quizzes, crafts and including an opportunity for guests to share their history and skills**
- **Being responsive to local communities and responsive and adaptive to changing guests**

These core processes relate to programme theory 3, 5 and 8. Creative approaches to dementia care have exploded over recent years, including the laughterboss (Spitzer, 2011), dramatherapy (Jaaniste, 2011), dance movement (Coaten, 2011), music therapy (Robertson-Gillam, 2011), art therapy (Baines,

2011), complementary therapies (James, 2011), storytelling (Kotai-Ewers, 2011), reminiscence (Schweitzer, 2011), photographs and video (Killick & Allan, 2011), (see Lee & Adams, 2011), and even puppetry (Marshall, 2013). In addition to these approaches, there has been the introduction of walking groups (Sensory Trust, Age UK and Paths for All), and nature based activities (Sensory Trust). The publication 'Transforming the Quality of Life for People with Dementia through Contact with the Natural World' (Gilliard & Marshall, 2012), is dedicated to nature based activities for people with dementia such as contact with animals, gardening and farming. The use of museums is another area that has gained increased attention (Camic, Tischler & Pearman, 2014; Livingston *et al.*, 2016; MacPherson, Bird, Anderson, Davis & Blair, 2009). Thus, there is now a myriad of ways to engage and support people living with affected by dementia and often their carers as well.

A draft consultation report by the National Institute for Health and Care Excellence, looking at assessment, management and support for living with dementia and their carers, highlights the low to moderate quality of evidence of a number of the approaches listed above. Only exercise and robotic pet therapy were identified as being underpinned by high quality evidence (NICE, 2018a). However, the studies used objective outcome measures as a way of measuring effectiveness, which may not capture the individualised views from people living with dementia about the activity. NICE's finalised report does recommend to 'offer a range of activities to promote well-being that are tailored to the person's personal preferences' (NICE, 2018b). The only specific type of approach recommended is group cognitive stimulation, with group reminiscence and cognitive rehabilitation or occupational therapy also considered to be possible

alternatives. The memory cafés provided a wide range of activities during the sessions; art, music, quizzes, games and trips out. Sometimes there were multiple activities, enabling guests to choose which ones they wanted to take part in and which ones they didn't. There were also a number of visiting entertainers, mainly music orientated that provided the activity for the café sessions. Three of the cafés provided a quiz based activity at the majority of their sessions and guests also spoke of completing quizzes and word searches in their own time. The use of activities based on 'intellectual stimulation' for people living with dementia can be viewed in relation to the increasing use of cognitive stimulation therapy (Camic, Baker & Tischler, 2016), recommended by NICE (2018b). None of the volunteers spoke of providing an activity for a particular reason other than to provide a wide range, to cater for different preferences. They also ensured they varied the sessions, so that they did not become repetitive. The skills of people living with dementia are often underestimated and their deficits emphasised (Camic, Baker & Tischler, 2018). Some of the guests appeared to enjoy the quizzes where they could work alone or together to solve the answers.

Music in particular appeared to be a popular activity across all the cafés and there has been increasing research in this area (Cooke *et al.*, 2010; McDermott, Orrell & Ridder, 2013) A study by McDermott, Orrell and Ridder (2014) explored the viewpoints of people with dementia and their carers about the meaning of music in their lives. They found that individual preferences were preserved throughout the course of dementia and music facilitated connectedness with others. A more recent study by Dowlen *et al.* (2018) concluded that engaging with music had a number of psychological, social and emotional benefits. The

Alzheimer's Society Singing for the Brain programme (see <https://www.alzheimers.org.uk/get-support/your-support-services/singing-for-the-brain>) incorporates aspects of reminiscence therapy and music. In this, people living with dementia and their carers take part in singing, facilitated by a musician/singer. Research into Singing for the Brain found that people living with dementia and their carers found it enjoyable and it helped them accept and cope with dementia (Osman, Tischler & Schnieder, 2016). A Singing for the Brain session was observed at one of the cafés and a number of guests commented that it wasn't 'their thing'. This suggests that people living with dementia and their carers are not a homogenised group and that a particular approach will not suit everyone.

The focus on the lasting effects of activities for people with dementia has ignored the 'in the moment benefit'. Killick (2011) in his chapter 'Being a friend of time' discusses how people with dementia are 'living in the moment' and the importance of just being present. The contemporary movement of mindfulness is very much about being focused in the present moment. A study looking at an art gallery access found that, whilst there was no evidence of lasting effects from the programme, feedback from a participant highlighted that the activity was worthwhile even if it only provided a benefit whilst in progress (MacPhearson *et al.*, 2009). Dowlen *et al.* (2018) also found that immersion in the moment was a benefit of music activities. These experiences can also provide the catalyst for connection (Ferguson, 2016). Some of the activities at the cafés involved people working together and connecting over a shared interest or working together to answer quiz questions.

The variety in schedules of running, structure and activities across the cafés, enabled guests to choose a café that best suited their needs. This suggested that people with dementia don't just go to what is provided close by but will make a choice based on trying different services. One of the participants commented that they had chosen to go the café in the next village, as she felt intimidated by the fact there were more men in the closer café. The data showed that the majority of the people attending the memory cafés were female. A survey that looked at carers attending memory cafés in the East of England, found that 74% of carers were female (Jones, Killeth & Mioshi, 2017). This mirrors the statistics internationally, where dementia is more prevalent in females and two thirds of informal carers are female (Alzheimer's Disease International, 2015). This may lead to memory cafés tailoring their activities towards having a larger female attendance, conversely this may make male guests feel the café is not for them. It is important that the cafés cater for the preferences of current guests but remain open and flexible to changing as their guests change. Also, by having a range of activities this can meet what Camici, Baker and Tischler (2018) describe in theorising about how art gallery interventions impact people with dementia and their caregivers; through intellectual stimulation, social interaction and changed perceptions.

### **Core Process**

- **Volunteers having a range of characteristics and knowledge on how to support people with dementia and their carers**

This core process relates to programme theories 1, 6 and 7, which focuses on the characteristics of volunteers at the memory cafés. Volunteering has a long history in the UK, with informal volunteering dating back 150,000-200,000 years ago and formal volunteering 10,000 years ago (Harris *et al.*, 2017). The UK does not have one accepted definition of volunteering and there are varying definitions set out in government reports, and in research on volunteering (Volunteering England, 2009). The Compact Code on Good Practice on Volunteering (2005, see Volunteering England, 2009) defines it as:

*An activity that involves spending time, unpaid, doing something that aims to benefit the environment or individuals or groups other than (or in addition to) close relatives.*

The role of volunteering is now more prominent than ever in public policy, both at a national and global level, with volunteering considered as integral for addressing a number of issues (Rochester, Paine & Howlett, 2010). In the UK, volunteering has become an increasing focus of successive governments with investments into training volunteers, to help achieve policy agendas (Rochester, Paine & Howlett, 2010). The 'Big Society' was a key element of the Conservative Party's 2010 agenda (Ockenden, Hill & Stuart, 2012) and was criticised for seeing the voluntary sector as a way to fill the gaps in service provision from the statutory sector (Levitas, 2012). Today there has been a shift from the 'Big Society' to social prescribing, as a way to link primary care with the voluntary sector (South *et al.*, 2008). Social prescribing encourages and enables people to access a range of community based activities and interventions to improve their health and well-being (Husk *et al.*, 2019).

The National Council for Voluntary Organisations (NCVO, 2019) started in 1919 and connects, represents and supports voluntary organisations. They have helped projects develop into what are now established voluntary organisations, such as Age UK. In 2017/2018, 20.1million people volunteered through a group, club or organisation, with 81% volunteering in their local communities (NCVO, 2019). Furthermore, in 2016/17, 82% of voluntary organisations were classified as micro or small. Today, volunteers are embedded in many services including libraries, hospitals, community groups and the emergency services (police, fire ambulance and coastguard).

The global increase in individuals living with dementia has led to a focus on how to best provide care and support, with voluntary services playing an increasing role, both in the UK and elsewhere (Alzheimer's Disease International, 2017; Smith *et al.*, 2018; Söderhamn *et al.*, 2012). Memory cafés are run by volunteers. Throughout the UK, many are run independently but some memory cafés are provided by larger charitable organisations. The majority of the volunteers were retired females which matches the national picture of females being more likely to volunteer than males, and higher rates of volunteering in the 65-74 age range (NCVO, 2019). Rates of volunteering are also highest in rural areas, with the south west region having the highest proportion of volunteers overall. Stoate and Jones (2010) also highlight that the majority of volunteers are high earners with a managerial background. This was reported to be the case at one of the cafés. Therefore, it is important that volunteers have a balance of characteristics and skills to meet the needs of the cafés, from organising the room and activities, maintaining accounts, knowledge of dementia and interpersonal skills for speaking with the guests. According to

some of the guests, the personalities of the volunteers were key to the success of the café and ensuring they felt part of it. For volunteers, it can require self-confidence to take a step back and enable spontaneity (Ward *et al.*, 2012).

Previous experience of caring for someone with dementia or of working in a health or social care setting, are often cited as necessary skills when supporting people with dementia. A number of the volunteers had previously worked in health or care roles, with some being retired registered nurses. Some guests expressed a need to give back to others or to support their local community.

According to the NCVO (2019), people volunteer for a number of reasons including; making a difference to the lives of others, personal experience of a particular issue/condition, spending time away from a busy lifestyle and to develop skills. Altruism, the concern for the welfare or happiness of others, has a strong connection with volunteering, however, not all acts of volunteering are altruistic and not all altruistic acts are volunteering (Haski-Leventhal, 2009, p.273). Altruism in volunteerism places the emphasis on the motivations of the volunteers to help others but does not consider what the volunteer gets back from the process, such as the relationships between volunteers and recipients (Haski-Leventhal, 2009). The majority of the volunteers at the cafés were retired, showing the contribution of older adults in supporting others and their communities, in maintaining social connectedness (Han, Brown & Richardson, 2019; Kahana *et al.*, 2013).

In relation to volunteering in dementia, a study by Brooks *et al.* (2014) looked at experienced family carers of people living with dementia volunteering in a carer support programme, and found that volunteers expressed positive emotions of

pride, increased confidence and enhanced self-esteem. Smith *et al.* (2018) looked at volunteers' experiences of providing peer support and befriending to carers of people living with dementia and found that the relationships were mutually beneficial. Providing emotional and social support to carers, led to volunteers feeling satisfaction in their role. The authors also commented that they felt volunteers may have been reluctant to voice any negative aspects of their role. A number of the volunteers at the memory cafés, whilst not expressing any negative aspects of their role, were often putting in additional hours and work outside the memory café sessions, adding to potential workload burden. Moreover, as the volunteers formed close connections with the guests, there was a risk of emotional labour, particularly when guests passed away.

