EXPLORING THE LIVED EXPERIENCE OF DEMENTIA FRIENDS CHAMPIONS:

POETIC REPRESENTATION

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Declaration

I hereby declare that this thesis is the result of my own independent investigation

I certify that this thesis has not been accepted in substance for any other award, nor is it being submitted currently for any other award.

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4. Placed In The Past
5. Danny
6. Your Presence
7. Fear Not The Future
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Glossary

Alzheimer’s Society

Alzheimer's Society is a United Kingdom care and research charity for people with dementia and their carers. It operates in England, Wales and Northern Ireland, while its sister charities Alzheimer Scotland and Alzheimer's Society of Ireland cover Scotland and the Republic of Ireland respectively (Alzheimer’s Society, 2019) https://www.alzheimers.org.uk/about-us/who-we-are last accessed 12/07/19

Dementia

Dementia is a syndrome in which there is deterioration in memory, thinking, behaviour and the ability to perform everyday activities. Although dementia mainly affects older people, it is not a normal part of ageing. Dementia has a physical, psychological, social, and economic impact, not only on people with dementia, but also on their carers, families, and society at large. (WHO, 2019) https://www.who.int/news-room/fact-sheets/detail/dementia last accessed 04/07/19

There are many different types of dementia, of which Alzheimer's disease is the most common. Some people may have a combination of types of dementia (Alzheimer’s Society, 2019). https://www.alzheimersresearchuk.org/about-dementia/types-of-dementia/ last accessed 12/07/19

Dementia Friends

This is an Alzheimer’s Society initiative, which started in 2013, to change people’s perceptions of dementia. It aims to transform the way the nation thinks, acts, and talks about the condition. Stigma and lack of understanding cause many people with the condition to experience loneliness and social exclusion. Dementia Friends hopes to tackle this by creating more communities and businesses that are dementia-friendly and more inclusive of people with dementia A Dementia Friend is someone who either attends an information session or watches the

Dementia Friends online video. They learn five key messages about dementia, a bit about what it is like to live with dementia and identify how they can turn their understanding into a practical action that could help someone with dementia living in the community. The action may be big or small as every action counts (Alzheimer's Society, 2017) https://www.dementiafriends.org.uk/ last accessed 12/07/19
The latest figures show there are 2.5 million Dementia Friends in England, Wales and Northern Ireland including people living with Dementia (Alzheimer's Society, 2017)
https://www.dementiafriends.org.uk/ last accessed 12/07/19

Dementia Friends Champion

A Dementia Friends Champion is a trained volunteer who runs information sessions for friends, family, colleagues, and the wider community. The information sessions cover five key messages that everyone should know about dementia and helps people to identify what they could do to help. Dementia friends champions attend a volunteer induction day and then organise their own Dementia Friends information sessions, with the support of the Dementia Friends Officer (Alzheimer's Society, 2017d)
https://www.dementiafriends.org.uk/WEBArticle?page=what-is-a-champion#.XShcuP57nIU last accessed 12/07/19

Dementia friendly community

A dementia friendly community can be defined as: a place or culture in which people with dementia and their care givers are empowered, supported and included in society, understand their rights and recognise their full potential (ADI, 2017).
https://www.alz.co.uk/adi/pdf/dfc-developments.pdf last accessed 12/07/19

Dementia Friends information session

An information session is a face-to-face session that lasts 45-60 minutes and is run by a Dementia Friends Champion, which anyone can attend to learn a little more about dementia. It covers the five key messages everyone should know about dementia through their activities and discussion but is not training. Anyone who attends is asked to commit to a dementia- friends action and is able to become a Dementia Friend (Alzheimer's Society, 2017) https://www.dementiafriends.org.uk/WEBArticle?page=what-is-a-friend#.XShdpv57nIU last accessed 12/07/19

Disability

Disability is a complex phenomenon that is both a problem at the level of a person's body, and a complex and primarily social phenomena (WHO ICF, 2001). It is a term covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty in executing a task; participation restriction is a problem experienced by an individual in life situations. It reflects an interaction between body and society The Equality Act (2010) define disability as resulting from a physical or mental impairment that has a substantial and long-term negative effect on the ability to do normal daily activities. Overcoming difficulties faced by people with disabilities requires interventions to remove environmental and social barriers (WHO, 2019g) https://www.who.int/topics/disabilities/en/ last accessed 12/07/19

Impairment

Impairments represent a deviation from certain generally accepted population standards in the body and its functions undertaken by those qualified to judge physical and mental functioning according to these standards. They can be temporary or permanent; progressive, regressive or static, intermittent or continuous. (WHO, 2019g) https://www.who.int/topics/disabilities/en/ last accessed 12/07/19

Interpretative Phenomenological Analysis (IPA)

IPA is concerned with obtaining, describing, explaining, and interpreting experiences. The approach looks at how people make sense of their experiences and the underlying meaning of the experiences. The focus on interpretation differentiates it from other forms of phenomenology (Howitt and Cramer, 2017; Smith et al., 2009; Hayes and Fulton, 2014).

Research poetry

Research poetry may be framed as found and generated poetry.

Found poetry is written to represent data, stay true and give voice to the essence of the participant’s experience (Patrick, 2016; Furman, 2012; Lahman et al., 2011). Generated poetry represents the researcher’s words to share understandings of own and other experiences (Butler-Kisber, 2010)

1 Abstract

1.1 Background

The Alzheimer's Society UK launched the Dementia Friends initiative in 2013 aiming to change people's perceptions of dementia and turn understanding into action to promote social inclusion and dementia friendly communities. Dementia friends champions are volunteers delivering information sessions covering five key messages about dementia, through activities and discussion, and provide an opportunity to commit to a dementia-friendly action. There is limited research into the experience of dementia friends champions.

1.2 Aim

To add to the current body of knowledge, the qualitative phenomenological research into the lived experiences of dementia friends champions was undertaken with a view to influencing and informing the existing and future provision.

1.3 Method

A qualitative phenomenological methodology (interpretative phenomenological analysis) was implemented from a social constructionist epistemology. Semi structured interviews were undertaken with eleven dementia friends champions, from London and the South East, to explore their experiences and insights from undertaking the role. The interviews were transcribed and analysed, and four themes were developed. Poetry was produced by the researcher from the transcripts and insights from the research with the aim of disseminating to a broader audience in an engaging and accessible way.

1.4 Findings

Four themes were developed from the research included being a dementia friends champion, knowledge and understanding in communities, experiences and insights and dementia friendly communities. Champions felt proud to be volunteers and experienced a sense of belonging to a bigger movement. They used a wide range of skills and knowledge in the role that did not reflect the training they

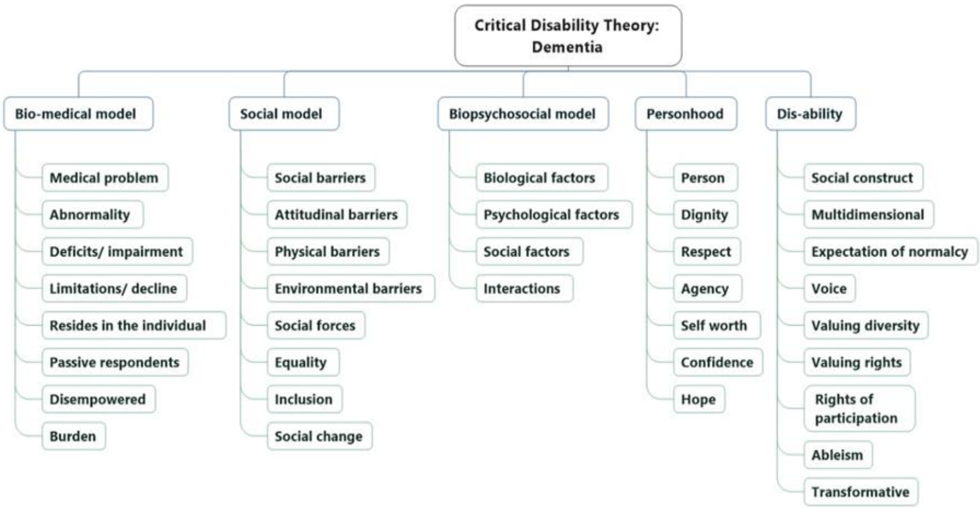
received. They experienced limited knowledge of dementia from people attending sessions, but the feedback received showed changes in attitudes, understanding and action. They encountered a fear of a dementia, distress and unmet needs and the role was emotionally demanding. Some champions were challenged by the key message that you can live well with dementia which did not reflect their own experiences or the people they met. Hearing from people living with dementia had a positive impact on champions and people attending dementia friends sessions. The need to reach younger people and future generations was highlighted to change the dementia landscape. They gained new understandings and were changed by their experiences

1.5 Discussion and conclusion

The research provided new knowledge into the experiences of champions from an individual and community perspective, including unmet needs. The research is presented in an academic format and research poetry to reach a broader audience, promote discussion, reflection, and understanding of dementia and the experience of being a champion.

2 Introduction

2.1 Introduction



The thesis explores the lived experience of dementia friends champions. Qualitative phenomenological research provides insight into the lived experience of dementia friends champions who deliver dementia friends information sessions. The sessions are designed to raise awareness and understanding about dementia, reduce stigma, and turn understanding into action to promote dementia friendly communities.

Findings and recommendations will inform the recruitment, training and support for champions and the design, delivery, and development of the Dementia Friends programme to promote social action. The findings reflect an individual and societal perspective providing insights into the knowledge, understanding and perceptions of dementia. How dementia is understood can be influential in shaping policy decisions, rights and entitlements, and influence practice (Innes and Manthorpe, 2012).

An overview of dementia as a public health priority and details of the Alzheimer’s Society (UK) Dementia Friends initiative are outlined. An organisational map shows models and approaches that have shaped how dementia is understood in society. Disability studies examines the meaning, nature, and consequences of disability and aims to address stigma and disadvantage associated with disease, illness, or impairment. Models and theories provide insight into the social, political, cultural, and economic factors that define disability and the personal and collective responses to difference (Goodley, 2017; Ferguson and Nusbaum, 2012; Young et al., 2019). Dis-ability theory reveals how disability and ability are socially constructed and not an inevitable consequence of impairment (Beard et al., 2009). The strengths and limitations of the biomedical, social model, biopsychosocial model and personhood are discussed in relation to dementia and the research into the lived experience of dementia friends champions. A summary and rationale for the research is included.

2.2 Dementia: A priority

On 29th June 2019 G20 (Group of twenty international forum for the governments from nineteen countries) singled out dementia as one of its global health priorities and said:

“We will implement a comprehensive set of policies to address dementia, including promoting risk reduction and sustainable provision of long-term care as well as inclusive societies aiming to improve quality of lives of people with dementia and caregivers.” (ADI, 2019)

There are 850,000 people with dementia in the UK, with numbers set to rise to over 1 million by 2025 and predicted to reach 2 million by 2051. The present figures show 1 in 6 people over the age of 80 have dementia in the UK. The figures from Alzheimer’s Disease International (2019) show dementia around the world is set to rise from 50 million in 2018 to 82 million in 2030 and 152 million by 2050 (ADI, 2019).

The numbers and predicted needs have led to increasing research to inform policy and practice.

Several leading organisations have been working to raise awareness of dementia as a public health priority for example the World Health Organisation (WHO), Alzheimer’s Disease International (ADI), Alzheimer’s Research UK and Gov.UK. Key themes include raising awareness about dementia, addressing attitude and stigma associated with the condition, promoting diagnosis and treatment, increasing research, and developing dementia friendly communities. Information outlined below represents the global perspective and issues specific to the United Kingdom.

The Dementia 2020 Challenge: 2018 review phase 1 (2018) built on the progress made since the launch of the implementation plan (Gov, UK, 2019, 2016). Eighteen key commitments were identified under four themes including dementia awareness, health and care delivery, risk reduction and research and funding. The review was conducted to assess whether the action identified in 2015 had been achieved and to plan for 2020. The review included dementia awareness and social action including Dementia Friends and Dementia Friendly Communities. The challenge outlined in 2015 was to turn dementia friends into a global movement and reach 4 million friends in England by 2020. The review found with the current trajectory there would be 3.25 million friends by 2020 and additional support was needed to meet the target of 4 million. They recommended conducting an impact assessment to identify the best way to deploy dementia friends to high impact areas and to look and learn from international examples. The Dementia Challenge included the goal that over half of England's population would be living in dementia friendly communities by 2020. Progress had been made and the expectation is the target would be met by 2020. The paper did not discuss the recruitment, support or training for dementia friends champions who deliver the Dementia Friends sessions.

A recent report by Alzheimer's Research UK (Wave 1. 2018) provides insight into the perceptions, attitudes and behaviours around dementia and dementia research in the United Kingdom (ARUK, 2019). 2361 people over the age of 15 took part in the survey interviews undertaken by Ipsos MORI. The questions explored awareness and understanding of dementia, stigma, risk, diagnosis, treatment, prevention, and research. The findings showed public awareness of dementia was high but there remained many misunderstandings. These included Dementia being an inevitable part of ageing and not being a cause of death as well as limited awareness of the impact of the condition. Fear and stigma associated with dementia remained with 42% saying it was the condition they feared most and 22% finding it hard to talk to someone with dementia. The monitor will be repeated every two years to guide future campaigns and identified needs. Dementia friends champions delivering Dementia Friends sessions aim to raise awareness, incorporate positive attitudes, and reduce the fear associated with dementia.

Within the UK the ‘New Deal on Dementia 2017-2022’ (Alzheimer’s Society, 2017f) set out a strategy for England, Wales, and Northern Ireland, in response to the research findings and recommendations. Alzheimer’s Society UK laid out their five-year plan incorporating priorities and action specifically for volunteers and employees. These were categorised under four pillars including support for people with dementia, families, friends, and carers, making change happen nationally and locally, research, prevention, care, and cure and supporting people to deliver change. The strategy included providing volunteers, employees, and supporters with the tools to work effectively. Dementia champions were not named specifically but were incorporated under the heading of volunteers who are providing information sessions and creating Dementia Friends. The strategy identified the need for improved technology to work more effectively but did not address training or support for dementia friends champions.

Alzheimer’s Disease International (ADI) commissioned the London School of Economics and Political Science (LSE) to create a survey about attitudes to dementia to inform the World Alzheimer Report 2019. The survey targeted the public, health and social care professionals, people living with dementia and carers of people with dementia. The survey closed in June 2019 and the results will be released in September 2019.

The Dementia Friends initiative, delivered by dementia friends champions, aims to change the public conversation about the condition, promote dementia friendly communities and promote inclusion.

2.3 Dementia Friends and Dementia Friends Champions

“Dementia: a public health priority” (WHO and ADI, 2012) raised awareness of dementia as a public health priority and identified the need for action. The report highlighted a lack of awareness and understanding of dementia in most countries. A lack of awareness resulted in stigma and barriers to diagnosis and care, which in turn affected carers, families, and societies physically, psychologically, and economically. Recommendations included advocacy and awareness-raising, developing, and implementing dementia policies and plans, health system strengthening, capacity-building, supporting caregivers and research. The report by the WHO and ADI (2012) was influential in the creation of the Dementia Friends initiative.

The Alzheimer’s Society launched the Dementia Friends initiative in 2013, influenced by the design of the Japanese initiative, which started in 2004 to change people’s perceptions of dementia and turn understanding into action (ADI, 2016).