The study of volunteerism has explored motivations, cost and benefits, characteristics of volunteers and turnover (Haski-Leventhal, 2009). However, despite the increasing role of voluntary organisations in supporting people living with and affected by dementia, the research on volunteerism in the context of dementia, particularly volunteer led services, is currently limited. Also the views of people living with dementia and their carers experiences of support and services provided by volunteers.

### **Core Processes**

- **Ensuring the environment is conducive for guests to interact with each other, such as how the tables are laid out and providing space for people to move around**
- **Having information on other services available for guests**

These core processes encompass programme theories 2 and 4. The settings in which the memory cafés were held were community buildings, therefore, not designed to specifically meet the needs of people with dementia. All the buildings had wheelchair access and had some parking close by. However, the rooms had to be set up and packed away at the end of each session. The physical environment can work well or create problems for people affected by dementia. Changes in cognition, mobility, and hearing and sight, can make environments confusing for people living with dementia. Dementia-friendly environment checklists are available to guide providers and carers on the changes that can be done to best support people with dementia (Alzheimer's Society, 2019c). Examples include good lighting, clear signage, reduced noise levels, and carpets and table cloths that do not have 'busy' patterns. As memory cafés are provided in public venues, many have not been designed to meet the needs of people living with dementia.

There is limited research on the impact of the environmental layout when running groups with people with dementia. However, principles from broader dementia-friendly design in group living, emphasise the importance of activity-focused spaces (Torrington, 2007), where chairs are situated around an activity to stimulate interaction. The large ring of chairs often associated with group living, is not conducive to enable people to interact with one another. The layout of table and chairs is important when providing a memory café session, to maximise interactions with each other and have space for people to move around freely. The layout at some of the cafés inhibited interactions amongst guests by restricting ease of movement.

The National Dementia Strategy (2009) and the Dementia Training Standards framework (2018), outline the importance of signposting to ensure people living with and affected by dementia receive information and can access support if needed. However, they acknowledge that there is a lack of good quality studies to determine the most effective models of provision of support and signposting, usually provided by the third sector. They recommended the implementation of a 'dementia advisor' who can act as a point of contact and signpost to other services. Despite this recommendation, models of coordinating interventions to support people with dementia are variable (Backhouse *et al.*, 2017). The fact that there are a growing number of memory cafés, even in rural and remote areas, suggests that they are in an ideal situation to provide information on other services available. The cafés, however, varied in the amount of information available to guests, with two cafés having an area dedicated to information leaflets. For one individual living with dementia, it was general information, such as benefit entitlement and contacting a local vicar that they had found most useful. As the volunteers generally lived in the community where the memory cafés were held, they often had knowledge available on other local services.

### **Core Processes**

- **Promoting the work of cafés through various routes and being part of the wider community**
- **Establishing strong links with statutory agencies**

These core processes look at the role of memory cafés within the wider community and how they can link with other services, encompassing programme theories, 4, 8 and 9. As outlined in the introduction, dementia is a social issue not just a health issue (Swafer, 2014), despite historically being viewed as a health responsibility (Ward & Sandberg, 2019). The dementia-friendly community movement has created a shift towards the social responsibility of supporting people with dementia (Keady & Elvish, 2019). However, there is no agreed meaning of dementia-friendly communities (Lin, 2017) and it has been suggested that the term may encourage division rather than inclusion (Swafer, 2014). The aim of dementia-friendly communities is to focus on inclusion for people living with and affected by dementia (Mental Health Foundation, 2015). The risk is that the solution to inclusion is seen as communities being kind and welcoming (Shakespeare, Zelig & Mittler, 2017). It could be argued that the term implies what society can do to help people living with dementia, rather than viewing people with dementia as equal and valuable members of communities and society.

Governments and dementia organisations in many places around the world have outlined their commitments to dementia-friendly communities and approaches, which typically include; language, awareness, community support and the environmental design of services and buildings. In the UK, the Alzheimer's Society has been at the forefront, providing information, resources and community teams to enable areas to become dementia-friendly. At an international level, Alzheimer's Disease International in their publication 'Dementia Friendly Communities: Global Developments', provides detailed insights into the many dementia-friendly initiatives from across the globe: Africa,

Americas, Asia Pacific, Europe and the Middle East (Alzheimer's Disease International, 2017). The report highlights how memory cafés in various forms, have been adopted in 15 countries, sometimes as part of wider dementia-friendly initiatives. They have also been the starting point in providing dementia support in places, where there are limited or no community projects available (Alzheimer's Disease International, 2017).

Reports such as this are raising awareness about the role of memory cafés in supporting people with dementia. Memory cafés have appeared to have had less focus in comparison to other psychosocial interventions for people with dementia and their carers. The findings showed that a number of volunteers had not heard about memory cafés until they started volunteering. The cafés also varied in how involved they were in their local communities. Some took part in local events as a means to raise money for the café, and guests were invited to attend other services such as Age UK lunches. However, there was little community input into the café outside of volunteers and family members, suggesting that cafés are in the community but not necessarily part of the community. As one of the volunteers stated 'It's a new community, a community within a community'.

The guests found about the cafés through a number of formal and informal means, including; a psychiatrist, a dementia practitioner, the Alzheimer's Society, through word of mouth and an internet search and. Statutory services such as a GPs, psychiatrists and memory assessment nurses are in an ideal position to inform people concerned about their memory or who have been diagnosed with dementia about memory cafés and what they do. There was

disparity in the amount of involvement from statutory services such as dementia practitioners at the cafés. The memory cafés can act as a link between the informal and formal sectors of society but this is difficult when links with the formal layers are not well established. One of the volunteers at one of the cafés even felt that they were seen as interfering by statutory services, highlighting the need for understanding and shared awareness of what is provided at the memory cafés.

The NHS long term plan (NHS, 2019) highlights the need for closer working relationships between voluntary services and the NHS, to ensure people have access to support which may reduce the demand for acute services. For example, volunteers are in an ideal position to make contact with NHS services if they are concerned about someone's health or safety. They can also, be used to inform guests about services that are available to them, such as one the cafés informing guests about annual flu vaccinations. Over the last 25 years resources to support communities has been reduced (Ferguson, 2016), placing greater demand on local communities and the voluntary sector. The risk to voluntary services is that this may lead them to expand their role to meet increase needs and changing or moving away from their initial focus. Voluntary services like memory cafés traditionally fill gaps in formal services whilst providing something different to those services. If voluntary services align more to statutory services then they are less able to provide additional and different support.

*This is a natural evolution experienced by many voluntary sector organisations and illustrates the fine balance to be struck between the need for organisation if you are to do anything meaningful and the*

*evolving organisation stifling the very informal person to person support it sought to nourish (Ferguson, 2016, p.25)*

### **6.3 Summary of conceptual platform**

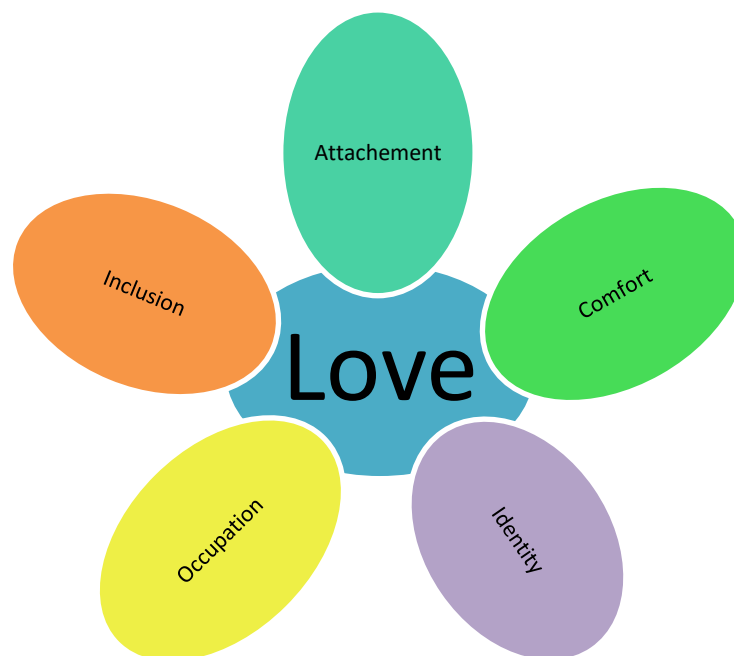
The core processes of the conceptual platform have been outlined and discussed in relation to the broader literature in dementia care. The core processes encompass both a conceptual and an instrumental use of the findings (Pearson *et al.*, 2015). At an instrumental level, the findings can be disseminated to memory cafés as a best practice guide. At a conceptual level they can be used to provoke critical discussions around memory cafés and applied to other groups and interventions developed to support people living with and affected by dementia.

In line with a theory-driven, realist approach it is important to contextualise the findings within broader theories and models in dementia care and consider to what extent they support or add to them. The next section of the discussion will focus on Kitwood's psychological needs, Nolan *et al.*s. (2003) Senses Framework, and then the current propositions within dementia research on the need for a social model. Thus, it explores the findings at an individual, relational and societal level.

### **6.4 Kitwood**

In his seminal text challenging the medical paradigm of dementia, Kitwood, (1997) outlined the psychological needs of people living with dementia, to achieve a person-centred approach. He proposed that there were five

overlapping needs; comfort, attachment, inclusion, occupation and identity that come together in the central need for love (Figure 6.1). Fulfilling one aspect will partly fulfil the other needs and provide person-centred care. Comfort relates to experiencing closeness, and receiving warmth and strength from another person. Attachment may be of particular importance when going through significant changes or losses. Inclusion relates to the need to be with others and to be part of a social group. Occupation isn't about a job but having something to do, to have a sense of purpose. Identity relates to who a person is, their values and beliefs, and being able to express a sense of self. Meeting these psychological needs combine to fulfil the need of being loved. This is not necessarily love that is felt for partners or family members but love that makes an individual feel valued and unconditionally accepted.



**Figure 6.1: The main psychological needs of people with dementia (Kitwood, 1997, p.82)**

When looking at these psychological needs in the context of memory cafés, they are able to meet these needs for people with dementia. The need for attachment is met through being able to form connections and broadening social networks. Comfort is achieved by being with others in a similar situation, and not feeling alone with the experience of dementia. The cafés also provide inclusion by enabling people living with dementia to be part of a group, where they may feel no longer able to contribute to previous social groups. Occupation can be met by being able to engage in a range of activities that provides fulfilment and mental stimulation. Lastly, Kitwood considered love the central psychological need where people feel unconditionally valued. What was evident at the cafés was that people were valued and accepted as they were. These needs could be equally applied to carers and to some extent volunteers. As previously discussed in the introduction a person-centred approach has limitations for focusing at the individual level, and what others can do to help, rather than recognising the reciprocity of relationships people with living with dementia have with others.