Dementia friends champions are volunteers trained to deliver Dementia Friends information sessions and five key messages

- Dementia is not a natural part of aging.
- It is caused by diseases of the brain.
- It’s not just about memory loss.
- It’s possible to live well with dementia.
- There is more to the person than the dementia

Over 10,000 dementia friends champions are delivering Dementia Friends sessions across England and Wales (The Alzheimer’s Society, 2017). This has resulted in 2.78 million people becoming Dementia Friends and 412 communities committed to becoming dementia friendly in England and Wales (Gov. UK, 2019).

There has been little research into the experiences of the dementia friends champions despite their existence since 2013 and over 10,000 champions recorded with the Alzheimer’s Society.

2.4 Disability studies

Disability studies are an integral part of educational research incorporating equality, diversity, and social inclusion. Goodley (2017) frames disability as the social world, a part of life and the human condition that is personal, embodied, physiological or psychological. There have been multiple understandings of disability and the problematic relationship between disability, impairment, and chronic disease, which influences language and the way society thinks (Grue (2017). The construction of dementia is explored in the chapter in relation to language and models of dementia.

Progress has been made in the language of dementia in many parts of the world for example in Japan (Hayashi, 2017; Aihara et al., 2016) and Norway (Grue, 2017). Dementia was formerly referred to as ‘senile dementia’ in many parts of the world reflecting the belief that serious mental decline is a normal part of aging and reinforcing the perception of incapacity and decline. Changes in terminology reflect the recognition that terminology such as ‘senile’ are negative and disempowering (Alzheimer’s UK, 2017). The perception of dementia as a normal part of ageing has implications for research, funding and understanding at an individual and societal level. Recognising dementia as a global health priority is influential in driving forward change through people centred community-based health and long-term care for people with dementia (AZI, 2019).

2.5 Bio-medical model

From a biomedical perspective disability is seen as a feature of the person, directly caused by disease, trauma, or other health condition, which requires medical care to correct the problem within the individual. Haegele and Hodge (2016) discuss how the medical model of disability shapes beliefs, with treatment directed to fixing the impairment towards function and independence. Health care professionals are perceived as experts rather than the person living with the condition, resulting in dehumanising relations between patients and staff, creating a language that is negative and disempowering.

Illness and disease are perceived as a deviation from the norm, dualist in separating mind and body, and independent from the psychological, sociological, or behavioural aspects. Limitations are linked to impairments, which may be physical, sensory, affective, or cognitive (Engel, 1997). The biomedical model has been criticised for its focus on the individual, medical condition, and deficiency rather than society. Describing someone in relation to their medical condition could lead to society taking an ‘us’ and ‘them’ stance that can be disrespectful and inappropriate (McInerney, 2017).

The biomedical model has been described as the dominant model within western countries but at present there is no cure for dementia and it should not be seen as independent from the wider sociocultural, physical or political environments which all impact on the ability to live well (Haegele, 2016). As people are living longer and with complex needs it does not reflect the diversity of factors that affect health and wellbeing. Dementia affects health in a variety of ways for example physical health changes linked to the ageing process, emotional health for example anxiety or depression and cognitive processes such as short-term memory, communication, and orientation. The delivery of information in the Dementia Friends sessions aims to reduce the fear associated with dementia but Hampson and Morris (2017) discuss how medicalising dementia and bringing it into public view creates negative views and perceptions. Biomedical advances in knowledge, the perception of dementia as an illness of old age, and cognitive decline have created a sense of fear in ageing populations. Cognitive decline may be linked to loss of function, dependence and have economic implications. Such views can lead people with dementia being perceived as objects of their illness, or cases to be compared with other people with dementia, rather than people with unique lives and stories to tell (Beard et al., 2009). The way society sees dementia and the language used shapes the experience of people with dementia and carers.

There are positive aspects of the biomedical approach including understanding disease processes, diagnosis, and treatment but it does not address the psychological, environmental, cultural, or social dimensions of illness (Engel, 1977). The ‘label’ of dementia has been criticised for creating division but Innes and Manthorpe (2012) and Gerritsen et al., (2018) discuss the benefits including diagnosis, treatment, services and providing some explanation about what is happening through the different stages of the disease. Biomedical understandings may provide support for policy decisions linked to funding, and cost-effective treatments, but not recognise the expertise of the person living with dementia. The focus on medical treatment and the quest for a cure will not address the wider social aspects and could result in money being directed towards cure rather than community support. Not recognising the psychological aspects of dementia could also result in people not accessing the right treatment and limit the care and support they receive. The biomedical model neglects to consider the ability of the person to adapt to their changing situation and achieve quality of life despite the changes experienced from a dementia diagnosis. Awareness and understanding of the interrelationship of different components of health in addition to other factors such as lifestyle and social support are not reflected in the biomedical model (Iliffe and Manthorpe, 2017).

The Alzheimer’s Society Dementia Friends initiative (2018) supports the belief that dementia should be recognised alongside other long-term conditions with the goal of removing the stigma associated with the condition. The Dementia Friends sessions, delivered by dementia friends champions, incorporates the impact of dementia from a biomedical perspective including it is not a normal part of ageing and is caused by disease of the brain. The messages encourage people to seek early diagnosis and access treatments and support.

The biomedical model reflects one part of the biopsychosocial model but does not address the bigger picture of dementia (Shakespeare and Watson, 2002).

2.6 Social Model of Disability

The strengths and limitations of the social model of disability (Oliver, 1996) are discussed in relation to disability, impairment, language, stigma, dementia, and dementia friendly communities.

The social model of disability represented a move from the medical model, with the focus on the person as the source of the problem and ‘can’t do’ attitude, to a recognition that oppression and exclusion are constructed by society. The medical view of disability regarded people as having something wrong with them and the source of the problem. The social model turned attention to externally imposed restriction with misfortune being the discrimination, exclusion, and oppression of people with impairments who were labelled as disabled (Barnes and Mercer, 2004).

The terms ‘impairment’ and ‘disability’ have generated discussion and controversy. Impairment has been described as an individual’s physical, sensory, or cognitive difference and disability as the social consequences of having an impairment and a social construct that can be changed (Inclusion London, 2015). The Equality Act (2010) states a person has a disability if they have a physical or mental impairment that is substantial and has a long-term effect on their ability to carry out day-to-day activities. Disability is seen as a socially created problem caused by an unaccommodating physical environment and brought about by attitudes and other features of the social environment. The responsibility falls with society to remove social barriers to inclusion and participation for people with disabilities (Owens, 2015).

There has been considerable debate about the relevance of the social model for people with dementia including whether Dementia is a disability. The label of disability has been dismissed by some as stigmatising and irrelevant during the early stages of the Dementia and the ability for self-advocacy challenged due to the degenerative nature of the condition (Shakespeare et al., 2019).

Tregaskis, (2002) and Gilliard et al. (2005) discuss how the social model focusses more on economic accounts of exclusion and suggests more attention should be given to the persistence of disabling attitudes. Although dementia has its highest incidence in the older age range there are over 42,000 (4.4 percent) people of working age with young onset dementia (Alzheimer's Research UK, 2017) and employment is an important consideration. The focus on employment and the economy in the social model could lead to stigma and discrimination towards people with dementia who are unable to work. The term 'burden' continues to be used in publications reflecting the economic impact of dementia. It is important to identify the financial implications but terms such as 'burden' have the potential to project blame towards people living with dementia (Launer, 2018; Potash, 2018).

The Social Model of Disability has also been criticised for not considering the different ways disability may be experienced and not representing those with mental health, cognitive impairment, or a learning disability (Owens, 2015). The Mental Health Foundation (2015) highlight the different stages of dementia in relation to cognitive ability, how dementia is talked about and the social construction of dementia, which continues to be shaped by fear, stigma, and negativity.

The move from the medical model has been influential in bringing attention to the unique personal experience of living with dementia and social practices through policy and research to promote equal access, rights and belonging (Nedlund and Bartlett, 2017; Shakespeare et al., 2017). Gabel and Peters (2004), Dewsbury et al. (2004) and Levitt (2017) acknowledge the social model has evolved but there is still a need to ensure it does not exclude dimensions of the person's life such as individual agency and knowledge.

The report by the Mental Health Foundation (2015) promotes the implementation of dementia awareness and education for personnel in organisations and suggests a social and cultural change.

The rise in user groups, with a focus on a condition, have been accused of giving priority to impairment, illness identity and biological existence rather than disability and the social processes which result in oppression and exclusion (Hughes, 2009). The social model represents a reconstruction of disability from the individual to the social but to engage as a collective group requires identifying as disabled. People living with dementia may not recognise the label ‘disabled’ or see themselves as part of a homogenous group (Barnes and Mercer, 2004). Raising awareness about dementia, reducing stigma, delivering key messages, and turning understanding into action are at the forefront of the Dementia Friends initiative and position the responsibility with communities to create dementia friendly communities.

One of the aims of the Dementia Friends initiative is to reduce fear and stigma. Gilliard et al. (2005) suggest the social model has something to offer in promoting inclusion for people living with dementia and reflects a community that cares.

There have been many criticisms of the social model but Oliver (2013) highlights that it was not intended as a holistic explanation for all aspects of exclusion but as a starting point (1996, p31). It may not capture all dimensions but can be an aid to our understanding of how the health and well-being of people with dementia can be affected by economic, environmental, and cultural barriers.

2.7 Dementia friendly communities

Creating dementia friendly communities is embedded in government policies and organisational strategies (Gov, UK, 2019; Alzheimer’s Society, 2019). Although the philosophy of social inclusion is supported, the term ‘dementia friendly communities’ has been challenged. Thomas and Milligan (2015) provide a list of examples of attitudinal and behavioural barriers imposed upon people living with dementia but perceive the term ‘dementia friendly’ to be patronizing and devaluing rights. Shakespeare et al. (2019) share the view that ‘dementia friendly’ is patronising and inappropriate leading to the belief that the solution lies in being welcoming and kind and not acknowledging the complexities of the situation. There has been concern that the term ‘dementia friendly’ may encourage division rather than inclusion and the potential for a tokenistic approach (Swaffer, 2014).The terminology is also discussed by Watson (2016) from the personal perspective of living with dementia and as a dementia friends champion. Swaffer

(2014) reflects on why people may not embrace the idea of being dementia friendly including links to mental health, feeling that they know all about it, stigma, and fear. Despite the concerns with the language she was encouraged by the positive attitudes she experienced and the desire to create dementia friendly communities.

2.8 Biopsychosocial model

Moving from a medical to a biopsychosocial model of illness involved the recognition and integration of the social, psychological and behavioural dimensions of illness (Engel, 1977) and led the way to the implementation of the International Classification of Functioning, Disability and Health (ICF, 2001). The ICF definition of disability has been described as an umbrella term incorporating impairments, activity limitations and participation restrictions. The WHO (2002) describe it as a framework and synthesis of health from a biological, individual and social perspective. The ICF incorporates environmental factors, recognised in the creation of disability, as well as the relevance of associated health conditions and their effects (WHO, 2002). Havelka et al. (2009) and Wade and Halligan (2017) describe the biopsychosocial model as an integrated approach that stimulates teamwork and gives a more complete account of healthcare but does not replace the biomedical model. The model, developed over the years, provides a greater emphasis on the person but has been criticised for neglecting choice, well-being, and personhood (Wade, 2015; Wade and Halligan, 2017). The key messages in the Dementia Friends initiative reflect the person living with dementia including respect while also recognising the social components.

2.9 Personhood

Kitwood (1997) discussed the culture of dementia and recognised people with dementia as sacred, unique, and bestowed with respect and trust. He discusses the need for comfort, attachment, inclusion, occupation, and identity. Well-being involves agency and the ability to control personal life in a meaningful way. Kitwood did not deny the biomedical dimensions of dementia but challenged the narrowness of the medical model with the focus on pathology, deterioration, and disease progression. The medical model defines dementia as a series of stages, which could provide some explanation for changes in ability or behaviour but does not recognise individual experience or the ability to adapt to change (Innes and Manthorpe, 2012). Personhood is represented in the biopsychosocial model but Kitwood (1997) extended the concepts of partnership working, identity and sense of self. A sense of self for people with dementia involves recognising the capabilities of the individual, the maintenance of meaningful memories and stories, and the ability to meaningfully interact despite decreased capacity (Beard et al., 2009). This contrasts with the collective approach in the social model or the focus on impairment and loss seen in the medical model.

One of the five key messages delivered by the dementia friends champions is ‘there is more to the person than dementia’.

2.10 Critical dis-ability and dementia

Goodley (2017) proposes dis-ability or dis/ability represent the complex interrelationship between ability and disability and outline the importance of developing inclusive ways of working. Disability is not an inevitable consequence of impairment but an interrelationship between impairment, individual response to impairment and the social environment (physical, institutional, and attitudinal). Waldschmidt (2018) describes disability as socially and culturally constructed and one side of a coin with the reverse side defined as health, ability, or normality.

2.11 Summary

Each model and approach have brought elements relevant to dementia and the research being undertaken but does not necessarily capture all components.

Shakespeare et al. (2019) propose a ‘laminated model’ that recognises the interaction between the biological, psychological, environmental, social, and legal components that produce the experience of disability which may lead to a better understanding of dementia. This research explores the experiences of dementia friends champions delivering Dementia Friends information sessions with the aim of transforming the way the nation thinks, acts, and talks about Dementia, to be more inclusive and promote dementia friendly communities. The chapter finishes with the poem ‘Inclusion’:

Poem 1

Inclusion

Ordinary me
In ordinary places
Extraordinary

3 Literature review

3.1 Introduction

The literature review set out to explore what had already been researched and what remained unexplored about the lived experience of dementia friends champions.

My approach to the literature review was methodical, explicit, and reproducible to identify, evaluate and synthesis the existing body of work produced by researchers, scholars, and practitioners (Booth et al., 2012; Grønmo, 2020; Fink, 2019). Aveyard et al. (2016) discuss the importance of the supportive literature review which draws on empirical, theoretical, and methodological literature to identify what is known and unknown about a topic area. A thorough approach was taken to searching, appraisal, synthesis, analysis, and presentation. I outline my standpoint as the researcher, the aims, and objectives, how investigation was undertaken and the evaluation (Booth et al., 2012; Hart 1998). I gave attention to gaps in the literature which contributed to the claim of original contribution to knowledge.

The research into the experiences of dementia champions incorporates qualitative, quantitative, and mixed method research. Textual descriptions, charts and grouping in the form of themes are included. An introduction and background to the topic is included followed by the literature review organised using the IMRAD format of introduction, method, results, and discussion. The synthesis and themes are explained including definitions of a dementia champion, training provided for dementia champions, roles and responsibilities of a champion, experiences of being a champion and dementia friendly communities. A summary is included identifying gaps in evidence into the experiences of dementia friends champions. Except for one paper the research did not relate specifically to dementia friends champions showing a gap in knowledge. A diversity of roles and training was evident with most dementia champions in paid employment in a health or social care setting. Justification for the research is outlined in the summary

Key words, databases, search strategies and inclusion and exclusion criteria are shown in appendices (10.4.1; 10.4.2; 10.4.9). These incorporate dementia champions in a range of settings and roles, qualitative, quantitative, and mixed method research designs, studies in and outside of the UK over a period of nineteen years.