## **6.5 Relationship centred care**

In addition to a person-centred approach to dementia care a second approach that emerged was in relation to ‘caring for carers’ (Adams & Gardiner, 2005). The focus being on supporting carers to provide care for their loved one with dementia at home. Again, this approach focused on the needs of the carer, rather than the caring relationship. Nolan *et al*’s. (2003) work on relationship-centred approaches focuses on the dyadic and triadic relationships the person

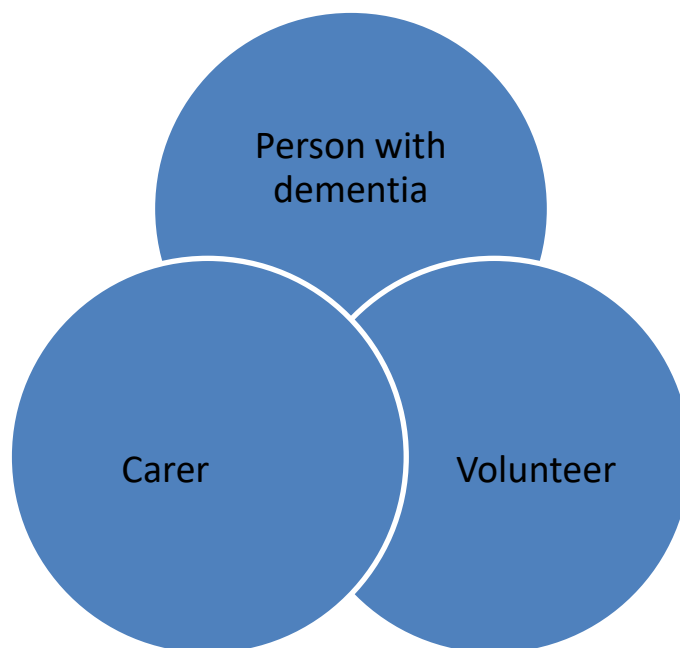
has with informal and formal carers. Relationship-centred care in particular recognises the interdependencies and reciprocity of those relationships, and as such promotes a more inclusive approach to the care. To conceptualise what is relationship-centred care, Nolan et al. (2003) have developed the Senses Framework which outlines six senses.

- Sense of security – to feel physically, psychologically and existentially safe
- Sense of belonging – to be part of a group and form and sustain relationships
- Sense of continuity – to be able to make links between, the past, present and future
- Sense of purpose – to enjoy meaningful activities
- Sense of achievement – to reach goals
- Sense of significance – to feel that you matter

The Senses Framework proposes that the older person, their carers and staff need to experience these senses for good care to be provided. Ryan *et al.* (2008) has considered the framework in relation to people living with dementia and propose that it can provide an analytic tool that can examine the dimensions of relationships.

When considering these senses in relation to memory cafés, they are able to meet these senses in particular people with dementia and their carers. Memory cafés create a place that is safe from the challenges and perceptions people may experience. It can provide a group where people feel like they belong and a sense of continuity can be achieved by connecting with people in their local communities. Memory cafés can provide a sense of achievement and purpose by enabling people to be engaged in activities, being able to work together and

share skills. Ultimately, they enable guests to feel like they matter. For the volunteers, these senses may be less clear. Supporting people with dementia can create demands on others but paradoxically these relationships can be central to their own feelings of purpose, achievement and significance (Ryan et al, 2008, p.81). It appears there has been little research to consider the relationship the volunteer may have with the person with dementia and their carer. Figure 6.2 proposes a model for the triadic nature of the relationships that occur at memory cafés



**Figure 6.2: Triadic relationships at memory cafés**

## **6.6 Social model of dementia**

The person-centred approach and relationship-centred approaches make important contributions in considering the needs of people attending memory cafés, and the relationships that form between volunteers and guests. However, these approaches fail to contextualise memory cafés within broader structures and societal responses to supporting people living with and affected by dementia. A report by the Mental Health Foundation (2015) proposes a new model for dementia research and practice, by examining dementia in the context of a social model of disability. As outlined in the introduction (Chapter one), ways of describing and viewing dementia today are still largely influenced by the medical paradigm, despite recognition of the psychological and sociological perspectives. Discussions and debates on dementia are focused on care and rarely in the context of rights, even though human rights laws and conventions are 'diagnosis neutral' (Mental Health Foundation, 2015, p.8). In the UK, the principles of United Nations Convention on the Rights of the Persons with Disabilities (CRPD) has been ratified into law, which protects the rights of a person with disabilities. The CRPD defines disability as a long-term 'physical, mental, intellectual or sensory impairments in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others' (Mental Health Foundation, 2015, p.11). The definition from the CRPD could be argued to apply also to people living with dementia (Mental Health Foundation, 2015; Shakespeare, Zeileg & Mittler, 2017), and framing dementia within disability, rather than older age, would be more inclusive to people with younger-onset dementia (Mental Health Foundation, 2015). However, Thomas (2004) argues that the focus has been on the physical

barriers to access and not the psychological and emotional impact of oppressions. According to Shakespeare, Zeileg and Mittler (2017), the CRPD promotes a liberal, individualistic view rather than reflecting the relational ways people live their life. The Memory Friendly Network also propose the need to explore dementia within the context of disability studies as well as intersectional analyses, rather than viewing dementia as a homogenised experience (Ward & Sandberg, 2019).

One of the challenges is how to move towards a rights based approach in practice. The development of dementia friendly communities seeks to tackle the environmental, social and attitudinal discrimination people living with and affected by dementia experience. However, the risk is that they become goodwill initiatives that are not embedded in a rights-based approach. With the dominance of the medical paradigm, these new ways of thinking about dementia may take some time to translate in to the real world (Shakespeare, Zeilig & Mittler, 2017). In the meantime there are people living with and affected by dementia that require support, and memory cafés provide a community-based response to enable people to connect with others in the local areas, in the here and now.

The findings highlight inequalities related to memory cafes. Whilst they provide a place for people with dementia and their carers, they are potentially continuing to perpetuate this separation of people from the wider community and not encouraging communities at large to be more inclusive. Participants spoke of having different needs and it is important that a 'one-size' fits all approach to memory cafes is not followed.

## 6.7 Reflexivity

As previously discussed in chapter two, researchers are social beings and are shaped by their beliefs, habits and experiences, therefore, the researcher cannot separate themselves from the research process, and the social world being studied (Hammersley & Atkinson, 1995). Reflexivity is the process by which the researcher identifies these beliefs and experiences and considers them in relation to all aspects of the research process. I have identified that my motivation for wanting my research to focus on memory cafés was due to my personal experience of setting up and running a memory café. In this 'situation specific wisdom' (Campbell 1988, cited by Pawson, 2013, p. 11), there is a potential bias towards me viewing memory cafés in a positive way, however, before this research, I had not visited any other memory cafés and so had no idea how they might run in comparison to others. As a mental health nurse, I am used to constantly reflecting on my behaviour, my language and my preconceived ideas when supporting people with mental health problems or dementia. Therefore I found the experience of always questioning what I was doing, what I was seeing, and what I was hearing, a familiar process.

From the start I was open and honest about who I was and my motivations for conducting the research. Spending time at the memory café before collecting data was important and useful to start the formation of relationships and have conversations outside the research (McKeown *et al.*, 2010). This also enabled me to ensure that everyone at the café was happy for me to attend and conduct the research, even if they did not want to be involved. Consent and trust are two different things; consent covers the ethical aspects, however, trust is about entering people's social world and being part of that world.

The recruiting of participants also posed some challenges, as it was not always clear who everyone was. Spending time talking to people in a more relaxed, conversational style enabled me to ascertain if people were living with dementia or they were carers, especially when people attended the café on their own. I was acutely aware of what Van Maanen (2011, p.98) describes as becoming the phenomenon. I would often help set up and pack away the café, and help the other volunteers and as such, this may have changed how the other volunteers viewed me. I could have been seen as another volunteer and not a researcher. This was evident in relation to the information that was shared to me in relation to guests that was outside the remit of the research questions.

The nature of an ethnographic way of collecting data meant that I built relationships with guests and volunteers over time. I was often asked if I was Cornish and I wonder if that in some way, in addition to running a memory café, helped me more accepted. Many shared aspects of their lives and struggles that they experienced. There is an emotional responsibility for the relationships formed (Dean, 2017) and when it was time to finish the data collection, I made sure the guests and volunteers were aware of what was happening.

There was also a balance of being a researcher and practitioner. People shared issues they were experiencing with me, and so I would advise them to speak with other volunteers or contact a health professional. On one occasion, I went to help a guest stand up from their seat at café C but was informed by one of the volunteers that I was unable to do this for health and safety reasons. I was also aware of how my personal thoughts might shape how I saw a particular café. For example café A made several references to religion, and as someone

who isn't religious, this had the potential for me to interpret the messages in a different way to the guests.

Part of this reflexive process was to member-check the findings (See appendix 19). Following the period of data collection and initial analysis, I visited all the cafés again to feed back what I had found. All the participants and the other guests confirmed that the findings were reflective of their experiences. Most were interested in what happened at the other cafés and ideas for activities. I kept jotted notes of my thoughts in my reflective diary and this enabled me to look at my findings through a critical lens, which was both important and useful. Van Maanen (2011a) discusses that ethnography makes the strange familiar, however, in this case I was looking for the strange in what may have been considered familiar. This research necessitated that I view each of the cafes as the unfamiliar environments that they were, given that the one familiar café where I volunteer wasn't one of the cases in this research. The reflective diary helped this process as I was able to document familiar and unfamiliar observations. Unexpected findings did emerge, such as guests visiting particular cafes for specific reasons or visiting a number of cafes rather than just the one closest to where they lived. Other unexpected findings included the level and scope of work put in by volunteers and how the cafes connected with the wider community. Each of these provided useful insights to further develop and refine the programme theories and the subsequent conceptual platform.

The next section explores the strengths and limitations of the thesis.

## 6.8 Strengths

This thesis builds upon and strengthens the current evidence base for memory cafés. Through a realist review and realist evaluation, programme theories have been developed and tested, culminating in a set of core processes that details how and why they work. The realist review enabled plausible programme theories to be developed, despite the limited research on memory cafés, by drawing upon relatable programmes. The cafés were purposively sampled to ensure they were reflective of the socioeconomic diversity of Cornwall. Hulko's (2009) work shows that social location impacts on the experiences of dementia. To date, there has been limited research looking at dementia in rural areas, specifically research on dementia and living in Cornwall. Therefore, this thesis makes a significant contribution to understandings about dementia and marginalised communities.