3.2 Scope of the literature review: Champions in mental health

I considered including champions in mental health rather than exclusively dementia champions. An initial search uncovered papers such as a qualitative evaluation of community health champions delivering health activities (Woodall et al., 2013). The study set out to identify the approach and effectiveness of interventions in seven community projects to promote healthier living but did not incorporate lived experience or the needs of people living with dementia. Other papers were discarded as they focussed specifically on mental health champions for particular ethnic groups (Mantovani, 2017), mental health professionals working in dual diagnosis assessment and treatment services (Pinderup, 2018), or research assessing the training and effectiveness of champions in delivering pharmaceutical health education (Micallef et al., 2019). Health education champions in the mixed method study undertaken by Micallef et al. (2019) were trained pharmacy staff employed across ten London Boroughs and not volunteer champions. Twenty-two interviews were undertaken but these were of fifteen-minute duration, did not incorporate the lived experience of champions and focussed on the development of pharmacy services. Another study reviewed and discarded included champions who were employees engaged in exploring organisational structures and cultures to promote mental health at work (Robinson et al., 2013). I also reviewed papers about champions working with older adults/ age champions. These focussed predominantly on physical health for example exercise programmes (Miyawaki et al., 2018), specialist medical care (Drach, 2017) and best practice nursing champions employed to influence and implement evidence-based practice (Ploeg et al., 2010).

Other champion's roles were not considered relevant for the literature review and did not reflect the nature and complexity of dementia that differentiates it from other conditions.

Dementia is defined as a syndrome, a group of related symptoms, not a disease and people may have more than one type or have other conditions linked to dementia. It is a progressive disorder of memory loss and impaired cognitive ability that cannot be accounted for by other psychiatric conditions such as depression, other mood disorders or psychosis (Scott and Barrett, 2007). It has a physical, psychological, social, and economic impact, not only on people living with dementia, but also on their carers and families (Greenwood et al., 2018).

Dementia is unique in its range, the impact on every aspect of health and well-being and the fear and stigma associated with the condition (ADI, 2019). Stigma and discrimination have also be associated with ageing and as a result people with dementia and carers may face additional challenges, such as negative portrayals, inequality and exclusion affecting their sense of self (Segal, 2015; Greenwood et al., 2018). Stigma may also be internalised because of ageing and dementia affecting identity (Bosco et al., 2019). Stereotypes can affect how older people view themselves, their capabilities and engagement in activities (Swift and Steeden, 2020.) Dementia may affect younger age groups but there is a higher rate in older adults, and it is a major cause of disability (WHO, 2019). Older adults, who are ninety years of age and above, have an increased risk of more than one form for example Alzheimer's and vascular dementia. They face challenges with cognitive changes, sensory and motor decline, activities of daily living, quality of life and inclusion (Kravitz et al., 2012). Dementia has been identified as the leading cause of death in England and Wales (ONS, 2019).

Shakespeare et al. (2017) suggest people with dementia are among the most excluded because of negative language and perceptions, through the loss of experience and relationships which they have enjoyed throughout their lives.

The lack of awareness and knowledge, the associated fear and stigma for people living with dementia and carers, stereotypes and dual complexities of ageing and dementia, make it distinct in relation to the needs, priorities and roles of champions (ADI, 2019, Greenwood et al., 2018; Kravitz et al., 2012).

Champions in mental health were therefore excluded to ensure the focus of the research aims, objectives and direction were maintained (Booth et al., 2012)

3.3 Background

3.3.1 Policies, strategies, and initiatives

Worldwide there are currently an estimated 47 million people living with dementia and it is projected to increase to 75 million by 2030 and almost triple by 2050. A lack of awareness and understanding of dementia can result in stigmatization, barriers to diagnosis and care, and impact on carers, families, and societies physically, psychologically, and economically (WHO, 2018). It is imperative that action is taken to raise awareness and promote social action.

From a socio-political standpoint ‘Living well with Dementia: A national dementia strategy’ was published in 2009 (DoH, 2009) followed by the national challenge and examples of best practice across England (DoH, 2012). Using an asset approach, it incorporated a synthesis of outcomes desired by people living with dementia and their carers. These include being treated with dignity and respect, to be open about the diagnosis without fear of stigma or discrimination and to be recognised and understood by the public and professionals to enable people to live well. “Dementia 2012: A National Challenge” was published in March 2012 (DoH, 2012) with Prime Minister David Cameron setting out plans to improve awareness, quality of care and research in dementia care. The report highlighted that nearly two thirds of people living with dementia did not feel part of their community and would like their communities to be better informed and inclusive.

The Alzheimer's Society's responded to the dementia challenge with the launch of the dementia friends programme in 2013. The design was influenced by the Japanese initiative which started in 2004, and was launched in 2005, to change people's perceptions of dementia, turn understanding into action and promote dementia friendly communities (ADI, 2017).

The Prime Ministers Challenge on Dementia (Gov. UK 2015) and the Alzheimer's Society New Deal on Dementia (2017f) followed the earlier strategy. In 2018 Public Health England published "Dementia: applying all our health" which included the statement that all healthcare professionals should complete dementia awareness e-learning or training to become a dementia friend. The Dementia 2020 challenge identified that there are more than 2.2 million dementia friends and 234 dementia friendly communities in England and Wales, and over 875,000 NHS staff have attended sessions (2018).

Papers and policies outlined above set out to raise awareness about dementia, develop skills and knowledge in the health and social care workforce and promote dementia friendly communities. Initiatives in health and social care settings and a diversity of training to raise awareness and promote person centred care were highlighted in the literature review. Research and policy documents also highlighted that the number of people living with dementia is increasing, it is a public health priority, there is limited knowledge within communities and there remains fear and stigma associated with dementia (ADI, 2019; Alzheimer's Research UK, 2018; WHO, 2012). It continues to be described as a global, regional, and national burden (GBD collaborators, 2019). 'Burden' may be used in different contexts but can have negative connotations that are dehumanising and suggest a person is a drain on time and resources (DEEP, 2014). The Alzheimer's Society (2018d) recognise its use when referring to issues of policy but suggest the use of the terms 'impact' or 'effect' as alternative terms to capture needs.

3.3.2 Alzheimer’s Society dementia friends champions

Volunteers are provided with a one-day training to deliver dementia friends information sessions. Numbers of new or active members continues to change but recent figures show there are 6,719 active dementia friends champions across the UK and 2.5 million dementia friends in England, Wales, and Northern Ireland. Dementia champions and dementia friends include people who are living with dementia. Sessions can be delivered face to face or through an online version (Alzheimer’s Society UK, 2017).

3.3.3 Alzheimer’s Society Dementia friendly communities

The ADI report (2016) outlined dementia friendly initiatives taking place across the world and how dementia friendly communities are changing the way people think about dementia and improving the quality of life of people with dementia. Also reflected in the report by the ADI (2016) was the need to drive forward the rights of people with dementia. This included access to timely diagnosis, opportunities for post diagnostic support and care, participation in the community through social engagement and voluntary and paid work opportunities, and freedom from medical and physical abuse.

3.4 Aim of the literature review

The review aimed to provide insight into the lived experiences of dementia champions highlighting what is known and what remains unknown or unanswered from health and social care and social policy perspectives.

3.5 Objectives for the literature review

- Define and identify the roles undertaken by dementia champions
- Review, discuss and analyse the experiences of dementia champions
- Critically appraise the research undertaken into the experiences of dementia champions
- Synthesize the findings to reveal what is understood from various perspectives, or unanswered about the experiences of dementia champions.

- Examine the use of arts-based approaches and research poetry within the relevant literature

3.6 Strategy and Stages

This section outlines the strategy and stages to search the available evidence. It includes a rationale for how the search was undertaken including electronic databases, the use of Boolean operators and truncation, grey literature, bibliographic searching, author searching and hand searching. I contacted experts from various perspectives in the field including the Alzheimer's Society UK and a Japanese researcher (Hayashi, 2017) to identify research in the UK and Japan that had shaped the design of the dementia friends initiative. Studies for selection were shaped by the PEOT framework and the inclusion and exclusion criteria.

The data extraction form (appendix 10.4.5) and summary sheets (appendix 10.4.6) highlight the attention given to documenting key details about the studies including a discussion of limitations. Quality appraisal of the literature was undertaken using the CASP tool which highlighted varying quality. Different methodologies and methods of data collection were used, and limitations were noted. I included papers that informed and added to the body of knowledge.

Information included in the chapter indicates that there was limited research into the experiences of dementia champions. A survey of dementia friends champions undertaken by the Alzheimer's Society (2018a) identified the champions expressed satisfaction with the level of support they received. The survey also showed the numbers of volunteers had decreased since 2016 and there was also a drop of nine percent who would recommend the volunteering experience (Alzheimer's Society, 2018a). Recommendations from the survey included a need to understand the reasons for the views but no research was identified that specifically looked at the experiences of dementia friends champions.

3.6.1 Search strategy

Stage one involved defining the scope of the research. Using a quick search strategy, I identified journals, e- resources and dissertations and highlighted a vast range of champion roles and settings. Miech et al. (2018) undertook an integrative review and identified eighteen different types of champions in healthcare settings including dementia champion. Some champions were linked to specific organisations (MIND, 2019) while others were linked to specific settings such as mental health in the workplace (Robinson et al., 2013), public health in community settings (Woodall et al., 2013), or promoting mental health for specific ethnic groups (Mantovani et al., 2017). Many of the champion roles were linked to paid employment unlike the dementia friends champions who are all volunteers with the Alzheimer's Society (Alzheimer's Society, 2019).

There has been a lack of clarity over the champion construct ranging from a generic definition of a person who vigorously supports or defends a person or cause (Brown et al., 2018) to champions specifically linked to staff in health and social care settings (Miech et al., 2018). Bartlett (2014) gave examples of champions who were living with dementia and actively engaged in research and Berry et al. (2020) discuss developments to engage and give voice and agency to people with dementia in a meaningful way. The literature review highlighted how the construct has been hampered by the inconsistent use across the published literature.

PEOT (population, exposure, outcome, type of study) was used to represent the component parts of the review question. PEO is often used for qualitative questions, for example when investigating experiences. Adding the type of study provided more detailed information about the research design (Bettany- Saltikov, 2012).

P	Dementia champions
E	Undertaking a dementia champion role
O	Dementia champion's experiences
T	Qualitative, quantitative, or mixed method studies

Inclusion and exclusion criteria are shown in appendix 10.4.1

Dementia Sage provided a platform to capture dementia research including champions. Health and Social Care journals also incorporated a range of relevant research particularly champions who were working in the health professions. The predominantly qualitative design of the studies affected the range of journals, with some favouring the inclusion of research from a positivist, objective, scientific stance (BMJ, 2016). A quantitative survey design could be advantageous in capturing responses to specific questions from many respondents with the potential to generalise but would not address what the experience of being a champion was like, the vividness or the detail. Reflection and narrative could not be captured in depth through a quantitative research (van Manen, 2017; Dilthey, 1987).

Details of the search strategy including database searching, grey literature searching, and other searches are shown in appendix 10.4.2.

3.6.2 Key terms

A review of the literature was undertaken using key words. These incorporated Boolean terms and truncation shown in appendix 10.4.9

3.6.3 Critical appraisal

Critical appraisal was undertaken using the CASP tool for qualitative, quantitative, and mixed method research.

Examples are included in appendix 10.4.7 and 10.4.8

3.6.4 Data extraction

17 papers met the criteria for inclusion in the literature review. A data extraction form was completed for each paper incorporating the author, year, title, aim, study designs, method, sampling process, results, conclusion, findings, and limitations.

Details of data extraction are shown in appendix 10.4.5.

3.6.5 Analysis and synthesis

Research may be synthesised in a variety of ways for example narrative synthesis, framework analysis, meta-aggregation, meta-ethnography, thematic synthesis, and meta-synthesis (Aveyard et al., 2016; Bettany- Saltikov and McSherry, 2016; Thomas and Harden, 2008). Narrative synthesis was undertaken as it has been found to be a suitable approach when the review question requires the inclusion of a range of research designs including qualitative and quantitative research and is well established (Popay et al., 2006; Bettany- Saltikov and McSherry, 2016). Narrative synthesis has been described as a form of storytelling which brings together evidence, weaves together a common line of argument, and summarises the findings from a body of research in a succinct and coherent manner. It uses words and text to summarise the findings of multiple studies and groups them together to show patterns. Popay et al. (2006) provide a process incorporating theory, preliminary synthesis, exploring relationships in the data and assessing the robustness of the data (Booth et al., 2012). The stages are outlined in appendix 10.4.3.

Narrative synthesis has faced criticism suggesting it is opaque, subject to author interpretation and linear in its approach (Campbell et al., 2018). Popay et al. (2006) outlines how in practice narrative synthesis does not necessarily proceed in a linear and sequential fashion but moves in an iterative manner between the different elements. A range of approaches can be undertaken but Barnett- Page and Thomas (2009) found nine distinct approaches. They found textual narrative synthesis made clearer the context and characteristics of the study but may not be as effective in identifying themes. Lucas et al. (2007) compared textual narrative and thematic synthesis highlighting the strengths and limitations of each approach with worked examples. In their view narrative synthesis was identified as beneficial in synthesising different types of research and evaluating the strengths of evidence in different areas of the research for example details about the participants. Campbell et al. (2018) and Lucas et al. (2007) both identified transparency as a limitation for example decisions about groupings and sub themes. Despite the limitations it has been suggested that textual narrative synthesis is suited to reviews that describe the existing body of knowledge, identify the scope and gaps in knowledge (Lucas, 2007).

The approach developed by Popay et al. (2006; 2005) provides a familiar and accessible approach to synthesising the literature and can be applied to data using methods such as focus groups and interviews. I deemed it appropriate in relation to the design of the studies and in creating a narrative to inform the research.

3.6.6 Results

Seventeen papers were included in the literature review. Studies were undertaken from 2011 to 2018 and published from 2013 to 2019 highlighting the increasing commitment to dementia research.

Fifteen papers were produced in the United Kingdom (England, Scotland, and Wales), one from the United States of America, and one from Australia. They included seven qualitative research papers, four quantitative research papers and six were mixed method. Qualitative research data collection methods included interviews, focus groups, discussions, and workshops. Quantitative methods included surveys, self-reporting, and service evaluation. Only one paper included an arts-based approach highlighting a gap in accessible methods to disseminate and inform dementia research (Bartlett, 2015).

One study focussed specifically on increasing awareness in a learning disability community and included Dementia Friends awareness sessions (Alzheimer's Society, 2018). Five studies focussed on hospital services and four were linked to care home provision for people with dementia. The nine studies were directed at staff working in health or social care settings from a range of disciplines, with the aim of raising awareness and developing skills and knowledge in dementia care.

Seven papers focussed on promoting dementia friendly communities.

A summary of all the papers included in the review are in appendix 10.4.6.

3.7 Defining and developing dementia champions

The term 'dementia champion' was used widely in the literature but there was a lack of clarity about the title, role, skills, or knowledge required.

Mayrhofer et al. (2015) outline how different health care providers define champions in different ways. Some define all healthcare professionals as dementia champions whereas others identified key clinicians or specific salaried posts to lead on dementia initiatives within an organisation. Mayrhofer et al. (2016) describe a dementia champion as someone with excellent skills and knowledge of dementia, an advocate, a source of information and a change agent. Banks et al. (2014) and Ellison et al. (2014) used the term dementia champion and incorporated the term “change agent” as a key component of the role reinforcing turning understanding into action. Findings from the study by Banks et al. (2014) included an anonymous questionnaire which prevented follow up to identify whether the health care professionals in Scotland had been successful in bringing about change in health and social care. The term “activist” was used rather than champion for the participants engaged in the arts-based study undertaken by Bartlett (2015) and the seven activists were all people living with dementia. Working with the researcher and an artist they transformed research into artwork followed by a touring exhibition to enhance the understanding of people with dementia as active citizens. Research undertaken by the Alzheimer’s Society (2018) included delivering three dementia friends sessions to people with a learning disability with the aim that they may go on to become dementia champions. There was limited detail about how the participants were selected and the study did not include any follow up to identify whether people with a learning disability went on to become champions. Lack of awareness about the links between dementia and learning disability and fear and stigma associated with dementia were identified as barriers to becoming champions or co- facilitators.

3.7.1 Champions in health and social care settings

The review of the literature highlighted the diversity of dementia champions in health and social care settings including geriatricians, junior doctors, nurses, healthcare assistants, therapists, emergency staff, managers, staff in primary care and social care settings. Research included champions from diverse backgrounds and roles within the organisations. Champions were mostly in paid employment with the role attached to their existing employment and responsibilities. In the study by Mayne et al. (2014) the dementia champions were geriatricians in permanent posts unlike the study by Wilkinson (2016) where junior doctors were undertaking the role of dementia champions in acute hospitals as part of a placement over a short period of time. The impact of taking on the role of dementia champion alongside other roles was picked up in several studies and was influential in their ability to bring about change in service provision. Undertaking a dementia champion role was identified as beneficial for career development and opportunities and patient care (Wilkinson, 2016; Ellison, 2014; Mayne et al., 2014). All three studies involved health care professionals and included concerns with the sustainability of the provision as they balanced the roles with other duties and responsibilities.

3.7.2 Training provided for and by dementia champions

The papers highlighted a diversity of training, or no specific training, to become a dementia champion. Seven papers gave specific details about the training undertaken. Only one included undertaking the Alzheimer’s Society dementia friends session with the aim of progressing to becoming a dementia friends champion (Alzheimer’s Society, 2018). Banks et al. (2014) outline the training undertaken by one hundred health care professionals working in acute settings across London. A blended learning programme was delivered to become a dementia champion incorporating five study days, half a day in a community setting, e-learning and an assessment involving three work-based activities. This was also supported by staff completing a change workbook aiming to bring skills and knowledge of dementia care to an advanced level with the goal of enriching the care of patients with dementia in care settings. A self-reported questionnaire was used at the beginning and end of the programme and showed a positive impact on patient care. Mayrhofer (2016) reviewed the training of thirty-four participants in professional roles in twenty-seven health and six social care settings in England using the Bristol online survey. Eighteen had undertaken a one-day training course, four did a short course without a qualification, and three undertook a course with a qualification. In three settings champions did not undertake any training prior to taking on the role. They identified the need for a dementia champion’s consortium of practice with a shared identity to address dementia training and development needs for the health and social care workforce. It cannot be assumed that health or social care practitioners have the knowledge and skills to become dementia champions without additional training. The Skills for Health training provision (tier one and two) was provided to nursing staff and health care assistants in the qualitative study undertaken by Brooke et al. (2017). Aims included creating dementia friendly ward environments, promoting person centred care and increased contact with patients. Several focus groups were undertaken, with nurses and health care assistants (HCA's). The study included focus groups specifically for nurses and HCA's and combined groups. Focus groups provide opportunity for sharing ideas and are time and cost efficient but can create barriers to the free expression of opinions due to a lack of confidentiality and anonymity. Different lengths of time in the role may also have affected how nursing staff and HCA's felt about expressing their views in a group setting. The findings were limited as staff did not have experience of working on the wards before the changes were implemented and could not easily explore the impact of the changes.

A mixed method study by Sheaff et al. (2018) provided another example of skills and knowledge required by dementia champions. Thirteen dementia champions delivered eight-hour dementia awareness multi-module training programmes to staff in care homes. The content outlined in the paper included details about dementia, communicating with people with dementia, influence of the environment, care planning, end of life, mental capacity, dealing with challenging behaviour and organisational change. The paper also highlighted that the training was followed up by support from the learning facilitators in the form of visits, conferences, and forums. Champions also needed to be familiar with the plan, do, study, act (PDSA) cycle for change management. A wide range of skills, knowledge, training and facilitator roles and abilities were required as a champion which could affect the uptake of the role and the success of the programme. The content, time and cost involved could affect the number of champions and opportunities for staff to attend thereby influencing the potential for long term change. Despite the demands of the training changes were identified in staff but these were found to come from better knowledge of the residents in the care setting. This was important when considering how the training was delivered and the need for collaborative working with people living with dementia and carers.

Fossey et al. (2018) also looked at care home practice and highlighted the importance of dementia champions tailoring the delivery of training to the staff. Time was needed for them to build confidence and develop skills in using the resources rather than expecting everyone to learn at the same pace. It highlighted the skills needed by the dementia champions to assess the environment and tailoring the provision to staff rather than taking a standardised approach in all settings. Sustainability was an aspect that came through in a range of studies as due to workload and time pressures. Cultural awareness was also identified in the design and delivery of sessions and the need for follow up later to identify whether changes had been implemented or sustained.

Two papers related to dementia champions within the medical profession. The experiences and opinions of consultant geriatricians in the UK was explored using a survey (Mayne et al., 2014). Fifty-five geriatricians in the study were identified as dementia champions with forty seven percent self-taught and fifty-six gaining experience through a clinical attachment. This highlighted a lack of standardisation in the role and training. Being a dementia champion was influenced by the geriatrician's interest and commitment to dementia care over other areas of practice. Recommendations included having specific modules, qualification, mandatory attachment to dementia care and exposure at undergraduate level to develop the required skills and knowledge in the medical workforce. The study also identified the need for a qualitative study to promote greater insights from the medical profession. A mixed method study undertaken by Wilkinson et al. (2016) explored junior doctor's experiences of being dementia champions in a dementia and delirium team in an acute hospital and found they developed skills and knowledge while undertaking the role of a champion leading to improvements in knowledge and skills in dementia care, communication and patient notes. The study undertaken by Wilkinson et al. (2016) related specifically to medical care in acute hospitals as opposed to reflecting care in the community. Junior doctors engaged with people with dementia over a short period of time reducing the ability to identify the long-term impact of changes implemented. The training provided in each acute trust was different and the commitment of those in senior roles could affect the sustainability of the initiative.

A wide variety of definitions, role descriptions, person specifications, aims and objectives were attached to the role which could be influential in the formal recognition of the dementia champion and makes comparisons difficult. Brown et al. (2017) point out the importance of not assuming the name champion equates with being an expert in the field. They describe the role as ensuring the voices of the person living with dementia, their family and supporters are heard loud and clear in the complex health and social care arena. They go on to support the view that until people living with dementia are fully accepted in society and not labelled as ‘other’ there is a need for dementia champions.

3.8 Experiences of being a dementia champion

The research highlighted strengths, weaknesses, opportunities, and threats in the role of dementia champion from various perspectives. These are summarised in appendix 10.4.4 and discussed below.

3.8.1 Strengths

Benefits were expressed in relation to personal and career development for champions and positive changes seen within the workplace and community settings. Junior doctors shared how their motivation to undertake the role was influenced by their personal experience of a relative living with dementia. Despite previous experience they developed knowledge and skills in dementia as a result of being a champion and a better understanding of their role in patient care. They also felt they developed leadership skills that would be of benefit in career development. Improved confidence in communicating with patients, carers, relatives, and the multidisciplinary team were identified by junior doctors working in acute hospital settings. There were personal benefits to being a champion as they identified how taking on the role gave them greater recognition by other members of the team and autonomy to make changes (Wilkinson et al., 2016). Dementia champions recognised changes in their own attitudes and behaviours as well as challenging others (Ellison et al., 2014). Care environments were changed and there was greater contact with patients and patient care (Brooke et al., 2017). Dementia champions were actively engaged with communities to bring about change (Bartlett, 2015).

3.8.2 Weaknesses

In the study undertaken by Wilkinson et al. (2016) junior doctors were engaged for short periods of time before moving to different areas of practice and handing over to another group of students who may not have the same commitment or interest in dementia care. The role was not established as an essential requirement but an opportunity that could be beneficial to their career. Undertaking the role during training could also result in competing demands and reluctance to initiate bigger changes because of the limited time available.

Mayne et al. (2014) identified variability of training of doctors across geographical areas which could also influence the interest and commitment to dementia care. Bringing about change takes time and without continuity of staff it may not be possible to see change implemented (Ellison et al., 2014; Fossey et al., 2018; Heward et al., 2017; Wilkinson et al., 2016)

Staff changes and retention were a factor in acute hospital settings affecting the number of staff trained in dementia awareness and the ongoing input required by dementia champions (Brooke et al., 2017). Changing jobs, organisational changes and competing priorities was also identified by Mayrhofer (2015) as a concern for future delivery. Many of the studies related to health and social care settings and did not reflect the bigger community.

Using an arts-based approach engaged the public but there was a need to identify the long-term effects of interventions (Bartlett, 2015). Engaging stakeholders was variable (Heward et al., 2017) and the involvement of carers continued to be affected by the stigma associated with dementia (Alzheimer’s Society, 2018). The research incorporated a range of designs, methods, and initiatives to reach a wider audience and promote dementia friendly communities through arts-based approaches (Bartlett, 2015) press releases, good news reports and stakeholder meetings (Heward et al., 2017). Having a range of approaches created difficulties in identifying what was most effective but brought together scientific and emotional learning and different ways to convey a message.

3.8.3 Opportunities

Opportunities were identified for people living with dementia and carers including influencing change in the care of people living with dementia and being actively engaged in decision making (Crampton and Eley, 2013). Undertaking the role of champion and the resulting development of skills and knowledge also created career opportunities for staff in the health professions (Wilkinson et al., 2016; Ellison et al., 2014). Communities of practice and networking were also developed (Mayrhofer et al., 2015). Collaborative working was evident in the studies but adapting to the changing needs of people living with dementia was not captured or the impact of impairment on their ability to participate in research or as change agents.

3.8.4 Threats

Threats to sustainability from various perspectives were influenced by time, cost, roles, and motivation. Ellison et al. (2014) discussed risks to the funding of the Alzheimer’s Dementia Nurse Consultant posts which would in turn lead to the dementia champions not being supported, a lack of leadership and reduced ability to bring about change. Workload pressures affected the ability of champions to deliver sessions in care home settings and additional time was required due to the range of abilities, skills, and knowledge of the workforce. Limited attention was given to cost implications in the research but developing specific dementia champion roles, undertaking training, providing information sessions and resources all have time and cost implications. It highlighted the need for studies that could demonstrate cost effectiveness for example by increasing the safety of people with dementia on the wards, or through staff morale and satisfaction leading to improved retention of staff. Dementia Champions act as leaders in good dementia care and advisers to staff in a range of settings (APPDG, 2011). Ellison et al. (2014) identified key factors in the success and sustainability of dementia champions as recruiting the right people, line management, collaboration, and organisational support. With increasing numbers of people living with dementia there is a need for all staff to receive training and not just dementia champions to improve the quality of care in all settings. Due to staff turnover and changes in service structures a long-term commitment is required to raising awareness and promoting person centred dementia care. Attitudes and beliefs as well as skills and knowledge are important in shaping dementia friendly services such as the belief that someone with dementia can lead a meaningful life (ADI, 2019; Alden et al., 2019). The Alzheimer’s Society sets out safeguarding strategies and monitoring mechanisms for champions (Alzheimer’s Society, 2020) but the literature review highlighted the need for support and mentoring for champions and ensuring services are providing quality of care (Mayrhofer et al., 2016; Mayrhofer et al., 2015; Woodall et al., 2013). The dementia friends initiative set out to raise awareness and action to promote inclusion through the delivery of five key messages. The initiative is one part of action identified which aims to transform services and meet the needs of people living with dementia and carers (DoH, 2016; 2015). People living with dementia are disabled by attitudes and the physical environment affecting inclusion and well-being (Shakespeare, 2019; Shakespeare et al., 2017, Shakespeare, 2013; ADI, 2019).

3.9 Dementia friendly communities

The literature review demonstrated a wide variety of approaches to raise awareness of the needs of people living with dementia and their carers and engage the community to promote dementia friendly communities. The inclusion of people living with dementia was important in promoting positive images and perceptions and showing what people could do rather than focussing on deficits and decline. Bartlett (2015) identified how arts-based approaches mobilised the emotional component and engaged the public in way that data collection tools could not. The banners, placards and documentary film enhanced an understanding of active citizenship of people with dementia in bringing about change in communities (Bartlett, 2015, 2014). Buckner et al. (2018) had a range of project formats including a care information point, training opportunities, key rings, and a road show in their pilot project. Phillipson et al. (2018) and Ely (2013) both engaged people living with dementia as spokespersons and educators through presentations, discussions, and educational events. Integrating a range of events and methods did however made it difficult to ascertain what had been most influential in promoting change. Studies included in the review demonstrated different types of knowledge including biomedical and personhood knowledge. Ebert et al. (2019) identified the need for a balance of biomedical knowledge and social comfort, and engaging with people living with dementia, to promote the development of dementia friendly communities. The survey of six hundred and forty-five resident of Wisconsin, USA, found people with biomedical knowledge benefitted most from personhood knowledge. They recognised a limitation was they had not captured the occupations of participants in the study. Results from the study undertaken by Ebert et al. (2019) may also have been influenced by roles and dementia initiatives taking place in Wisconsin. Overall, the studies highlighted the need to use a variety of approaches to engage individuals and communities.

3.10 Discussion

3.10.1 Lived experience of dementia friends champions

Since the launch of the Alzheimer’s Society Dementia Friends initiative in 2013, dementia friends champions have been delivering sessions across England, Wales and Northern Ireland aiming to raise awareness about dementia, reduce stigma associated with the condition, and turn understanding into action with a view to creating dementia friendly communities. No research was identified specifically about the lived experience of dementia friends champions. This highlighted a gap in the evidence into what motivated people to become champions, the meaning associated with the role, the lived experience of being a champion, insights and understanding at an individual and societal level.

3.10.2 People with dementia as champions

Different levels of engagement were seen in the literature review for people living with dementia. This ranged from participation in the research process, consultation or obtaining feedback after changes have been implemented. Ellison et al. (2014) undertook six interviews with people with dementia and their carers and Phillipson et al. (2018) included people with dementia as educators and spokespeople. Crampton et al. (2013) took a creative approach to engaging people with dementia using a ‘walk the patch’ approach in addition to a ‘sounding board’ group discussion. Quantitative and qualitative methodologies were used and different methods of data collection (appendix 10.4.5). Bartlett (2015) was the only one that used an arts-based approach, with sixteen people with dementia as activists highlighting the commitment to engaging people with dementia but also reflected the challenges. The methods used highlighted that in most instances participants needed to be able to articulate thoughts, ideas, and feelings either verbally or in writing. Quantitative survey designs and self-reporting require short term memory, reading ability and reflection. As most surveys are now undertaken online, they also require access and the ability to use a computer. Focus groups or individual interviews as a method of data collection require the ability to comprehend and express content and feeling in a focussed way which may be a challenge where speed of processing information is affected. The methods and approaches seen in the studies would limit the opportunity for those with moderate to severe dementia to engage. Active engagement of people with dementia requires awareness of needs for example people with a learning disability and dementia (Burke and Charlesworth, 2018). The Alzheimer's Society (2018) adapted the design and delivery of the dementia friends resource pack specifically for people with a learning disability with the goal that they will go on to become dementia friends champions but this was not evident in other studies. Brett (2016) discusses the importance of authentic voice in research and the need for non-verbal and creative approaches to be used to enable views to be expressed. The research undertaken by Brett (2016) related to young people but is equally relevant in hearing the voices of people with dementia.

3.10.3 Arts based approaches identified from the literature review

Using an arts-based approach can create opportunities to engage in different ways and could provide greater opportunities for people living with dementia to engage in research and dementia friendly initiatives. It has been suggested that arts-based research starts with the belief in creativity as a form of enquiry and a mode of thinking and knowing to promote engagement with a wider audience (Bhattacharya, 2018). A scoping review undertaken by Phillipson and Hammond (2018) identified a variety of approaches being used with the aim of engaging people with dementia. These included photovoice, action research, case study, narrative production, ethnography, participatory filmmaking and theatre, co- research, and mixed methods. They found the diversity of methods could enhance inclusion, empowerment, and expression but flexibility was needed to be able to accommodate different needs for example recognising changes that may take place for people living with dementia over the period of a research study.