An ethnographic approach to collecting the data enabled immersion in the social phenomenon, to help uncover mechanisms and develop new programme theories that may not have come to light by interview alone. Being there enabled a deeper understanding of the context and the application of multi-methods, and provided the opportunity to compare accounts to what was being observed. Hammersley (2018) discusses some of the challenges that ethnography may face in the future, particularly in relation to the generation of big data. Ethnography is a lengthy process and there is a risk it provides just another account of a culture and local experiences (Hammersley, 1992). The application of realist methodology and an ethnographic way of collecting data meant there was an overarching theoretical framework, from the programme theories prior to data collection. It provided some structure to the observations

and interviews whilst enabling new information to be gathered. Hammersley's (1992) subtle realism provides a useful way of dealing with the conflict of realism and ethnography. Ethnographers create a social world based on multiple perspectives, rather than representing an independent reality of the phenomenon. The programme theories provide one interpretation of the reality of memory cafés, however, they can then be further tested and refined to develop understandings. They provide an interpretation of the lived experience not the lived experience.

The thesis also questions how we measure outcomes in dementia research, and the importance of understanding what is important to people living with and affected by dementia, not what practitioners and policy makers feel is important. The thesis has highlighted that the development of psychosocial interventions, whilst being framed as a way to support people with dementia, often have a medical focus of ameliorating a particular symptom or problem. Memory cafés have developed outside of this focus and appear to be more of a community response to a particular need. Nolan *et al.* (2003) argue that social validity and meaningfulness should be the main criterion on which to establish significance for people with dementia. The thesis also draws attention to the importance of relationships, and obtaining different viewpoints on a service for people with dementia. The findings have real world meaning and can be considered in relation to other support groups and interventions for people living with and affected by dementia. Patient and public involvement, through meeting with the Leadership Group at the Alzheimer's Society, and the Cornwall Memory Café Network Forum, ensured the research was relevant and the data collection methods appropriate. As the research was qualitative, the findings were

member checked with all the cafés that took part as well as with the wider Memory Café Network Forum (Appendix 19), to ensure they were representative of their own experiences of the cafés. Thus, the findings from this research have the potential to make significant contributions to the existing body of knowledge underpinning practice and policy, both nationally and internationally.

## **6.9 Limitations**

Firstly, the findings presented in this thesis provide one interpretation of the reality of memory cafés. Different participants and different cafés may have elicited different information. Therefore, the diversity of experiences may not have been captured. However, within realist research, all knowledge is considered partial and open to further scrutiny. The cafés were all located in Cornwall, so the findings are not necessarily transferable to urban areas or even other rural areas but they have translational and explanatory potential.

The use of a realist methodology was challenging and frustrating. As a novice researcher, the development of programme theories that could be tested and refined was particularly difficult and there is still a lot to be learnt and improved upon. Full realist interviews may have enabled more detailed exploration of the programme theories but would have lost the importance of ‘in the moment’ to provide a context to what was being asked. Furthermore, asking questions at the time did not put added pressure on cognitive recall but having disjointed conversations around the activities was a challenge, to maintain continuity and flow of what was being discussed.

Additional focus groups may have been another option to explore the findings and programme theories. However, there was a delay with starting the data collection due to challenges from the University Ethics department about working with people with dementia and issues around capacity. There were assurances needed that capacity would be checked before consent and throughout the period of data collection. It is important that research is available and inclusive of people with dementia, in line with a rights based approach previously discussed. An interesting finding was that there some people with dementia that wanted to be involved in the research but their carer usually a spouse, dissuaded them from doing it as they were concerned about the added stress it may put on them.

### **6.10 Original contribution to research**

This thesis provides an original contribution to research in two key ways. Firstly, the findings add a significant contribution to the limited literature available on memory cafés. It has provided the first explanations theorising how and why memory cafés work, through the formulation of testable programme theories. The core processes developed from the programme theories have an instrumental and a conceptual application that will be applicable to future research. The findings have clearly shown a role for memory cafés and how they might be improved. It has also highlighted the importance of having support groups, outside of the usual approach of focusing on the specific symptoms associated with dementia. Moreover, it shows the importance of community-based responses to ensure people living with and affected by dementia have somewhere to go in their local communities.

Secondly, the thesis makes an original contribution methodologically by conducting a cycle of theory development, using both realist review and evaluation. Currently there are not many examples of realist research studies that have applied the two realist approaches. It also adds methodologically, to how ethnography is compatible with a realist approach. Whilst there are papers that have discussed theoretical issues, there is little practical guidance on how these approaches can work together. This thesis provides a worked example of how it can be done. The application of realism with ethnographic research methods provides an interesting development. Not only by being able to meet some of the challenges about the future of ethnography, as outlined by Hammersley (2018) but ethnographic approaches enables programme theories to be explored whilst 'living' the social phenomenon of interest.

### **6.11 Future research**

There are many avenues for future research around memory cafés. Initially, exploring the conceptual platform with other cafés; it is proposed that this could take the form of a pictorial representation of the conceptual platform, to maximise the dissemination of findings and also provide a tangible output. A rough sketch of how this might look is in (Appendix 20). Another area of useful research would be to compare cafés across different areas, rural and urban, and also across countries, given that memory cafés are now located in 15 different countries. This would enable their similarities and differences to be explored, and to test and refine the conceptual platform.

The café concept as a way of providing support has been adopted in other areas. Death cafés have been developed to enable people to have a space to talk about dying and death. They were developed by Jon Underwood and his mother Sue Barksy Reid, as a means to increase awareness of death and make the most out of life (Death Café, 2019). There are now a 1938 death cafés listed in the UK and 9261 globally (Death Café, 2019). They are provided in a range of venues including cafés, private houses and even cemetery (Tucker, 2014). At a death café, people have a cup of tea and cake and talk about death. The cafés are run by volunteers and provide discussion group not grief support or counselling. Death café is a 'social franchise', so people who sign up and use the guide and principles can call themselves a death café. Future research should be undertaken to explore how the conceptual platform identified in this research translates to a different type of café.

Another area for research could look at how cafés may change and adapt, and ultimately how compatible they are with current propositions in dementia, to viewing dementia within a social disability model. The uniqueness of the cafes need to be retained, to minimise the risk of a 'one-size fits all approach', and yet this research has revealed theories that help to explain what works, for whom, and in what circumstance within this population in Cornwall. The learnings from this research need to be disseminated so that the theories can be further refined and tested. Whilst all places within local communities should be accessible and inclusive towards people living with and affected by dementia, the findings highlight the importance of being with people in a similar situation that understand. Awareness raising can increase knowledge and understandings of the challenges of dementia, as the dementia-friendly

community initiative seeks to do but having a lived experience provides a different perspective and insights. Since the period of data collection, café C which was run by the Alzheimer's Society, is now an independent café. The Alzheimer's Society no longer runs cafés in Cornwall and are providing other services to support people with dementia and their carers. It would be useful to explore how a change in who runs the café possibly impacts on the delivery and structure.

Currently, many memory cafés are held in church halls, due to their central location in villages and low cost for hiring. As was seen from some of the comments made by café guests, this can lead to an assumption of a direct association with the church in which the café is held. Furthermore, this could pose a challenge for individuals with no religion or of a different religion than the denomination of the church. Whilst this was not raised as an issue by any of the participants in the study, it was highlighted by the Alzheimer's Society Leadership Group during patient and public involvements (See section 2.8) as a potential problem. It may be that those for whom this is an issue, do not attend the cafés, however this does require further investigation.

There is a need to explore why people don't attend memory cafés. Is there a stigma associated with attending and not wanting others to know that you attend? Is it due to lack of awareness about what happens at the cafés? This would highlight whether, in addition to future research, awareness raising is needed. Is the term memory café off-putting for some and would a different name be more representative of what happens at memory cafés, such as a

friendship café or activity café. It is hoped this thesis will inspire more research to be carried out on, and with memory cafés.

Lastly, the study has potential impact outside the scope of memory cafes and Cornwall by providing useful insights of how social groups in the context of health and social care work. The findings reinforce the importance of social connections for those experiencing a particular condition or issue, and the need for these opportunities to be available in local communities. Furthermore, that groups are not solely focused on managing or ameliorating a particular symptom but about creating positive experiences and what is important to those that attend.

## **6.12 Chapter summary**

This chapter has detailed a conceptual platform comprised of twelve core processes that explain how and why memory cafes work. These core processes have been discussed in relation to the wider literature. It has also considered how the core processes fit with broader models on dementia care at an individual, relational and societal level. The section on reflexivity has highlighted some of the issues with conducting qualitative research including being a practitioner and researcher, and the use of ethnographic approaches. The chapter also details the strengths and limitations of the thesis, and how it makes an original contribution. It concluded by looking at the potential impact the study has on future research, particularly in relation to the importance of social connections and the development of a conceptual platform that can be further tested. The next chapter provides a conclusion to the thesis.

## **7 Chapter 7: Conclusion**

The first paragraph of chapter one outlined how the thesis would take a different approach to what is typical in dementia research, where there is a focus on the increasing global numbers, the financial burden and the negative perceptions. The aim was to understand more fully how communities support people living with and affected by dementia. It in no way sought to sanitise the challenges that people face on a daily basis but rather to highlight that positive experiences are not only a possibility but should be a right.

The thesis provided a series of consecutive chapters that explored the process of theorising how and why memory cafés work. The introduction provided an overview of the different theoretical perspectives on dementia, highlighting the pervasive nature of the medical paradigm. It also discussed how psychosocial interventions have gained considerable interest in the absence of drug treatments and a cure. It explained the evolution of memory cafés from the original concept of Alzheimer's café and the development of support groups to support people with dementia and their carers. Finally, it looked at issues of rurality and dementia.

Chapter two outlined the methodology and methods used, and provided an explanation of a realist approach. It also discussed how ethnographic research methods can align with realism. It detailed the aims and objectives of the research, and the process for recruitment, data collection and analysis. Chapter three, the realist review, captured the development of initial programme theories when there was limited research available on memory cafés, by looking at relatable programmes.

Chapter four provided the background context to the memory cafés used for the data collection by describing the numbers, activities provided, and their similarities and differences. This led onto chapter five which examines the programme theories in light of the data collected from the memory cafés. It also outlined the new programme theories that had been developed from the information gathered from interviews and observations that did not align to the initial programme theories.

Finally, Chapter six the discussion, set out the conceptual platform comprising core processes, extrapolated from the programme theories. The conceptual platform provides reusable core processes that can be applied to future research in memory cafés and similar programmes. The core processes were then discussed in the context of the wider literature and then considered in relation to broader models of dementia care, at an individual, relational and societal level. The strengths and limitations of the thesis were identified and how the thesis makes an original contribution to research.