Collaboration between researchers, artists and experts by experience also encourages inclusive and innovative approaches to be developed (Fennessy et al., 2019). The literature review reinforced the view that participants should inform the design of the study and the way it is presented. Further work is required to identify how best to engage people at the later stages of dementia and methods that will capture skills and abilities that have been retained. Arts based approaches in research requires the development of skills and abilities to capture the aesthetics of the form and imagine in an expanded way, allowing information to be available to a wide audience (Bhattacharya, 2018). Engaging people with dementia as co- producers endeavours to facilitate a research design that promotes inclusion (Ridout, 2016).

3.11 Summary

The detailed method used to review the literature aimed to offer clarity, internal validity, and auditability to identify what was known and unknown about the roles undertaken by dementia champions and the experiences of being a champion from various perspectives. Methodologies and methods were reviewed including the use of arts-based approaches.

A range of champion titles and roles were identified with most attached to an existing job role and paid employment. (Banks et al., 2014 ; Brooke et al., 2017 ; Mayne et al., 2014 ; Wilkinson et al., 2016). Some champions received training while others learnt on the job (Mayne et al., 2014; Mayrhofer et al., 2016).

Being a dementia champion was perceived as beneficial in developing skills and knowledge and bringing about change in hospital and community settings (Banks et al., 2014; Brooke et al., 2017; Ellison et al., 2014).

There was some participation from people living with dementia and carers but more action was needed to promote voice and engagement particularly at different stages of dementia.

Sustainability was a concern due to a lack of clarity about the role, staff turnover, competing demands and variable stakeholder engagement. The literature review did not identify any research specifically about the lived experience of dementia friends champions highlighting a gap and limitation in knowledge supporting the need for the investigation.

Reflexivity was essential at every stage recognising that as a dementia friends champion I came with experience and that my enthusiasm in raising awareness could influence interpretations. Interpretative phenomenology recognises the self and the world belong together in a single entity and denies the possibility of fully detached reflection from the participant or the researcher (van Manen, 2017; Gill, 2014). The act of interpretation does not come from a neutral stance but recognises the effect of the present, past and future in shaping perceptions (Wisnewski, 2013; Horrigan- Kelly, 2016; Willis, 2001)

4 Methodology

4.1 Introduction

This chapter includes the aims and objectives of the research and the ontological and epistemological position. Justification for using a qualitative phenomenological methodology is outlined with specific reference to interpretative phenomenological analysis (IPA). Strengths and limitations of IPA are incorporated including debates and interpretations from leading researchers in the field. The reasons for rejecting alternative methodologies and data collection methods are included. Research poetry is explained and justified including the strengths and limitations of arts-based approaches. An explanation of the process of undertaking IPA analysis is included with examples from the transcripts. Examples of initial noting, grouping into themes and then into superordinate and subordinate themes are included. Moments of significance and phenomenological reflection are identified as participant’s explored meanings and endeavoured to make sense of experiences. Ethical considerations and action are outlined demonstrating quality, rigour, participant engagement, reflexivity, and ethical integrity.

4.2 Aim

Explore the lived experience of dementia friends champions: poetic representation.

4.3 Objectives

- Define and identify the roles undertaken by dementia champions
- Review, discuss and analyse the experiences of dementia champions
- Critically appraise the research undertaken into the experiences of dementia champions
- Synthesize the findings to reveal what is understood from various perspectives, or unanswered about the experiences of dementia champions.
- Examine the use of arts-based approaches and research poetry

4.4 Overview

The last chapter systematically examined the current literature, and highlighted a gap in knowledge, concerning the experiences of dementia friends champions. The research identified the importance of the champion role in promoting quality in the dementia care provision and as a change agent to raise awareness and turn understanding into action. Most champions were staff working in health or social care and took on the role in addition to other duties. There was considerable variation in the training provided and concerns about sustainability. This was pertinent with the estimated number of people with dementia around the world set to rise from 50 million in 2018 to 82 million in 2030 but limited knowledge and understanding about dementia (ADI, 2019a). The report “From plan to action” provided the results of a four-month scoping exercise undertaken by Alzheimer’s Disease International (ADI, 2018). ADI (2018) identified that all fifty member countries had at least one public health campaign on dementia to foster a dementia inclusive society by 2025. A subsequent report the following year recorded over sixteen million Dementia Friends in fifty countries worldwide and the implementation of dementia friendly projects were identified as a key priority (ADI, 2019a). Creating more dementia friends requires more champions to deliver sessions but the approach to recruitment, retention and support for champions was not highlighted in the report. Since the launch of the initiative by the Alzheimer’s Society in 2013, champions have been delivering sessions in a wide range of settings and developed insights and understandings of dementia in the 21st century (DoH, 2012). To date their lived experiences have not been researched.

4.5 Ontology

Ontology has been described as the beliefs about the nature of the social world and ‘knowledge’s’ rather than ‘knowledge’ which are constructed and shaped by social and cultural contexts (Braun and Clarke, 2013). The research took a constructionist ontological approach reflecting the belief that knowledge is socially constructed (Gergen, 2009). Reality can be understood from the lived experience of the participants and at any one time there are multiple discourses and storylines to make sense of situations (Gaudet and Robert, 2018). Knowledge is produced by exploring and understanding the social world of the people being studied or participating in jointly constructed understandings of the social world. Social constructionism focusses on the meanings and interpretations in a time and place. This was pertinent to the study where champions worked with different groups in different settings and subjectivity and reflexivity was valued. It is concerned with the detail, exploration and realisation of meaning associated with individual experience.

Converse (2012) describes the ontology of the phenomenological approach as being concerned with ‘being’. Wilcock (2006) and Hitch et al. (2014) describe ‘being’ as the way we understand ourselves incorporating motivation and self-efficacy that directs action. The research undertaken was concerned with the lived experience and meaning associated with being a dementia friends champion.

4.6 Epistemology

Epistemology has been described as how knowledge is acquired (Braun and Clarke, 2013) and IPA recognises the importance of people’s phenomenological experience to inform us about the way the world appears (Langdridge, 2007, p7). Within a constructionist theory knowledge is socially constructed and requires the close collaboration of researcher and participant in seeking out meaning (Yin, 2003). Coming from the belief that reality is subjectively constructed, my research aims to understand reality from the perspective of the dementia friends champions (Gaudet and Robert, 2018).

Three theoretical underpinnings of IPA according to Oxley (2016) are hermeneutics, phenomenology, and ideography. Hermeneutics is influential in IPA because of the emphasis on interpretation in a social and political context (Howitt and Cramer, 2017). Phenomenology considers how people ascribe meaning to their lived experiences in their interactions with the environment. It has been described as inductive, employing techniques that are flexible enough to allow unanticipated topics or themes to emerge during analysis. The ideographic nature of IPA gives attention to each case incorporating detail and depth of analysis. There is a commitment to the detail and depth of analysis and a commitment to the single case in its own right (Smith, 2004).

4.7 Rationale for qualitative research

A qualitative methodology provides opportunity to explore, clarify and gain insights and meanings into experiences that could not be achieved through quantitative methods. Qualitative research acknowledges reflexivity and promotes reflection and awareness of the relationship between the researcher, their lived experience, and the participant. The researcher is an instrument to observe, listen, and explore content and meaning. Gaudet and Robert (2018) discuss the inductive process in qualitative research, observing patterns and trying to establish explanations that could apply to other similar situations, to understand localised reality and produce meaning. Braun and Clarke (2013) outline ten fundamentals of qualitative research highlighting that it is about meaning not numbers and that context is important. It has been socially constructed, value laden, flexible, descriptive, holistic and context sensitive. Qualitative research involves an in-depth description of a phenomenon from the perspective of the people involved.

My research aims to expand awareness and understanding of the experiences of dementia friends champions to inform and shape the design and sustainability of the provision.

4.8 Choosing an approach in qualitative research

Five main traditions within qualitative research have been described as phenomenology, grounded theory, discourse analysis, narrative analysis, and ethnography (Gaudet and Robert, 2018; Braun and Clarke, 2013). Phenomenology was selected due to the focus on the lived experience, rather than focussing on the development of theory, analysis of language or narrative or an interactive inductive approach to explore the cultural aspects of being a dementia friends champion.

4.8.1 Phenomenology

Phenomenology has been described as a philosophy and a way of returning to and exploring the reality of life and living (Dowling, 2007). Smith et al. (2009) recognise that it concerns particular people, times, events, and contexts but offers a unique perspective on phenomenon of interest. This research gives a unique perspective on the lived experience of dementia friends champions.

There are different schools of phenomenology and the justification for selecting Interpretative Phenomenological Analysis (IPA) is outlined below. Husserl believed that the researcher could describe the participants lived world, but this required bracketing and adopting a view not influenced by the beliefs, values, preconceptions, biases, or experiences of the researcher (Zahavi, 2019). Husserl's approach requires being able to distance oneself and being open to the voice of the participant and the essence of the phenomenon. Bracketing is complex as the researcher comes from a specific place and time in life. Butler- Kisber (2010) suggests a different interpretation of bracketing involving suspending understandings in a reflective way. As a researcher with experience in the field of dementia care from a professional and personal perspective this would not be possible to achieve. Acknowledging that we all come with life experiences, identifying assumptions and values from a society is important to avoid being automatically shaped by these (Braun and Clarke, 2013). Heidegger proposes an interpretation of the lived world recognising the position of the researcher, requiring reflexivity but not bracketing, and moving from description to interpretation (Zahavi, 2019; Gaudet and Robert, 2018).

Phenomenology has faced several criticisms including questions about validity, generalizability, and rigor but the criticisms come from a positivist tradition and criteria (Zahavi, 2019). Qualitative research should not be judged from a quantitative paradigm but from the notion of trustworthiness, credibility, and persuasiveness (Butler- Kisber, 2010). Other criticisms have been directed towards it only being suitable for participants who are articulate and likely to be found in middle class groups (Finlay, 2011). The aim within phenomenology is to find different ways of communicating to give voice to all participants and promote inclusion. Andrews et al. (2019) challenge the marginalisation of people with disabilities in research and propose research collectives involving family, friends, and support staff to bring together all they know about the person. The paper relates to people with autism but provides insight into strategies and approaches to understanding participants experiences. Undertaking interviews with participants required the ability to recall and a level of insight. Champions in the study were able to articulate and reflect on their experiences in a semi structured interview through narratives and metaphors. Probing, returning to experiences and clarification all served to capture the meaning of the experience.

4.8.2 Interpretative phenomenological analysis (IPA)

IPA was selected as it examines how people make sense of their experiences. It is dependent on what the participants say but also requires interpretation by the researcher and described as a double hermeneutic (Smith et al., 2009). The approach to analysis has been described as a set of common processes or a series of steps but Smith et al. (2009, p80) emphasis that it is not a linear process and encourages researchers to be innovative in the ways they approach it. Writing research poetry added another layer to the analysis enabling me to continually return to the words, phrases, metaphors, and meanings of participant’s experiences.

Finlay (2011) outlines three stages in the IPA process. Stage one is described as exploring the ‘phenomenological attitude’ to push beyond what you already know and ‘see afresh.’ The term ‘dwelling’ is used to describe the second stage as the researcher engages with the data. ‘Explicating meanings’ and the metaphor ‘woven’ were used by Finlay (2011) to explain the third stage. Biggerstaff and Thompson (2008) propose four stages but like Smith et al. (2009) and Finlay (2011) they also discuss a cyclical process. This involves moving continually between parts and the whole of each transcript and across transcripts to form clusters, concepts, subordinate and superordinate themes. I continually returned to parts of the transcripts and then took a fresh interrogation of the whole of the text.

Through questioning, exploration, and analysis my goal was to illuminate and make sense of the lived experience of dementia friends champions bringing new insights to the phenomenon and uncovering aspects that may not have been evident to the participant. dementia friends champions have the role in common but their backgrounds, culture, age, ethnicity, life events and the meaning associated with being a champion are different. They deliver sessions to different groups in different settings, and their experiences are different. A phenomenological approach facilitates the use of storytelling embedded into the sociocultural context (Bond et al., 2007). Cipriani and Borin (2014) explored how dementia was perceived in ethnically diverse groups and cultures. The way dementia was understood affected attitudes and behaviour and could lead to differentiation, stigma, blame and discrimination. Champions shared their own beliefs and experiences and how the people they encountered from diverse backgrounds understood dementia from different viewpoints.

IPA enabled dementia friends champions to share their experiences, to be self-reflective and self-interpretative (Braun and Clarke, 2013). Each case had value exploring particular people in a context. Through the interviews champions gave rich accounts but it was also important to move beyond the text to interpret the meaning of their experiences. With its focus on capturing the lived experiences of particular people and expert groups, it was a suitable methodology. In depth interviews provided a suitable space for participants to express their experiences in a confidential space and incorporated different ways of expressing the meaning associated with being a champion.

There have been challenges directed towards IPA suggesting it is descriptive and not sufficiently analytical to be considered phenomenology. Other debates have related to whether it captures meanings and experiences or opinions (Zahavi, 2018; van Manen, 2017a; Tuffour, 2017). Smith et al. (2009) argue that IPA uses hermeneutic, idiographic, and contextual analysis that explores past events and histories. IPA is recognised as a subjective research approach (Tuffour, 2017). In phenomenological research meaning and knowing are social constructs which are always incomplete and developing (Gergen, 2009; Grossoehme, 2014).

4.9 Reasons for rejecting a quantitative research design

Bryman (2012) discussed the strengths of a quantitative approach and survey design in providing opportunity to reach a large population and obtain findings that can be measured and generalised to the wider population. It is important to not over generalise and review the strengths and limitations of the studies. Quantitative research was undertaken by Alzheimer's Research UK (2018) and showed positive steps in awareness and education around dementia. ADI (2019) also commissioned a survey on attitudes with 70,000 respondents and identified stigma and limited knowledge were still major barriers to inclusion for people living with dementia. Two of the ten recommendations from the research included the global evolution of dementia friends programmes and dementia friendly/inclusive communities (ADI, 2019). The scale of the studies, potential number of responses, ability to undertake statistical analysis, cost effectiveness and generalisability make quantitative research and survey data collection methods an attractive option.

A quantitative methodology, whether descriptive, correlational, quasi-experimental or experimental would not capture what it means to be a dementia friends champion. It would not for example capture motivations, experiences, or insights from undertaking the role. A quantitative methodology would not facilitate the storytelling or capture the emotional or experiential aspects of being a champion.

Surveys may be designed in a variety of formats for example multi-choice or Likert scale and may or may not include open ended questions or a narrative qualitative component. Participants may not consider any of the options reflect their views but may be forced into giving an answer or record 'not known' without the opportunity to share views or give alternative responses. A survey does not allow participants to share why or how they came to acquire certain attitudes, or factors that influenced their beliefs or perceptions. It does not facilitate storytelling or new understandings to develop or to be shared that were required to capture lived experiences and meanings. Online surveys require the use of a computer and literacy skills which can limit the opportunity for large groups of people on low incomes, those in situations of poverty, or with cognitive challenges to take part. Survey questions are determined by the researcher, based on the aims and objectives of the research, and informed by the literature. Only the questions asked will be answered which limits the opportunity for new ideas or perspectives to develop or become apparent. Online survey questions are not known in advance and if a question has been misunderstood, or the participant wishes to amend their answer, the online surveys rarely provide an opportunity to return to an earlier question. Making changes to a postal questionnaire will equally make it invalid (Grønmo, 2020)

When researching sensitive topics, it is important to consider whether any questions are likely to cause distress or upset and opportunity for participants to obtain support may not be available. Questionnaires are confidential and anonymous but as the researcher is not present it is not possible to ascertain whether any of the questions have had a negative effect on participants even if there has been pilot testing (Braun and Clarke, 2013) . Undertaking a worldwide study also requires awareness of language, terminology, interpretations, and the sociocultural context of dementia (Cipriani and Borin, 2014)

In summary a quantitative methodology could have enabled a wide distribution and analysis through descriptive or inferential statistics, but this would only be in response to the questions raised. Questions from a literature review can shape the design of a survey but there was limited literature on the topic of investigation. Quantitative research was rejected as it would not explore the lived experience or meanings associated with being a dementia friends champion.

4.10 Rationale for the incorporation of research poetry

I integrated IPA and research poetry to reach a broader audience in an accessible way, capture the voice, feelings and emotion of the participants and promote social justice (Prendergast et al., 2009; Barone and Eisner, 2012; Eisner, 1997). Poetry should make the reader want to return and see things in new ways (Faulkner, 2009).

4.10.1 Social justice

Dementia has been identified as a social justice concern drawing attention to issues of visibility, voice, and inclusion (Fennessy et al., 2019; Herrmann et al., 2018; Gilmore and Brannelly, 2010).

Research poetry can be read, listened to, reflected on, and performed. Johnson et al. (2017) argues that spoken word poetry can deliver powerful, high impact messages to address socio political messages. Using the spoken word can promote inclusion for those who are unable to read, has been seen to give “voice” to marginalised groups, and captures the essence of what has been said in a unique way (Foster, 2012; Furman, 2006). Spoken word poetry provides a way to encourage people to talk about dementia and address the fear and stigma associated with the condition (AZI, 2019, Cipriani and Borin, 2014).

4.10.2 Being and becoming

In educational research, poetry is seen to express the human experience through knowing, being and becoming (Butler- Kisber, 2010; Barone and Eisner, 2012). ‘Being’ represents how people feel about what they do and how they understand themselves reflected in the meaning and experience of being a dementia friends champion. ‘Becoming’ recognises champions changing dynamic self, development and growth in the role captured in the quotes and the poetry (Hitch et al., 2014). The poetry included in the thesis and the research poetry book (Appendix 10.1.1) incorporates experiences directly from the transcripts (found poetry) and insights from the researcher (generated poetry) (Butler- Kisber, 2010).

4.10.3 Research poetry as a reflective tool

I found the act of writing poetry, found, and generated, required the continual returning to the transcripts and recordings to capture the essence of what was being said and added another layer to the analysis.

Arts informed research has been used in health sciences as a means of being immersed in the person's journey and has been found to be a form of self-reflection incorporating metaphor, repetition, phrases and words from participant's stories (Morrison 2019; Lapum et al., 2014; Zeilig, 2013). I noted the metaphors, motifs and terminology used by the participants which captured the uniqueness of the individual experience and how they made sense of situations. Poetry writing served as a reflective and reflexive tool in the process of reading, reviewing, revising, and revisiting the participant's words (Butler-Kisber, 2010, Van Manen, 1997, Wakeman, 2015); Faulkner, 2009). Reading and sharing my poems with others enabled me to reflect on the words and explore beliefs, attitudes and understanding of dementia and issues of dignity, equality, citizenship, and inclusivity. Lampum el al. (2014) discussed how participant's felt discomfort as they read poetry and revisited experiences of heart surgery and I was conscious of the potential emotional impact of champion's revisiting experiences through the poems. Meeting with participants, sharing and discussing the poems, and checking their perspective was very important. Presenting the research in an academic format and arts-based approach, including the creation of the poetry book (Appendix 10.1.1), brings an innovative way of sharing what it means to be a dementia friends champion.

4.11 Participants

Inclusion criteria	Participant details
• dementia friends champion • Undertaken training by the Alzheimer's Society UK	• N= 11 (8 women, 3 men) • 9 white UK, 2 defined by participants as 'other' • 9 in employment, 2 retired

- Delivered a minimum of three dementia friends sessions - In London or the South East	- 9 with past or present employment links to health or social care (HSC) - 2 with no employment links to HSC

4.12 Recruitment

I undertook purposive sampling and twelve participants were recruited to the study. One participant withdrew due to a change in personal circumstances and eleven participants engaged in the research. The demographics are outlined in the table showing male and female representation, employed, and retired, and representing some ethnic diversity. The research was advertised through the Alzheimer's Society website, and through London South Bank University. It was not possible to recruit any dementia friends champions who were living with dementia despite the wide distribution of information. Nine of the participants had past or present connections with health or social care and eight of the nine were also delivering sessions to a diverse range of groups in a wide range of community settings.

4.13 Method of data collection

Walker (2011) outlines decisions to be made including the style of interview, making initial contact, the context of the interview, eliciting the lived experience, capturing the lived experience, determining the boundaries, and concluding the interview. This section outlines my decision making including the use of semi structured interviews, within the interpretative phenomenological analysis (IPA) framework, and my reflection on the content and process.

4.13.1 Semi structured interview

An interview has been described as a conversation that has a structure and a purpose. It is seen as a careful questioning and listening to obtain thoroughly tested knowledge (Brinkman and Kvale, 2015). Smith et al. (2009) discuss unstructured interviews and focus groups within IPA but these were not considered suitable for this research because they may not have captured the range of information of lived experience. Focus groups would have allowed multiple voices, but it is unlikely that they would have captured the range of storytelling, the personal experiences, or depth and insights expressed during an individual interview. Time and individual attention are required to move to a deeper level and interpretation. Probing into the content, meanings and understandings could not be achieved to the same level in a group setting. Focus groups also require attention to group dynamics ensuring everyone has opportunity to speak. Some champions had met in different forums which would have compromised confidentiality and anonymity. In a one to one setting it can also be easier to observe non-verbal behaviour and build a rapport. In practical terms it would have been extremely difficult to get participants together with their different commitments and distances for travel. Individual interviews also allowed comprehensive transcripts to be produced.

4.13.2 Interview guide

Smith et al. (2009) suggest six to ten open questions with prompts in a forty-five to ninety-minute interview.

I developed the interview guide from the literature review and pertinent information from the Alzheimer's Society dementia friends champions site (Alzheimer's Society UK, 2019). I included eight questions to explore what it meant to be a dementia friends champion, benefits, challenges, learning and insights from the experiences, understanding and beliefs about dementia, creating dementia friendly communities and key words or phrases to capture their experience (Appendix 10.3.4). The interview guide was available at each interview, but participants shared their experiences and meanings in the order and format of their choice and the flow was guided by the participant.

The semi structured approach to interviewing worked well with opportunity for participants to share their stories and experiences and opportunity for me to follow up important issues and explore personal experience (Smith, 2004).

I included only essential demographics at the beginning of the interview to maintain anonymity.

4.13.3 Pilot interview

I undertook a pilot interview with participant one and included it in the study as changes were not required. Questions were loosely structured, in plain English and easily understood. The guide was reviewed with supervisors to consider whether data was addressing the research question, but no changes were made

4.13.4 Undertaking the interviews

Seven participants elected to be interviewed in their workplace, two participants chose to be interviewed at home and two came to an agreed meeting place. Being in the place of work could lead to divided attention and present the risk of being called away to work commitments, but it did not present a problem for the seven people interviewed. They all selected the location, date and time that worked best for them.

Having a familiar home environment can be helpful in the relationship between the participant and researcher, and reduce any power issues, as I was an invited guest in the person’s home. Participant eight chose to be interviewed at her kitchen table and participant two undertook the interview in her sitting room. The digital recorder was placed on a table on both occasions and was unobtrusive. Building in time for disruptions is important for example when participant two and eight paused the interviews to deal with issues in the home. Active listening, and flexibility in approach, was necessary to be able to quickly summarise the content and response prior to the pause in the interview. The interviews in the home environment were between one and a half hours to two hours duration and I checked that participants were happy to continue throughout the process. Braun and Clarke (2013) outline how interviews are time consuming for the participant and the researcher but provide rich and detailed data about individual experiences and data. Refreshments were provided for those who had travelled, and the rooms were comfortable, quiet, and confidential spaces to share their experiences.

Terminating the interview is an essential part of the process providing opportunity to check the well-being of the interviewee and answer further questions. Each participant was thanked for sharing their experiences and I followed this up with an email and a thank you card. The sequence of actions taken were important to demonstrate respect and value participant’s time and contributions.

4.14 Reflexivity

Self- awareness and reflexivity included questioning my attitudes, thoughts, and reactions throughout every stage (Yilmaz, 2013; Butler Kisber, 2010; Biggerstaff and Thompson, 2008). Bulpitt and Martin (2010) highlight the ‘self’ as a research instrument and the distinction between a research and therapeutic interview. It was important to maintain boundaries, but good listening skills and compassion were essential. During one interview the participant became tearful as he shared the experience of someone attending who had early onset dementia. He asked for the recording to be stopped and shared the impact of the experience before deciding to return to recording the interview. I considered the emotional impact of returning to experiences, verbal responses, non-verbal gestures, and how information shared in the interview was explored or developed. Reflecting, asking open questions, and giving time to answer questions were key components during the interview process (Biggerstaff and Thompson, 2008). I continually reflected on my responses considering my professional and personal experiences of dementia. Note taking during the interviews was kept to a minimum to ensure I paid full attention to the participant, the interview content and exploring meanings.

This was the first time the eleven participants had been interviewed about their experience of being a dementia friends champion and it provided opportunity for them to explore and reflect in a way that had not been possible before. Forums and networks through the Alzheimer’s Society did not provide the same opportunity for exploration and reflection.

4.15 Undertaking Interpretative Phenomenological Analysis (IPA)

Smith (2011, p10) used the metaphor of a ‘chain of connection’ to explain the IPA process from embodied experience, talking about the experience, participants making sense of the experience and the emotional reaction.

IPA has been criticised for having a formulaic approach and described as a psychological rather than phenomenological analysis capturing description and perceptions rather than meaning and analysis (Zahavi, 2018). Smith (2009) and Finlay (2011) emphasise that listing the stages in the process should not detract from the rich accounts that can be captured within IPA including embodiment, emotion, cognition, language, and culture. A systematic approach offers rigour, robustness, and transparency in the conduct of the analysis. IPA has been used widely adding credibility and familiarity with the process which can be beneficial for the reader. The process should not be a rigid method to be followed but one that encourages creativity, flexibility, engagement with metaphors and arts-based approaches (Smith et al., 2009).

Undertaking the analysis involved a reflective focus on the subjective individual accounts of the participants and a commitment to the meanings attached to their experiences in the context of being a dementia friends champion.

4.15.1 Stages

Stages undertaken are explained and shown in the table below. Examples from the transcripts demonstrating the coding and grouping of data into themes are shown in appendices 10.5.1; 10.5.2; 10.5.3; 10.5.4; 10.5.5; 10.5.6; 10.5.7; 10.5.8; 10.5.9.

Step	Detail	Activity
1	Reading, re-reading and immersing oneself in the original data	Each transcript was analysed individually before moving to the next transcript until all eleven had been completed. The process started with the thorough reading of the transcript paying attention to the content and listening to the recording of the interview. The active engagement with the digital recording of the interview provided

		opportunity to hear the voice of each participant, the way they expressed their experiences, the words used and identifying aspects that were given greater emphasis. Listening to the recordings also captured the emotional elements of their life stories. This was followed by returning to my notes taken during or immediately after the interviews had taken place. I also reflected on how the interview had begun, how it moved to specific events, how I probed and checked understanding and how it came to an end. Participant's experiences, concerns and understandings were explored to the level that as I read a piece of text, I could identify who they were and hear their voice
2	Initial noting, free association and exploring semantic content	Each transcript was read many times in detail to document the content and the meaning. The exploratory comments incorporated descriptions of the experiences, the use of language and what it meant to be a dementia champion. I noted points of interest and the way the participant had spoken about an experience, relationship, place or event. I explored the use of metaphor, figures of speech and emotional responses including what each participant emphasised in the interview. The pauses, and the emotional expressions were also noted. This stage also involved reflexivity considering what I had followed up, and how I had responded. At times I read from the beginning to the end and at other times I took sections or sentences with the aim that I would move beyond a simplistic reading.
3	Developing emergent themes	During this stage I returned to chunks of the text to develop themes that represented an understanding of the experiences. I looked at the interrelationships, connections and the patterns in the notes while checking that I stayed close to the words and experiences of the participants.
4	Identifying connections	This stage involved several processes.

	across themes, abstraction, and integration	*Abstraction*: I laid out the typed themes and brought similar themes together. I returned to the transcripts and quotes to remind myself of the meaning and context. *Subsumption*: I brought together themes that would acquire a superordinate status. *Polarization:* I looked at differences as well as similarities. *Numeration*: I paid attention to the frequency with which a theme was supported in each interview and the patterns developing but did not record the exact number of times a theme was supported. *Bringing it together:* Creating organisational maps and tables helped me to visualise the structure of the themes
5	Analysis of each transcript individually	I analysed each case individually using the steps outlined above while also being attentive and noting times when I started recalling similar experiences expressed by other participants.
6	Looking for patterns across cases including shared qualities and noting idiosyncratic instances	This stage involved looking across cases for patterns, superordinate, and subordinate themes. I produced a table to show recurrent themes across the eleven transcripts.
7	Taking interpretations to deeper levels, exploring the phenomenon and how participants make sense of their experiences	This stage involved: • Returning to the question of what it meant to be a dementia friends champion. • Commitment to understanding the participant's point of view. • Being aware of the importance of reflexivity and the responsibility of the double hermeneutic • Interpreting the meaning associated with their experiences.

(Smith et al., 2009; Smith, 2011)

4.16 Moments of significance

Smith (2019) uses words such as digging, uncovering, witnessing, coming to light and showing itself to capture moments of significance.

The metaphor of gems and diving for pearls has been used to capture the IPA analysis through a word, a phrase or a passage that demands attention. Smith (2011b) describes a spectrum of gems where some may already be present (shining) and expressed readily by the participant. Other gems may be suggestive requiring attention to be brought forth by the researcher and participant. The secret gem of understanding is hidden, to be drawn out and revealed by the researcher and participant (Smith, 2011b). I found the metaphors a helpful way of visualising the levels or layers to reach the essence of the phenomenon and moments of significance. I engaged in different levels of analysis which are outlined below.

At a literal level I included how participants defined and described a dementia friends champion or activities associated with the role.

At the second level I puzzled over and unravelled not only what was said but what was meant. For example, being a volunteer could be seen in a literal sense but for the participants it represented passion and commitment. For many participants it came from a place of sadness when returning to their own experiences and compassion when seeing the challenges faced by people living with dementia. The dementia friends badge was not just something worn on the lapel but a symbol of making a difference in relation to attitudes to dementia and understanding. Wearing the badge became a recurrent mode of experience and a motif that had meaning and reflected being part of a bigger community and movement.

Moving to a deeper experiential level, I probed to explore the experiences and meaning of being a dementia friends champion. They engaged on an emotional level, finding answers, and seeing situations in a new light, and recognising what could have been different. Finlay (2014) describes this stage as a tension between old perceptions and understandings, dwelling and seeing things afresh. It involved bringing to the fore aspects that were unsettling, for example recognising how personal beliefs, attitudes or behaviours had changed. There were new insights into what really mattered for participants, for example the importance of emotional memories, personal and relational aspects and not events. Moments of significance required interpretation, for example what it meant when participants conveyed, they had been changed as a result of their experiences of being a champion.