The findings indicate that the cafés adopted a structured volunteer-led approach or an unstructured guest led approach. The structured approach focused on activities, and the unstructured cafés had more opportunities for conversation. However, it is important cafés encourage and enable guests to shape the sessions, so that the outcomes are relevant to them. Memory cafés can be seen as a ‘third space’, providing a place outside of home and work that enables connections to be made. They are also in a position to strengthen connections with other services in their local communities.

Memory cafés are an example of a community-based response, rather than a policy based response to dementia. They have developed outside the dominant medical perspective on dementia, and are not explicitly outcome focused. They are not about reducing negative symptoms but about adding positive experiences. In a world where we can connect in an instant, for some people living with dementia and their carers they can feel cut off from their communities and become increasingly isolated. Research has shown that perceived and actual social isolation are associated with increased mortality. Also, that relationships are integral to wellbeing. Health is social.

The findings uncover, for the first time, that memory cafés are multi-faceted, providing a place where people can meet with others in a similar situation, where they can share skills and experiences, and can engage in a wide range of activities. Furthermore, they provide a place of continuity for carers, when their loved one has moved into long-term care or passed away. The findings identified the valuable role of the volunteers, and that they are often seen as key in the success of the cafés. The cafés are also a source for information on other support services available. They create opportunities for humour and laughter, and enjoyment outside of normal routines. Most importantly they foster relationships, new social networks and even friendships.

**They are much more than tea and cake.**

## 8 Appendices

### Appendix 1 – Initial information leaflet for memory cafes

#### About me



Hello, my name is Lisa Burrows and I am a registered mental health nurse. I initially began my career in adult mental health and then moved to dementia care. I have worked in both NHS settings and the private sector, supported people from diagnosis through to end of life care. I have lived in Cornwall all my life, other than 6 months nursing in New Zealand. I am passionate about dementia care and Cornwall. I am also learning to knit, thanks to a carer who attends our café!

Contact details

[lisa.burrows@plymouth.ac.uk](mailto:lisa.burrows@plymouth.ac.uk)  
07900987957

#### My experience

In September 2014, I helped set up St Agnes memory café, which opened in January 2015. I am actively involved in the running of the café, as well as being the treasurer. My experience like yours, has shown that the cafes are more than 'tea and cake'. I have witnessed people become more engaged and form friendships. My aim is to produce research evidence that supports our experiences, and increases the recognition of what our cafes provide.

#### What you can do to help

To ensure my project considers a wide range of views, I need your input on how and why the memory cafes work. I will be holding a meeting to gather this information and I would be grateful for any feedback. I look forward to hearing from you.



# More than tea and cake: Evaluation of Memory Cafes



Hello my name is Lisa Burrows and I'm a researcher from Plymouth University. I am a nurse and I also help run a memory café in Cornwall. My experiences have shown that the cafes are more than 'tea and cake'. The aims of my research is to explore how and why the cafes are working, and what users value most. This will enable best practice to be shared.

I would like to attend your café and join in with what you are doing. This way I can see, hear and feel how the different cafes run. I will collect information through observation and speaking with you.

The information that you give will be confidential and stored securely.



This research was funded by the National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care, South West Peninsula. The views expressed are those of the authors and not necessarily those of the NHS, the NIHR, or the Department of Health.

## Appendix 3 – Participant information sheets

RESEARCH  
WITH  
PLYMOUTH  
UNIVERSITY

NIHR CLAHRC  
South West Peninsula

**NHS**  
National Institute for  
Health Research

### Participant Information Sheet

**Title of research study - More than tea and cake: an evaluation of memory cafes in Cornwall**



Hello my name is Lisa Burrows and I am the researcher for this study.

This information sheet explains why the research is being done and what taking part will involve.

Please take the time to read through the information sheet and discuss with others if you wish. If you have any further questions then you can contact me on 07900987957 or email me [lisa.burrows@plymouth.ac.uk](mailto:lisa.burrows@plymouth.ac.uk).

#### What is the study about?

There are now over thirty memory cafes in Cornwall. Despite their growing popularity there is very little research evidence on how they benefit people that attend. The aim of this research project is to investigate how and why memory cafes work, and find out the views of the people that use them.

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### **What does taking part involve?**

I will visit your memory café a number of times, during the year, and join in with the sessions. Whilst there I will observe what is going on and take simple notes. I will also speak to people that attend and the volunteers, to gain their views and experiences of the memory café. I will take simple notes of these conversations.

If you decide to take part, I will go through a consent form with you which you will need to sign.

Even if the committee of the café have agreed for me to do the research, you do not have to take part. No information will be collected about you through observation and I will not approach you.

If you change your mind and would like to join in, then I will speak with you and go through this information sheet.

---

### **How will the study benefit me?**

I hope that you will find talking to me about your experiences beneficial. Collecting your views and experiences will provide evidence of what happens at memory cafes.

This information will also help memory cafes share what works best for the people that attend. I will inform you of the findings at the end of the study.

There are no perceived risks of being involved in this study but if you do feel you require further support, I will recommend who you can contact.

---

### **Will my confidentiality be maintained?**

All information I collect about you through observation and speaking with you will be confidential. I will take simple notes during the memory café which I will make in a notebook. I will keep the notebook with me at all times. You will be assigned a number, and no names or initials will be recorded in the notebook. I may use your actual words in my write up but you will not be identified.

The only time I would break confidentiality, is if I were concerned about someone's safety and welfare.

---

### **Storage of information**

Your consent forms will be stored in a locked filing cabinet. Only I and my main supervisor will have access to this. The notes I take will be typed up as soon as possible after the memory café. My laptop is password protected and encrypted. I will then shred my paper notes.

My computer files will also be uploaded to a secure Plymouth University server.

Once my study is completed, all data will be the responsibility of my main supervisor and stored securely for ten years.

---

### **What if I change my mind?**

You can change your mind at any time and withdraw from the study. Any information I have collected about you will be destroyed and I will collect no further information.

If you choose to no longer take part, this will not affect you attending your memory café.

---

### **What if there are any problems?**

I hope that you will not experience any problems.

If you do have any concerns about me or my research then please contact my main supervisor, Professor Bridie Kent on 01752 586500 or email her at [bridie.kent@plymouth.ac.uk](mailto:bridie.kent@plymouth.ac.uk)

Or you can contact the Research Administrator to the Research Ethics Committee on 01752 585339.

---

### **Who is funding the study?**

The study is funded by the National Institute of Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care, South West Peninsula (PenCLAHRC).

---

### **Ethics approval**


The study has been approved by an ethics panel at Plymouth University, 18/8/2016, ref no: 15/16-605

---

## Participant Information Sheet

**Title of research study - More than tea and cake: an evaluation of memory cafes in Cornwall**

**Who is doing the research?**

	<p>Hello my name is Lisa Burrows and I am the researcher for this study.</p> <p>I am a nurse and I help run a memory café in Cornwall.</p>
--	--

<p><b>RESEARCH WITH PLYMOUTH UNIVERSITY</b></p> <p><b>NHS</b> <i>National Institute for Health Research</i></p>	<p>The study has been approved by an ethics panel at Plymouth University, 18/8/2016, ref no:15/16-605</p> <p>The study is funded by the National Institute of Health Research, South West Peninsula.</p>
---	--

**What is the study about?**



The study is about memory cafes.

I want to find out how and why memory cafes are working.

**What would happen?**



I will attend your memory café a number of times over a year.

I will join in with the activities.

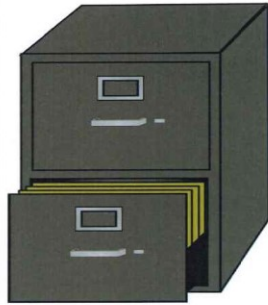


I will watch what is going on and take notes.

I will ask you about the memory café and take notes.



You do not have to take part.



Any information you give is confidential.

It will be stored in a locked filing cabinet.



Or on a password protected computer.



Only I and my main supervisor will be able to access this information.

Once my study is completed my main supervisor will be responsible for the information and stored securely for ten years.



I would only break confidence if I were concerned about someone's safety.

	<p>You can change your mind at any time and no longer be in the study.</p> <p>This will not affect you attending your memory café.</p> <p>The information you have given will not be used.</p>
	<p>Hopefully you will find talking to me about your experiences beneficial.</p> <p>If you have any problems you can contact my supervisor Bridie Kent 01752 586500 or the Administrator to the Ethics Committee 01752 585339.</p>
	<p>Thank you for reading this information.</p> <p>If you would like to speak to me, my contact number is 07900987957</p> <p>Or email <a href="mailto:lisa.burrows@plymouth.ac.uk">lisa.burrows@plymouth.ac.uk</a></p>

## Appendix 4 – Ethics letter

**RESEARCH  
WITH  
PLYMOUTH  
UNIVERSITY**

18<sup>th</sup> August 2016

**CONFIDENTIAL**

Lisa Burrows  
S06, 2<sup>nd</sup> Floor,  
Plymouth University  
Knowledge Spa,  
Royal Cornwall Hospital  
Treliske  
Truro  
TR1 3HD

Dear Lisa

**Reference Number: 15/16-605**

**Application Title: More than tea and cake: a realist evaluation of memory cafes**

I am pleased to inform you that the Committee has granted approval to you to conduct this research.

This approval is for three years; after which you will be required to seek extension of existing approval.

Should any MAJOR changes to your research design occur which effect the ethics of procedures involved you must inform the Committee. Please contact Sarah Jones (email [sarah.c.jones@plymouth.ac.uk](mailto:sarah.c.jones@plymouth.ac.uk)).

Please note in addition that research which, under the Mental Capacity Act 2005 requires approval by an NHS Medical Research Ethics Committee or the Social Care Research Ethics Committee cannot be authorised by this University committee. Ethical approval is only given for research which is consistent with these legal expectations.

Yours sincerely

  
 **Professor Michael Sheppard, PhD, FAcSS**  
Chair, Research Ethics Committee -  
Faculty of Health & Human Sciences and  
Peninsula Schools of Medicine & Dentistry

Faculty of Health & Human Sciences  
Plymouth University  
Drake Circus  
Plymouth PL4 8AA

T +44 (0)1752 585339  
F +44 (0)1752 585328  
E [sarah.c.jones@plymouth.ac.uk](mailto:sarah.c.jones@plymouth.ac.uk)  
W [www.plymouth.ac.uk](http://www.plymouth.ac.uk)

Professor Michael Sheppard  
CQSW BSc MA PhD FAcSS  
Chair, Faculty Research Ethics  
Committee

## Appendix 5 – Research partnership agreement with Alzheimer’s Society

**From:** ResearchPartnerships <ResearchPartnerships@alzheimers.org.uk>  
**Sent:** 20 February 2017 10:11  
**To:** Lisa Burrows <lisa.burrows@plymouth.ac.uk>  
**Cc:** Parsons, Teresa <Teresa.Parsons@alzheimers.org.uk>  
**Subject:** FW: Research Partnership Application

Hi Lisa,

I’ve had no opposing feedback from Jane and Teresa, and as such we are happy for you to proceed with the project as discussed. I’ve cc’ed in Teresa the services manager for the area, going forward it would be best for you to contact Teresa directly. She will put you in touch with the relevant café coordinator to organise times/days etc. Please don’t hesitate to get in touch if any issues arise.