The reflective boxes in the findings chapter show examples of moments of significance, capturing the lived experience of dementia friends champions.

4.17 Research poetry

I found writing poetry provided a way to capture creatively the metaphors, meanings, significance, and gems of meaning in a different light (Smith, 2011b, 2004). The inclusion of poetry expanded the emotional dimension of the experience to communicate an empathic sense of being there (Todres, 2007; van Manen, 1990). Research poetry also created an additional layer of analysis as I went back to the transcripts to investigate meaning and the ways participants made sense of their experiences

I wrote the poems from the words of the participants (found/ research poems) and from my interpretations of the meanings behind their words (generated/ interpretative poems) at every stage of analysis. I read the transcripts over and over and listened to their words, phrases, and the language they used to express their experiences. Attending to how participants used metaphors and rhythm in their speech, the tone, the pauses, and moments of silence brought forward what it meant to be a champion. Writing and reading the poetry to supervisors, fellow students and at forums provided opportunity to express the emotion, the experiences, and moments of significance in a condensed form. The goal was always to hear the voice of the person through the poem.

4.18 Ethics

Ethics relates to every aspect of research including moral principles and best practice. This section address quality in qualitative research, rigor, reflexivity and essentially the action taken to avoid harm or distress to participants.

4.18.1 Ethics approval

The proposal was submitted to the University Research Ethics Committee (UREC) in January 2016. A response was received in March 2016 with approval to proceed subject to clarification of some points. I provided clarification and the amended version was signed by the supervisors and submitted to the chair in March 2016. An email was received at the end of March 2016 confirming ethics approval and permission to proceed with the research. I received the official letter with the UREC number (1618) was received in June 2016 (Appendix 10.3.1).

4.18.2 Rigour

Miles and Huberman (1994, p278-379) discuss the importance of credibility, dependability, and trustworthiness in qualitative research. Principles that should be evident include sensitivity to the context, commitment and rigour, coherence, impact, and importance. Transparency should be evident in the philosophical background and study design including the context, data collection, management, interpretation and presentation, informed consent, and participant well-being (Tufour, 2017; Yardley, 2000). I have included justification for the decisions and actions at every stage.

I provided participants with the initial information, participant information sheet (PIS) (Appendix 10.3.2) and consent form (Appendix 10.3.3) in advance. There was also opportunity to ask questions before agreeing to participate and before the start of each interview. Individual contact was made only after they had expressed an interest in participating in the research. Only the essential demographics were included to avoid the risk of any person being identified. Open questions were designed to encourage participants to share their experiences and the flow of the interview was shaped by the participant and not by the interview schedule. I was not in a senior position to any participant to avoid any potential power issues. Time was available with participants at the beginning and at the end of the interviews to ensure the sharing of experiences had not had any negative effects. Contact details were provided on the PIS, should support be required later.

4.18.3 Participant engagement

Respondent validation is an important component of qualitative research to question, challenge or seek clarification (Howitt and Cramer, 2017; Wagstaff and Williams, 2014; Mays and Pope, 2000). I invited participants, research colleagues and supervisors to a meeting and lunch was provided for them. Email invitations were sent out three to four weeks before the scheduled meeting and alternative arrangements were made for those who could not attend. These included meeting with one participant the day before the event and meeting with two other participants the following week.

The session was organised midday to make travelling easier for those outside of London, and to enable those with work commitments to attend. I arranged the room in an informal way and provided lunch and refreshments for everyone to promote a relaxed and friendly atmosphere.

This provided opportunity to share the research findings including a presentation, thematic maps, quotes and commentary, and research poetry. Anonymous written feedback was recorded by the participants which was collated and informed the wording of the themes (Appendix.10.3.6). For example one champion when reading the wording ‘limited knowledge and understanding’ interpreted it to mean the champion had limited knowledge but it was meant to convey the limited knowledge about dementia from people attending the Dementia Friends sessions. As a result of the feedback the wording was changed to ensure it could not be misinterpreted.

4.19 Limitations of the study

The limitations of the study are explained in relation to the participants and design of the study.

4.19.1 Involvement of people living with dementia

Every effort was made to recruit dementia friends champions who were also living with dementia, but this was not achieved. I contacted the Alzheimer’s Society to request support in advertising the research and they agreed it could be advertised via their newsletter to reach a broader audience. The Alzheimer’s Society regional office also gave permission for my research to be discussed on two occasions at the London and South East Dementia Friends Champions Committee meetings. Information was also included on the minutes of two meetings with my contact details. Participants were not living with dementia but did provide additional insights from their lived experience as carers.

4.19.2 Data collection methods

Semi structured interviews were undertaken and provided an effective way of capturing in depth the lived experience of the participants. On reflection the research could have incorporated a second method such as the use of a diary, to enable participants to capture their experiences and reflections, or an alternative arts-based approach. Brown (2018) used creative data collection methods to explore the lived experience of fibromyalgia. In addition to interviews, participants created identity boxes incorporating photos, objects, song lists, poetry and more to reflect a series of questions presented by the researcher. These were brought to the interview and used to get as close as possible to the participants experiences. This approach could have been a useful tool leading up to the interviews and incorporated alternative modes of communication such as objects, photos, and letters. Brown (2018) also created an installation for an art gallery (fibromyalgia chair and table) to demonstrate what it was like to have fibromyalgia. Dementia friends champions used metaphors in their storytelling, and shared correspondence from people who had attended the Dementia Friends sessions, but this was not a method that was structured into the original design of the research.

Tools such as the Kawa model (Teoh and Iwama, 2015) could have also been incorporated to enable participants to draw their journeys as dementia friends champions. The Kawa model was an effective tool for reflecting on the doctoral journey and as a tool to capture insights from the interviews (Appendix 10.2.2. 10.2.3, 10.2.4).

Reading and engagement with arts-based research has given me a greater understanding of arts-based approaches to capture lived experience for future research (Johnson et al.,2017; Barone and Eisner, 2012)

4.20 Summary

In this chapter I have provided an overview of the ontological perspective and inductive process to capture meaning and understandings into the lived experience of dementia friends champions. The chapter includes justification for the research, decisions about the methodology, method of data collection and analysis. I have explained each stage in the analysis using examples from the transcripts. Details of the grouping of data and themes and moments of significance are included. The chapter outlines the benefits and limitations of research poetry. Ethical considerations and reflexivity are addressed.

5 Findings

5.1 Introduction

This chapter provides an overview of the findings from the interviews with eleven dementia friends champions. The research explored and analysed their lived experience using interpretative phenomenological analysis (Smith, 2011) and research poetry (Faulkner, 2009). Moments of significance are captured in the reflective boxes.

The findings from the research will be presented in four superordinate themes. These include being a champion, knowledge and understanding in communities, experiences and insights and dementia friendly communities. They are presented together in tables which give an indication of the grouping, how many participants shared the themes, connections, and variations in the themes.

The findings are further interrogated by research poetry. I created the poetry reflecting the words of the champions and my insights as the researcher, to express the experiences of dementia friends champion in an innovative and accessible form. Found poetry represents the subjects voice as the primary transmitter of data in a compressed form and the generated poetry fuses the perspective of the participant with insights from the researcher (Langer and Furman, 2004; Butler- Kisber, 2010).

The poems are presented under the relevant headings and incorporate an account of how they represent the findings with links to the transcripts.

Research poetry provides a different way to engage in social justice, to dwell on the experience and create an inner dialogue (Barone and Eisner, 2012). Emotions can be captured through poetry to recreate the experience and bring art into the text (Percer, 2002; Richardson, 1993). On reading the poem, the aim is to hear the person speaking, trigger imaginations, picture the context and think and behave differently (Goldblatt, 2006; Dewey, 1997). van Manen (1997) advocates the inclusion of an artistic dimension. He argues that a phenomenological text is most successful when readers can engage with the textual emotion, capturing the intensity and tone of the experience. Through poetry a story, rhythm, feeling, emotion, and voice of the participants can be shared (Butler- Kisber, 2010). I paid attention to clarity and transparency in showing how the poems reflect the experiences associated with being a dementia friends champion in a concise and meaningful way (Percer, 2002).

Champions were passionate about the volunteer role and their new identity. They believed they were making a difference and received positive feedback. They were happy with the design and content of the sessions and developed skills as they planned, delivered, and communicated with participants and organisations. Using the resources and engaging with people living with dementia brought new insights and understanding of dementia and for some answers to questions from their own experiences. They received support from the Alzheimer's Society but meeting with attendees, including people with dementia and carers, had an emotional impact and they needed resilience as they returned to their own experiences and heard stories of hardship. They gained insight into their experiences of caring and gained different perspectives on their own situations. They recognised what could have been different and this further motivated them to bring about change in knowledge and attitudes to dementia. Some participants faced inner conflict and challenges in delivering the message that you can live well with dementia when reflecting on their own experiences particularly end of life care. They witnessed fear and were affected by the unmet needs of people with dementia and the carers they met. Champions were encouraged by positive action in communities. They recognised more needed to be done to promote inclusion and expressed concern about sustainability. They experienced challenges when organisations were reluctant to engage, influenced by time and money. They were changed by the experience of being a champion and came to a different understand of themselves, their situations, and their experiences.

5.2 Being a champion

Subordinate theme	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10	P11	Total
Proud to be a volunteer				✓	✓	✓	✓	✓			✓	6
Understanding in a new way	✓	✓		✓		✓	✓	✓	✓		✓	8

The superordinate theme captures what being a dementia friends champion meant to the participants. The table shows the two related subordinate themes and the prevalence of these across the participants.

Being, being there and being conscious of something, are key concepts within phenomenology (Zahavi, 2019). The study explored the experience of champions within the context, culture, and language of dementia, in relationship with others and the things that mattered to them (Zahavi, 2019; Larkin and Thompson, 2012). ‘Being’ relates to what is visible or not fully known and involves self-discovery, awareness, thinking and reflection (Morris, 2012; Hitch et al., 2014). ‘Being’ is not fixed but changes over time reflecting the champions experiences, how champions saw themselves, their identity, their personal capacities, abilities, and motivating factors.

Being a volunteer champion meant experiencing a sense of pride in the role, believing they were making a difference by getting people to talk about dementia and being part of a community. It also meant finding answers and seeing their past situations and experiences differently. As they engaged on a practical and emotional level they used and developed a wide range of communication and presentation skills. They built a rapport with people attending sessions, expressed empathy as they heard stories of hardship, and confronted the myths and stereotypes associated with dementia. Champions shared how delivering key messages brought them back to their own life events. One champion was challenged to question his own beliefs and attitude to a diagnosis of dementia. As they shared their stories, they demonstrated sensitivity, emotional intelligence, and resilience. What it meant to be a champion represented far more than delivering a one-hour information session.

5.2.1 Proud to be a volunteer

They all perceived volunteering as a choice, an identity, commitment, sense of purpose and a personal goal. Six of the participants discussed the importance of being a volunteer. It was not part of an existing work role, position in an organisation or career development. Participant eight shared:

“It's been enjoyable. I'm glad because I am a volunteer and I do stress that I'm a volunteer especially when I'm in places of work. They haven't paid me to come, you know that I am a volunteer.” (P8)

Participant four and six shared their feelings about making the decision become a champion and how the desire to make a difference became a driving force for change:

“When it's a personal passion it's going to be much more solid than if it's something that has been either imposed or taken on board at the end.” (P6)

For participant two the motivation and commitment came because of her husband’s diagnosis with early onset dementia. Becoming a champion helped her to understand her situation in a new way. It gave her a purpose, something positive that she could do and resulted in new friendships. She also expressed feelings of guilt as being a champion had resulted in new opportunities and a different life:

“I think it is quite horrible that my husband’s illness has given me a really good life” (P2)

The word ‘pride’ was expressed many times as the participants embraced delivering sessions with enthusiasm and vigour but also some trepidation. Being a champion resulted in seeing themselves, their situations, and their experiences differently.

They all had other roles and commitments but being a champion became an identity and they felt empowered by the role. Despite feeling nervous before delivering a session, participant four described how he had found a new confidence and sense of ‘showmanship’.

In ‘The Champions Hat’ I use the metaphor of wearing a different hat to represent how the champions embraced the role, how it was empowering, and created a new identity.

Poem 2

The Champion’s Hat

Put on a new hat
A different shape and colour
Try it on for size
Look in the mirror
See yourself differently
Wear the hat with pride

Six of the participants spoke of ‘wearing the badge’ as a symbol of their commitment to changing the way dementia is seen, dispelling myths and getting people to talk about dementia. Despite working autonomously when they wore the dementia friends badge, they felt a sense of belonging to a bigger community. The meaning of the badge is shared in the words of participant eleven:

“ Tend to wear my badge because I think if nothing else even if it is subliminal, someone will be sitting across a train, look at my badge and think oh why I know that name or equally they will know that name. I've had a couple of occasions where I have had people give me a thumbs up and say I'm a Champion you know, well done sort of thing and I think okay, cool.” (P11)

I wrote the poem ‘wearing the badge’ from their words to reflect the connection they felt with people attending sessions, being in it together and shared experiences. Wearing the badge represented changing attitudes and behaviour but also brought about change in their own understandings of past situations and their identity.

Poem 3

Wearing the Badge

Delivering the session
A bit of showmanship mixed with fear
A partnership, in it together
I share stories, they share lives
Touched by dementia
Asking questions, finding answers
Change is possible, not impossible
And in that moment
I find a better side of me

Reflective box 1: Proud to be a volunteer: Wearing the badge

Six of the participants spoke with passion about the importance of being a volunteer.

There was a moment of significance as I understood in a deeper way what being a volunteer and wearing the badge meant to participants. It represented not just giving their time but giving of themselves emotionally. It also became evident how much they gained from the role. They described a sense of satisfaction and positive feedback from people attending sessions and a new identity. Skills and knowledge were development and they became known in their communities.

I reflected on how I felt on hearing what being a champion meant to them. I reflected on my motivation to become a champion because of seeing the impact of dementia on people’s lives, my experience of being a carer, and the decision to do the research. I recognised it was not possible to bracket my own lived experience and the importance of acknowledging and noting how it could influence what I heard and how I felt. I did not consider it to be a disadvantage as my knowledge enabled me to pick up on the subtleties in the stories they shared. I had some understanding of their drive to raise awareness of dementia. I felt a connection to the champions with our shared experiences but also aware of the need to capture and interpret their experiences and not mine.

5.2.2 Understanding in a new way

Champions shared stories of the changes they saw in individuals and communities. They also recognised changes in their lives as they gained new understandings about dementia. They found the analogies and metaphors used in the session helped people to make sense of the key messages but also helped them as they reflected and made sense of their own experiences

Champions were positive about the structure, design, activities, and resources used in the sessions. All eleven participants discussed the effectiveness of the bookcase analogy (Appendix 10.6.4) as a metaphor for the impact of dementia on the brain incorporating facts, memory, emotions, and life story while recognising it affected people differently (Appendix 10.6.5). Participant eleven described it as a time of understanding and went on to say:

“I always found the sort of linchpin of where the penny dropped for most people was always the bookcase, alright, everybody seems to just absolutely understand that the bookcase analogy.” (P11).