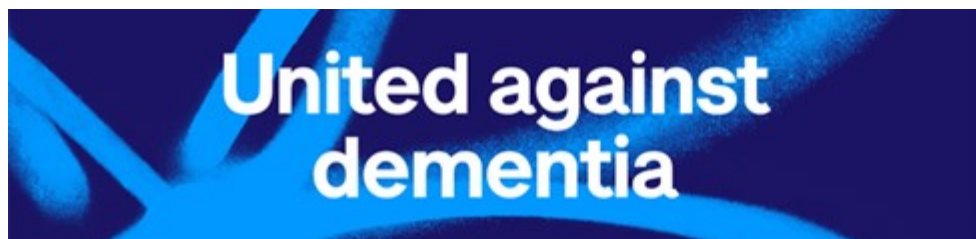
Best wishes,

Halle

**Halle Johnson**  
Research Assistant  
Alzheimer’s Society  
Office phone 020 7423 1029  
[Halle.Johnson@alzheimers.org.uk](mailto:Halle.Johnson@alzheimers.org.uk)  
Alzheimer’s Society, 43-44 Crutched Friars, LONDON, EC3N 2AE

**Do you know an early-career researcher whose work deserves recognition?  
Nominations are now open for the [2017 Dementia Research Leaders awards](#)**

[alzheimers.org.uk](http://alzheimers.org.uk)  
[facebook.com/alzheimerssocietyuk](https://facebook.com/alzheimerssocietyuk)  
[twitter.com/alzheimerssoc](https://twitter.com/alzheimerssoc)



## Appendix 6 – Consent form

**RESEARCH  
WITH  
PLYMOUTH  
UNIVERSITY**

NIHR CLAHRC  
South West Peninsula

**NHS**  
*National Institute for  
Health Research*

### Consent Form

Please read the following statements	Initials	Researcher Initials
I have read and understood the Participant Information Sheet		
I have been given the opportunity to ask questions		
I understand that taking part will involve being observed and being interviewed		
I have been given adequate time to make my decision		
I understand that my information will be kept confidential and stored securely		
I understand that my words may be use in the final report but my name will not be used		
I understand that I can withdraw from the study at any time and do not have to give a reason		
I agree to take part		

**Signature Participant:**

**Print name:**

**Date:**

**Signature Researcher:**

**Print name:**

**Date:**

Appendix 7 – blank observation form

Café:

Date:

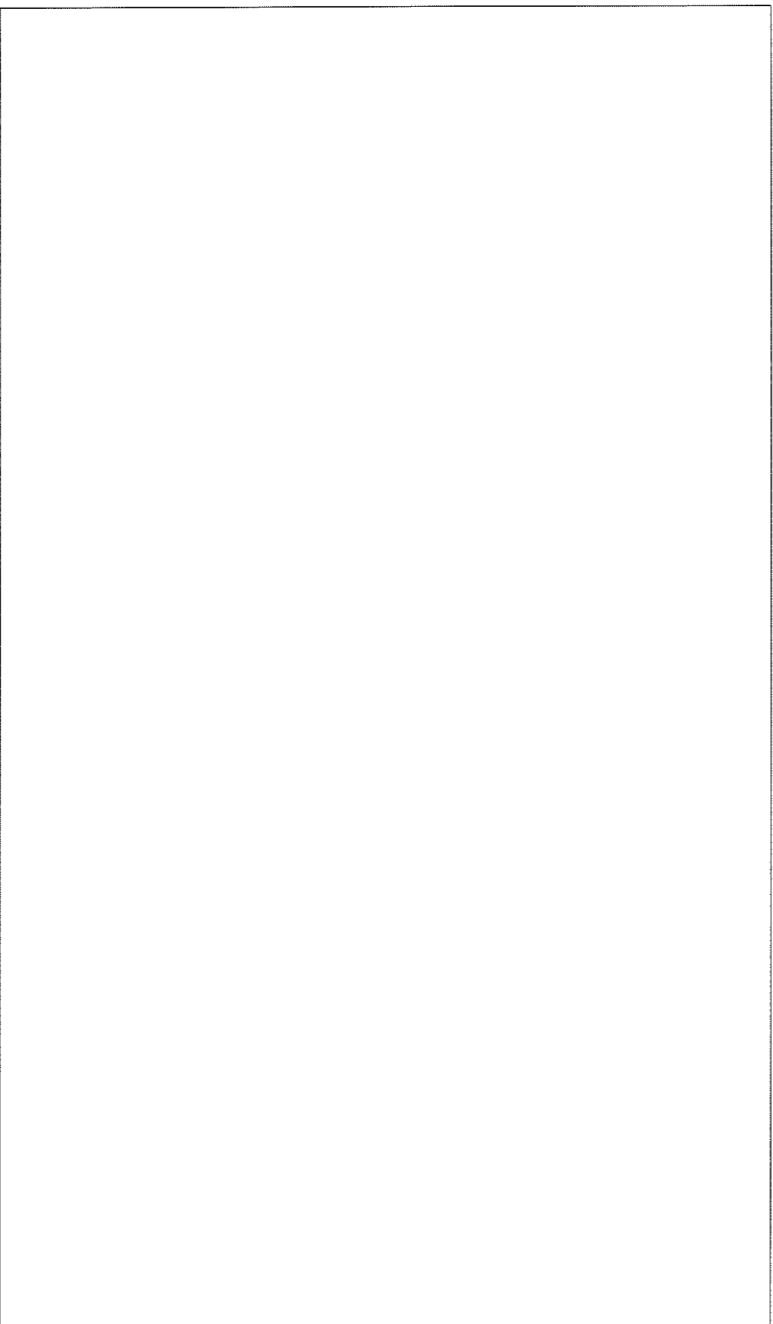
Observation Sheet

Room layout		Descriptive data		
	Weather	Number of people attending	Men/Women	Guestimate of ages
	Activity	Other events that day	Refreshments	

Café:

Date:

Structure of session (how session is delivered, characteristic of facilitator etc)

A large, empty rectangular box with a thin black border, intended for handwritten notes or a diagram related to the session structure.

## Appendix 8 – Example of observation sheet (café A)

Café: (a) Date: 23/1/2017

Observation Sheet

Room layout	Descriptive data		Men/Women Approximation of ages
	Weather	Number of people attending	
<p>projector</p> <p>Chairs Table Chairs Chairs Table Chairs Chairs Table Chairs</p> <p>Chairs Table Chairs Table Chairs Table Chairs</p> <p>Table</p> <p>welcome table</p>		7 helpers 33 guests	one younger couple noted
	Activity	Other events that day	Refreshments
	Off to Australia - video clips of the Cornish festival in	None aware of	Dishes and food.
	Guess the price of everyday items		

Date: 23/1/2017

Café: A

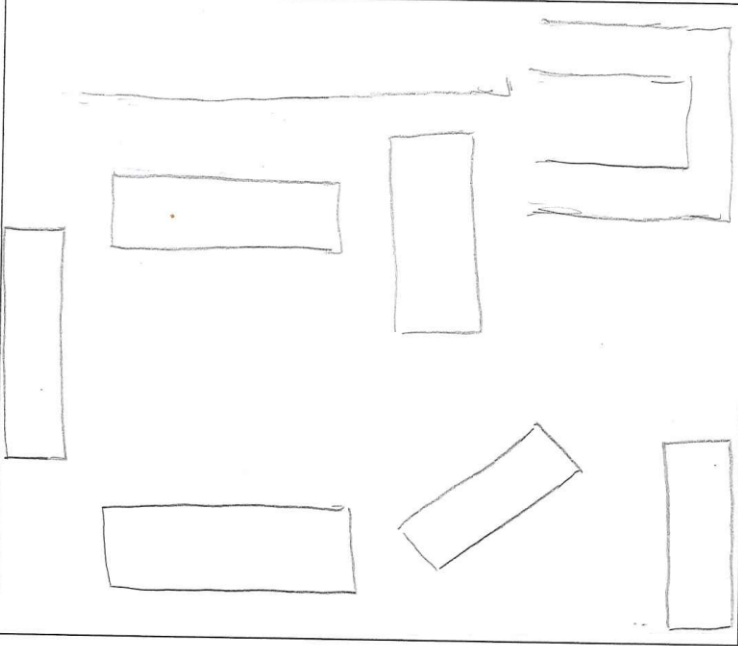
Structure of session (how session is delivered, number of volunteers, characteristics, interactions etc)

Badges & register drinks to start welcome using microphone 'Off to Australia' Australian flags on table and daily sparkle introduction by group leader and then another volunteer took over (who had lived in Australia) showed two video clips of Carnish festival in Australia Quiz on Australia third clip - some guests appearing to lose interest Primary care dementia practitioner visited for second half of café	* People sat in small groups - 2 due to table layout - do people always sit in same groups * Guests remembered me * Some guests from local care homes * x2 consented, need to get these earlier next time due to limited time to talk ↳ no questions from P1 forms * Signs of traditional helper model - ? is this what guests want * some volunteers seems to stay in kitchen	Close by leader offers of support at the end - chicken people you want seen for a while may needed help with anything shopping etc.
drinks and food Guess the price of everyday items Guests given the opportunity to say ↑ or ↓ Person closest won item	<ul style="list-style-type: none"> <li>↳ This part was facilitated by another volunteer, who told stories and related items to life history e.g. what did you have for breakfast when you were young?</li> </ul>	

# Appendix 9 – Example of observation sheet (café B)

Café: (b) Date: 13/5/17

Observation Sheet

Room layout	Descriptive data		Men/Women Guestimate of ages
	Weather	Number of people attending	
	Sunny	18 volunteers due to AGM 9 clients 13 carers 1 visitor	14 M 14 F
	Activity AGM started 14.40 free hmo 14.00-14.40 14.52 stopped food	Other events that day None aware of	Refreshments No food to offer AGM - fruit - splits - soft drinks - cakes

15.05 - flowers  
 2 food share  
 everybody left by 15.50

memory boxes some people took at

behind of one

Café: b

Date: 13/5/2017

Structure of session (how session is delivered, characteristic of facilitator etc)

- \* Sign in for AGM
- \* Mingle of noise and conversation - people moving around catching up with each other
- \* Leader back from hols
- \* AGM - board sat at the front
  - ↳ agenda, expenses on the tables
- \* Propose and second of minutes, hands up to sign off minutes.
- \* Annual report from management committee (committee, trustees, volunteers - thanks)
- \* Carols 1/4 lunch monthly, if service monthly 1/2
  - ↳ unit volunteers rota basis to keep costs down
- \* Musical instruments, first aid training for 8 volunteers
- \* Propose and second for accounts
- \* Elect four officers - chair, vice chair, secretary, treasurer
  - ↳ no more people than proposed - election committee
- \* Independent examiner
- \* People noting guests missing

## Appendix 10 – Example of observation sheet (café C)

Café: C Date: 6/9/2017

### Observation Sheet

Room layout		Descriptive data		Men/Women Approximation of ages
		Weather	Number of people attending	
Usual layout		Dry/ sunny	vol 8 clients 9 careers 5	Male 7 Female 15
		Activity	Other events that day	Refreshments
		Poetry Quiz	None aware of	Tea at beginning

Café: C

Date: 6/9/2017

Structure of session (how session is delivered, number of volunteers, characteristics, interactions etc)

\* Quieter today ? due to activity  
- guests have a card, so know what is on  
\* Introduced back to cafe - people recited remembered  
\* Small groups talking, quizzes and spare time handed out  
\* 1340 activity - MADE read a couple of poems. Then asked people to work in pairs - what is your favourite poem (lots of discussion). Carol read out a poem that he had written. Next write a poem in groups - given a starting line 'Autumn leaves begin to fall'. When poems completed, read out to group. Activity finished 14:30. Quiz answers (famous couples, Cornish quiz) time to talk got people working together. \* Some said they  
\* Volunteers sat with guests. we were not interested in poetry

# Appendix 11 – Completed observation sheet (café D)

Café: **d**

Date: **28/3/2017**  
**first visit**

Observation Sheet

Room layout	Descriptive data		Men/Women Approximation of ages
	Weather	Number of people attending	
		<b>Guests 15</b> <b>Vol 3</b>	<b>M 3</b> <b>F 15</b>
	<b>Activity</b> <b>AGM</b> <b>Bookle</b> <b>dive</b> <b>poem read</b> <b>out about</b> <b>mushrooms</b>	<b>Other events that day</b>	<b>Refreshments</b> <b>Tea &amp;</b> <b>biscuits</b> <b>midway</b>

Café: d

Date: 28/3/2019

Structure of session (how session is delivered, number of volunteers, characteristics, interactions etc)

- \* Initial thoughts
  - ↳ relaxed, feels like a family, guests involved in the cafe, laughing and joking.
- \* Am happy for me to continue attending for my research project

## Appendix 12 – Data analysis



## **Appendix 13 – Changes from the review**

As the review progressed it was clear that answering the original title 'What is the impact of memory cafés for people with dementia and their carers: a realist review' would be difficult due to the limited papers available. Thus the title was amended to 'Exploring the potential impact of memory cafés for people with dementia and their carers: a realist review'. It was apparent that the included papers would only provide a partial knowledge of explaining memory cafés and generate further lines of enquiry. Other changes from the review protocol were that both reviewers LB and AH screened the abstracts and RG checked a sample of the data extraction not AH. All papers were quality appraised by LB and a sample checked by all the other reviewers AH, BK, JL and RG. An expert advisory group was originally going to be established to aid with the review but due to the fact that memory cafés are run by volunteers or a charity, and are not a commissioned service, it was felt that seeking input from commissioning and health and social services would be difficult. Consequently, due to time constraints, patient and public involvement with a group of people living with dementia and meeting with other memory cafés were chosen. These two groups member checked our initial programme theories and then the findings from the review.

## **Appendix 14 – Search Strategy**

### **Search terms**

- 1. Dement\***
- 2. Alzheimer\***
- 3. 1 or 2**
- 4. Memory café**
- 5. Alzheimer café**
- 6. Dementia café**
- 7. Peer group**
- 8. Support group**
- 9. 4 or 5 or 6 or 7 or 8**
- 10.3 and 9**

**Appendix 15 – Quality Appraisal for review (used with kind permission of Jagosh, 2012)**

Article reference number:
Reviewer:

<b>Realist Review Appraisal Form</b>			
Title:			
Authors:		Date:	
<b>Appraisal Assessment of documents</b>			
Documents to be appraised on relevance and rigour			
<b>Relevance (usefulness) – contribution to theory building and/or testing</b>			
High	Moderate	Low	None
<b>Rigour – whether the method used to generate the data is credible and trustworthy</b>			
High	Moderate	Low	None
<b>Brief description/diagram of programme theories (how the intervention is working, outcomes and theoretical assumptions)</b>  <div style="border: 1px solid black; height: 150px; margin-top: 5px;"></div>			

This document has been adapted for the purpose of this review from an original design, with the kind permission of Justin Jagosh Senior Research Fellow, Liverpool University.

<div> <div>Article Number:</div> <div>Reviewer:</div> </div>				
<div> <div>+</div> </div>				
Country where study conducted	Type of study	Methodology	Data collection methods	Results

#### High

Rigour - study shows congruity between methodology, methods, data analysis and conclusions

Relevance - Provides strong support or opposition to the preliminary programme theories. Generates new programme theories

#### Moderate

Rigour - study shows some congruity between methodology, methods, data analysis and conclusions

Relevance - provides some support or opposition to the preliminary programme theories

#### Low

Rigour - study shows limited congruity between methodology, methods, data analysis and conclusions

Relevance - provides limited support or opposition to the preliminary programme theories

#### None

Rigour - study that should not have passed full text screen. Further exploration shows no congruity between methodology, methods, data analysis and conclusions

Relevance - provides no information for the preliminary programme theories.

This document has been adapted for the purpose of this review from an original design, with the kind permission of Justin Jagosh Senior Research Fellow, Liverpool University.

## Appendix 16 – Data extraction sheets for review

Target group	Focus of study	Recruitment	Participant characteristics	Intervention characteristics	Methodology	Data collection methods	Primary outcome
People with dementia	Description of the setting up of a long-term support and self-help group (10 sessions) - a time-limited holistic psychoeducation group and a long-term support group	Referrals from OPMH team (people living in the community). MMSE more than 20/30.	6 men 1 women - participants had had 'successful careers'. On the caseload of one of the team.	Overall purpose of group was to support people in the earlier stages of dementia. Group involved in deciding on topics for sessions. Start of session coffee and biscuits, recap and questions, asking members to share a positive experience, main speaker 45-60mins, coffee break, recap and plans for next session - debrief (not always complete). All members given a file about sessions.	Reflective account	Planned to evaluate every session but not given out every session - so not analysed	Socialising (clients and leaders saw this as a benefit). Authors suggest that psychological gains were probably greater than the educational gains'.
People with dementia and their carers	Setting up of an Alzheimer café. Authors identified that there was no combined service. Also, that people with dementia and their carers were socially isolated and no longer able to continue with previous activities. Descriptive accounts of AC's and few evaluations.	People with dementia and their carers invited to attend initial café, asked to complete questionnaire, conclusive response that they wanted a café.	30-35 people each month. Core group that attends each month and one couple that have not missed one.	Initial café held in a residential and day care centre for people with dementia. Questionnaire completed by those that attended and also sent out to those that couldn't (85% response rate) - responses conclusive - wanted the café. The café brings together people with dementia, their carers, and concerned professionals in an informal environment where they can socialise together, without embarrassment, share information about the condition, and provide support to each other. The activities have changed over the years from a combination of educational talks or discussions followed by music or similar activities such as quizzes. By common consent, the members prefer the lighter, social gatherings and love any excuse for a party. Music plays a large part.	Action research pilot study	Focused on perspective of carers due to the advanced stages of dementia of experienced attendees. Not possible to include professionals as very few attend. Six carers agreed to participate in an hour long discussion. The aim was to explore the ways in which the group was meaningful to those who find it so. Tape transcribed and contents analysed to identify common themes.	Normalising emotions/changes
Carers	Description of Dutch support groups, review of the international literature and report of a study among 110 participants of support groups in which the change mechanisms of the groups were examined.	110 participants of 21 support groups. Quantitative part - questionnaire pre, after end of group and six months later. Interviews conducted at same intervals.	110 participants - questionnaire, 11 participants - semi-structured interviews. No other characteristics outlined.	A study on the change mechanisms and effects of support groups	Mixed methods	Questionnaires and semi-structured interviews	Caregivers find benefit in a support group, especially those who feel heavily burdened.
Carers	Reflections on 12 years of facilitating Alzheimer's caregiver support groups	Self-referral	Women from the start have been predominant	Support group developed due to results from a survey 1991-93 that showed more people than expected were caring for a loved one with dementia. Mission of the council, for people to stay at home as long as possible. Support group seen as a way to help carers. Evening and daytime group. Group reflected on in the article based on peer support model.	Reflective account	Past and present members comments about the benefits to support authors reflections - ? How obtained	Decreased isolation, increased empowerment and improved self-care

## Appendix 17 – Data extraction sheets for review

Relevance score	Mid-range theories or models	Concepts	Outcomes	Intended (Y/N)	Details/quotes/evidence for outcome
Moderate - LB High - AH	None	Not being alone, socialisation, frustration, self-esteem, interest, motivation, non-stigmatising	Socialising	Unclear	The leaders noted that attending the group was the only time that one member went out of the house. For a number, it was their only regular social event, indicating a huge increase in socialisation. Clients saw this socialising as a successful accomplishment (which it was - all interactions are work) and increases in self-esteem were noted on home visits.
			Recall of sessions	Unclear	Once they felt secure, the ability of members to remember was, on occasion, very striking. For example, in the last session, the group leader, in telling the relatives about the sessions we had had, omitted one. T reminded her that there had been a session on pills and potions.
			Group support	Unclear	The group members are now quite vocal in their views and have accepted a request to become a 'focus group' for the older people's mental health service to refer to when needed. The group members have proved very supportive to each other, sharing their experiences with each other. When a session was postponed for a week, one member invited the others over for coffee.
Moderate - LB Low - AH Moderate - JL	None	Non-clinical, non-didactic, non-pathologising, unstructured, normalising emotions, equals, frustration, social isolation, affective empathy, sharing experiences, safe place	Affective empathy (carers) 'Our ability to perceive the world through another person's perspective'.	Unclear	In the group, encouragement was given by those with positive experiences and difficult experiences were accorded affective empathy. This suggested that coming into contact through the with people who had undergone similar events had helped develop participants' affective empathy.
			Normalising emotions/changes	Unclear	The results from the group discussions and from our experience in setting up and organising the café suggest that it provides an important venue in which, through meeting with others in a similar position, carers may be helped to normalise the emotions that the experience of caring has evoked in them and the changes in relationships that have occurred since the onset of dementia. People with dementia may be helped to normalise their changes in functioning and supported in coming to terms with living with dementia.
			New social network	Unclear	For families who find themselves becoming increasingly socially isolated, the café may provide a secure base and provide a new and different social network.
			People with dementia not benefitting from the café	Unclear	There was initially some doubt as to whether the people with dementia gained from attending the café. However, as the discussion continued, benefits were identified. The very fact of being encouraged to look at specific benefits to those for whom they cared seemed to cause new thinking, bearing out the benefits of the group processes.
Moderate - LB	Lazarus (1981) Stress and coping theory - '...groups can offer different types of support that can influence the appraisal of the situation, the coping process, or the resulting stress'.	Burden, change mechanisms, coping processes, informative support, counseling support, normative support, emotional support	Positive effects	Unclear	Participants get a better view of their situation, learn to use new and more efficient ways of coping with their situation, and are better able to handle the care emotionally.
Moderate - LB	None	Peer support, friendships, openness, warmth, sharing, homogeneity, decreased isolation, increased empowerment, and improved self-care	Friendships	Unclear	...one of the most positive spin-offs of the support groups has been the bonds and friendships that have formed that go beyond the monthly meetings. EC states 'The friendships of the wonderful people in the group, all of whom had similar but unique experiences to share, was for a non group person like me something to look forward to and reflect on and to realise how much even one meeting per month could help'.

## Appendix 18 – Data extraction sheets for review

Theories	Outcomes	Context	Mechanism		
	Socialisation - Social connectedness	Community setting, non-stigmatising, views of river - Non-stigmatising environment	Expressing feelings of frustration	Not feeling alone	Shared identity/universality
	Recall of sessions - Underestimating memory	Homogeneity of group members -	Information on relevant topic	Reduced anxiety	Discussions being relevant
	Group support - Friendships				
	Affective empathy - Connectedness	Non-clinical, non-didactic, non-pathologising, non-stressful and unstructured - Non-clinical environment	Meeting as equals	Co-working	Shared identity/universality
	Normalisation emotions/changes - Normalisation situation				
	New social network - Social connectedness				
	People with dementia not benefitting from café - Benefits to people with dementia not always clear				
Lazarus (1981) Stress and coping theory - '...groups can offer different types of support that can influence the appraisal of the situation, the coping process, or the resulting stress'.	Positive effects - Skills development		Informative support, counselling support, normative support, emotional support	Different frame of reference	Different types of support
	Friendships - Friendships	Open group - Open ended	Sharing information	Knowledge	Information
		Similar members - Homogeneity of members	Sharing experiences	Not feeling alone	Sharing feelings
		Shared diagnosis - Shared diagnosis	Information	Knowledge/empowerment	Informed
		Café-style environment - Café-style environment	Relationship of trust	Accepting help	Trust
		No fixed programme - No fixed programme	Support from café	Reduced anxiety	Combined support
		Paid workers - Paid staff	Support from other	Not feeling alone	Friendships

## **Appendix 19 – Member check**

Following the period of data collection and analysis of findings, all the cafes were visited again to feedback and check whether they thought it was representative of their experiences. All emphasised the importance of relationships and being with others that understand.

Café A – in agreement, wanted to know what was the best activity I had seen and if all the cafes were different.

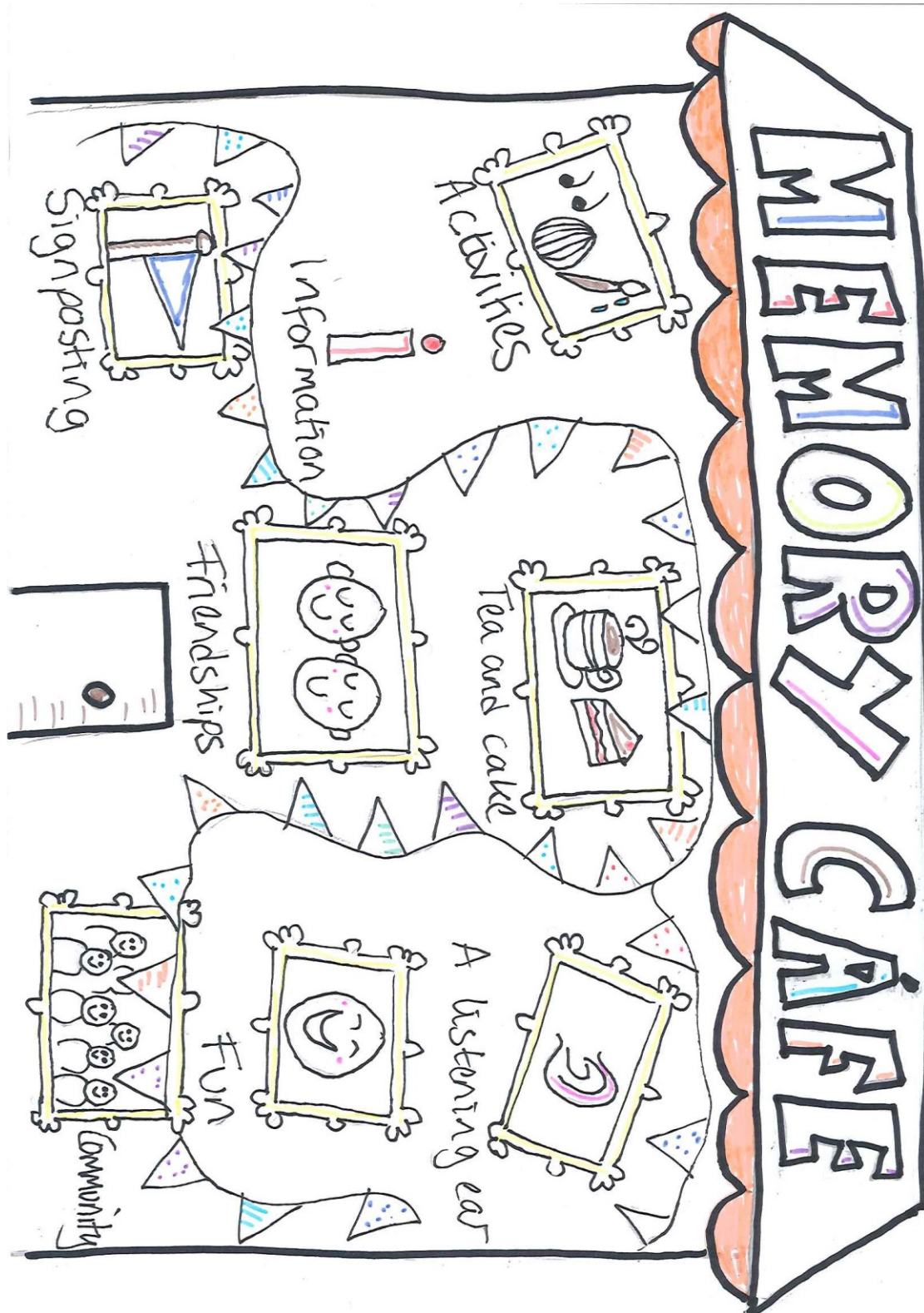
Café B – in agreement.

Café C – in agreement.

Café D – in agreement, wanted to know if all the cafes were different.

I also attended one of the Cornwall Memory Café Networks quarterly meetings and fed back the findings, to the board and a number of cafes throughout Cornwall. They also were in agreement with the findings and were keen for the information to be distributed more widely to evidence what they do.

Appendix 20 – Sketch of findings



## **Appendix 21 – Presentations and training**

### **Presentations:**

Informal seminar - Community and Primary Care Research Group - Plymouth University - November 28th 2017 - More than tea and cake: a realist evaluation of memory cafes in Cornwall

Poster presentation and three minute thesis competition - CLAHRC RCDGP workshop London - 9th-10th/11/2017 - More than tea and cake: a realist evaluation of memory cafes in Cornwall

Three minute thesis competition - Plymouth University - 16/6/2017

Oral presentation - 2nd Annual Clinical School Conference - Royal Cornwall Hospitals Treliske - 10/5/2017 - More than tea and cake: exploring the effect of memory cafes

Oral presentation - Postgraduate Research Society Showcase - Plymouth University - 15/3/2017 - More than tea and cake: a realist evaluation of memory cafes in Cornwall

Poster presentation - for Professor Whitty visit - PenCLAHRC, University of Exeter - 17/2/2017 - More than tea and cake: a realist evaluation of memory cafes in Cornwall

Oral presentation - 3rd Clinical Research Symposium of the Clinical Schools with Plymouth University - 16/12/2016 - Exploring the potential impact of memory cafes for people with dementia and their carers: a realist review

Poster presentation - Research Capacity in Dementia Care Programme Workshop - Windsor Great Park - 23rd-24th November 2015 - More than tea and cake: a realist evaluation of memory cafes in Cornwall

Poster presentation - The State of the Art of Realist Methodologies Conference - University of Leeds - 5th-8th November 2015 - More than tea and cake: a realist evaluation of memory cafes in Cornwall

Group poster presentation - Complex Interventions Conference - University of Exeter - 14th-15th October 2015 - PenCLAHRC Dementia Care Programme: A collaborative approach to complex interventions development - I also provided the one minute verbal presentation to attendees 'Come and see my poster'

### **Training:**

How to use the media to publicise your research, 23/11/2017, University of Plymouth

Introduction to Teaching and Learning module (ITL), January – May 2016, Plymouth University

Dementia Summer School for the CLAHRCs running the research capacity in dementia care, in Sweden, September 2016

Transfer process session, 26/6/2016, Plymouth University

Onedrive training, 25/4/2016, Knowledge Spa, RCHT Treliske

Patient and Public Involvement workshop, 7/3/2016, University of Exeter

Introduction to Endnote session, 18/2/2016, Plymouth University

Research Ethical Approval session, 8/2/2016, Plymouth University

Research Capacity in Dementia Care Programme workshop, 23rd – 24th November 2015, Windsor Great Park

NVIVO session, 17/11/2015, Plymouth University

Joanna Briggs Institute training, August 2015, Plymouth University

Realist Summer School, 30th June – 2nd July, University of Liverpool, held in London

Health Statistics Course, 4 days, June 2015, University of Exeter

Systematic Review Searching, April 2015, University of Exeter

### **Conferences:**

The State of the Art of Realist Methodologies Conference, 5th-8th November 2015, University of Leeds

### **Other:**

Realist Hive, 29/6/2016, University of Exeter

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