The analogies were identified as resonating with the audience and captured the importance of being in the person’s reality. Rather than trying to reinforce the present it was important to engage with the person where they are. Participant one discussed how the sessions helped her to understand her aunt’s dementia in a new way. She said:

“…also my Aunt had died just before I did the dementia friends training… she had vascular dementia so you know… the training actually gave me some answers as well because she was at that stage where she couldn't place somebody in the present, so she was bringing them way back into her past.” (P1)

I wrote the poem ‘Placed in the past’ from the words of participant one. Dementia had caused her aunt to mentally return to an earlier time in her life when she lived in Ireland and came to believe her niece was her neighbour. Delivering the sessions and using the resources helped participant one to recognise that it did not matter that her aunt thought she was her neighbour and it was better to be in her aunt's reality during a happy period on her life. The insights gained from being a champion were reassuring and a comfort to her.

Poem 4

Placed in the Past

Placed in the past
The present was gone
Drawing me into her past
When she was a teenager
I became her neighbour
In a little village
In the west of Ireland

Imagining the brain as a collection of thousands of fairy lights is used to represent a memory, skill, or function of the brain. Participant one, five and seven all discussed the effectiveness of this representation in the sessions. Participant seven discussed how it represented changes in the brain but how each person affected will be different and said:

"…the twinkling fairy lights and the fact that, you know they dim or go out and it's different for every single set of fairy lights and things like that. So, it's a different way of delivering a session but actually they quite engage with it." (P7)

Participants shared how the metaphors used in the sessions had meaning for them reinforcing how each person is different and that although there is loss and change, some parts remain. It brought to the fore the champions belief in valuing people not just for their cognitive ability but seeing the person, their past, their stories, the lives they have led and finding the person, not just the disease. This is expressed in the words of participant eleven:

"..suppose I would just like people to appreciate that we are all the same, we are all human beings and I would like people to just be open minded enough to not buy into all the ways that people get segregated you know" (P11)

Participant six shared his experiences of the changes he saw in a man he knew as a result of dementia. He described feeling shocked at the change he witnessed particularly the changes in personality and behaviour. What became apparent as he told the story was, he was able to separate out the effects of the disease with the person. The term 'he was one of life's gentleman' was repeated several times throughout the telling of the story. He did not have personal experience of dementia but what he came to understand from being a champion was the importance of seeing the person and not just the effects of the disease.

From the words of participant six the poem 'Danny' (pseudonym) was written to reflect the impact of dementia while still holding on to personhood. Using repetition in the first and last line aims to move from the medical model to capture the essence of the person.

Poem 5

Danny

He was one of life's gentleman
Always a good word to say
Until today
No smile on his face
He paces back and forth
Not recognising his friends
He ends the visit
Without a word
I heard
He had Dementia
He was one of life's gentleman

Participant one also reflected on how the experience of being a champion had reinforced the importance of finding the uniqueness of the person:

“I think I love the stories that they include. So the one about the person who was tapping away on a nursing table, I think that really reinforces, you know actually around valuing people for their skills, their background, their knowledge and actually looking behind behaviour as well.” (P1)

Activities in the session were delivered through a storytelling format. They identified this as an effective way to get the message across and provided opportunity to interact and engage with people attending the sessions. I recognised the extent to which being a champion meant moving beyond the factual delivery of information to engaging on an emotional level. It was not evident from the interviews whether champions recognised the emotional level of engagement in undertaking the role, but they all embraced the connection and engagement with people attending sessions. Interacting with people was described as a rewarding part of the role and the positive encouragement they received was a strong motivator to continue. Participant seven shared:

“I've had quite a range of different types of feedback that have made me really think gosh actually this is actually a really worthwhile thing to do. So yeah it's been quite amazing really” (P7)

Their experiences highlighted how they had developed emotional intelligence. As they delivered activities, they were attentive to how the messages were being received. Participant five gives an example of sensitivity required in the role:

"….I think it's nice and engaging but it still has to be done sensitively and you need to kind of think actually there might be audience in there that right now are going through a difficult time with someone with dementia….." (P5)

Participant six and nine reflected on the importance of keeping to scenarios in the resource pack (Appendix 10.6.1) and not bringing in examples from personal experience. Participant nine shared the emotional impact of suddenly being faced with situations that brought her back to her own experiences and the need to keep some emotional distance. She explained it as:

".if you use potentially your own examples then sometimes your own emotion can kick in and then you think well this session isn't about me." (P9)

From the words of participant nine the poem 'Your presence' was written representing how she would sometimes meet someone in the audience whose experiences mirrored her own. She recognised the need to check herself and not be overcome with the emotion from her past

Poem 6

Your Presence

In her eyes I see
What you were to me
I check myself, stand tall
I wasn't expecting you

Reflective box 2: Understanding in a new way: Finding answers

A moment of significance emerged as eight of the participants shared how being a champion helped them to understand their own experiences of dementia. The training, delivering sessions, and hearing the stories of people attending, brought them back to their own experiences. I became aware of how being a champion had provided answers to past experiences for participant one and this developed as other participants returned to difficult and emotional times in their lives. Four participants came to understand what was happening to relatives living with dementia in a deeper way. As they shared stories they came to see and understood past situations and experiences in a new light altering the memory and the interpretation of events. Four participants came to a place of acceptance and reconciliation that they could have handled situations better or differently, but they were doing the best they could at the time.

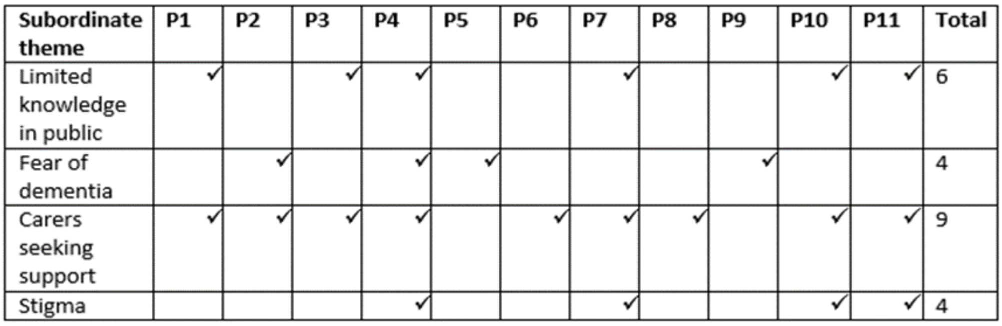
I reflected on how much I had learnt from hearing their stories and how I was constructing new understandings. Challenging or painful life events may be left buried affected by what could have been different. Revisiting and exploring experiences can be difficult but can also bring a deeper understanding and resolution. The act of articulating the experience creates space to reflect afresh on events and see them in a new light.

As I listened to the interviews, I considered my responses and how I had probed as they gave me access to personal and emotional stories. I was aware of the affective nature of experience as stories were told and received. I paid attention to thoughts, feelings and emotions expressed and words used by participants.

I felt a sense of satisfaction that their voices and stories would be captured in the thesis and a responsibility to express their experiences in a meaningful way. I wanted to capture the sense returning to feelings as well as events and finding answers. I hope the quotes and the poems give voice to the participants and how it felt to return to past times. It was a time of recognising that past events and actions could not be changed but understanding and interpretation of events could alter. I used different poetic forms to capture meaning for example the 'I' poem.

By writing poetry I hope the emotions attached to participant's experiences will be felt. I hope it will also serve to raise awareness of dementia for those who read, hear, and reflect on their experiences in the words they use and through the poems.

5.3 Knowledge and understanding in communities



Subordinate theme	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10	P11	Total
Limited knowledge in public	✓		✓	✓			✓			✓	✓	6
Fear of dementia		✓		✓	✓				✓			4
Carers seeking support	✓	✓	✓	✓		✓	✓	✓		✓	✓	9
Stigma				✓			✓			✓	✓	4

The superordinate theme captures knowledge and understanding in communities. The table shows the four related subordinate themes and the prevalence of these across the participants.

Champions expressed concern at the limited knowledge, understanding and fear of dementia in communities. They shared how carers feared their loved one would not remember them, and they would not be able to cope. Stigma and marginalisation were also apparent as the people they met shared how dementia had affected them and their families. Ten of the eleven champions interviewed had a relative who had dementia and felt a connection with the people they met.

5.3.1 Limited knowledge in public

Champions felt a sense of responsibility to get the key messages across in a one-hour session. Participant four shared:

“…it kind of surprises me that there are still people out there who don't know anything and then they hear about it and then they become interested and then they want to kind of find out more.” (P4)

Dementia training is provided in health and social care curriculums (SfH, 2019) but participant four highlighted the importance of not making assumptions about knowledge. Participant seven reflected on how she was confronted with different beliefs about dementia. Some health care students attending sessions expressed the belief that dementia was associated with evil:

“some of the students that come from Africa for example would come up to me and say gosh we look on this as something really evil in our communities and you have really enlightened us ……..I am going to talk to my family and friends about not treating people as if they are evil or have evil spirits and that was very emotional for me and they got quite emotional about it.” (P7)

Being a champion meant recognising the importance of getting out into communities. Participant eleven said:

“…not a lot of people go out looking for that information, it has got to come to them.” (P11)

Champions were positive but also saw people struggling and faced inner conflict at not being able to meet the needs. Participant eight felt that information was helpful in knowing how to deal with situations. She also recognised the needs of people with dementia and carers were beyond what could be achieved from a dementia friends session but felt that:

“..if you have more understanding and more information it can help you actually deal with it (P8)

5.3.2 Fear of dementia

None of the participants said they were fearful of getting dementia, but four of the eleven participants interviewed discussed fears expressed by the people they met. These include the fear of diagnosis, fear of deterioration and cognitive loss. Carers expressed the fear that they would be forgotten, or they would be unable to cope. The shared how being a champion helped them to understand the fear associated with dementia at a deeper level and led others to confide in them. Participant two shared the experience of a friend calling her and said:

“A friend of mine phoned me when her husband was out because her husband obviously has developed Alzheimer's disease…... and the question was about euthanasia. So, she has got that fear.” (P2,).

Participant four gave several examples of people coming up at the end of the sessions to share their fears and carers seeking information, support, and reassurance. As he listened, he understood the fear and anxiety felt and said:

“She came up and said you know her own experiences with her sister and she was worried about am I going to get it, sister had it, mum had it, am I going to get it, that was her anxiety.” (P4)

And goes on to say:

“People are terrified that you know their loved ones are going to forget who they are.” (P4)

Participant five also discussed the impact of fear on seeking help and said:

“…I think there is a fear, the fear kind of stops people seeking help or fear of you know having a relative that is diagnosed with dementia so I think to reduce that fear I think that would make a big difference for people with dementia.” (P5)

The generated poem “Fear not the future” was written to acknowledge how champions experienced and understood the impact of dementia. They recognised the many challenges and losses caused by dementia but also held on to what remained and the essence of the person. I build on the words of participant two as she shared her experiences, the importance of emotional memory and connection with the person with dementia. The tree represents the person, often in the winter of their life. There are losses associated with dementia, whether through changes in cognitive ability, physical ability or in relationships with others but personhood remains, incorporating recognition, respect, and trust (Kitwood, 1997).

Poem 7

Fear not the Future

Fear not the future
The tree laid bare in winter
Stands strong in the wind
(Carers UK, 2016 p 77).

Four champions shared how they recognised the fears in the people they met. Hearing the fears of others also brought them back to their own experiences. Participant nine witnessed her mother’s fear and said:

“…my mum was petrified of then getting Alzheimer's or Dementia. I think just knowing her anxiety makes you then think well it's going to happen to one of us at some stage isn’t it.” (P9).

Reflecting on the fear associated with dementia led me to write the poem ‘branches’. The generated poem uses the metaphor of branches to represent hands, not kept apart by fear or stigma but stretching out to bridge the gap and bring people together. Champions captured the importance of bringing people together and talking about dementia. Participant six shared a memorable moment when someone in the audience felt empowered to stand up and share her diagnosis for the first time.

Poem 8

Branches

Branches reaching out
Touching the edges of fear
That keep us apart

During the interview participant two and nine shared the effects of dementia on relatives but also came to understand and found comfort in the knowledge that emotional connections remained. I wrote the poem ‘May’ to capture the words of participant two and participant nine:

Poem 9

May

May is coming soon
I don’t remember her face
Or the place we met
But I feel safe when she’s here
And I don’t fear dementia

Champions were able to connect, hear and interpret the fears associated with dementia and reflect on their own feelings, beliefs, and new understandings. The interviews highlighted how they engaged on a practical and emotional level and the skills they used in managing challenging situations

Reflective box 3: Connecting with fear

A moment of significance developed as four of the participants reflected on the fear of dementia. I returned to their words to explore how they responded and what dementia meant to them. Participant nine shared how she was only fourteen when her grandmother was diagnosed with dementia but years later, she still recalled her mother’s fear and anxiety. The interviews captured how champions understood fear not in the diagnosis but because of stigma. Participant five shared how focussing on deficits prevented people from talking openly about dementia and stopped them from seeking help. She emphasised how information was needed to bring about a change in attitudes and behaviour towards people living with dementia. Participant two captured her understanding of dementia at the end of the interview in the words ‘emotional memories last’. Memories of events may be lost due to the symptoms of dementia but what remained and what had meaning for her were emotional connections. I left the interview reflecting on those three words ‘emotional memories last’ and the importance of connecting on an emotional level, seeing the person and not the disease.

5.3.3 Carers seeking support

Nine of the participants shared examples of carers coming to sessions seeking information, looking for answers, and struggling to provide care. Participant four shared how being a champion gave him greater insight into the impact of caring on mental health:

“Yesterday a lady come up to me and she was talking about her mother who had dementia and passed away but actually what she was really talking about was her own mental health and about how she couldn't get support.” (P4)

Participant three, six and eight used words such as desperate, struggling and looking to convey what they recognised in carers attending sessions:

“I very often find that I might get an elderly gentleman turn up who was concerned about his partner or his wife and she won't know that he is there, you know he is looking.” (P6)

Participant three shared how being a champion helped him to recognise the needs of carers and said:

“I perhaps had not anticipated quite how much people were just sort of desperate for support, you know there was one man in particular who was trying to support either his mum or his mother-in-law and really struggling.” (P3)

There was an emotional cost as champions were emotionally moved by the stories they heard and the people they met:

“..That session I noticed one of these girls getting quite upset and I also noticed the other one beginning to be concerned…..and you know what is coming, the younger sister was recently diagnosed and she was soldiering on as best she could.” (P10)

Listening and reflecting on the champion's words about the emotional impact of caring led me to write the poem 'Reasons not to visit' (Carers UK, 2018, p65).

Poem 10

Reasons not to visit

I didn't visit because she doesn't remember me
I didn't visit because she's not the person she used to be
I didn't visit because I didn't know what to say
I didn't visit because she lives so far away
I didn't visit because it makes me feel upset
I didn't visit because she starts to fret
I didn't visit because I feel afraid
I didn't visit because she seems dismayed
I didn't visit because I couldn't show
The loss I feel when it's time to go (Carers UK, 2018, p65)

Being a champion also led them to return to and reflect on the impact of caring for someone with dementia from their own lived experience. Participant two recalled how she felt unnoticed and neglected in the caring role and shared the struggles she faced. The challenges of caring and finding new ways to manage at different stages in the journey led me to write the poem 'Invisible':

Poem 11

Invisible

Under the radar
Not noticed, not detected
Finding a new way
To care for you

5.3.4 Stigma

Four champions discussed challenging the stigma associated with dementia by encouraging people to talk and share. They described the experience of starting the sessions by asking attendees to say what words came to mind when they heard the word ‘dementia’ and how this led them to dwell on the perceptions of dementia.

Participant ten shared why the development of dementia friendly communities meant so much and how she had recognised ‘us and them’ situations. She said:

“…if we can talk about those people over there who are experiencing that then we can sort of distance it from us. So, it's difficult sometimes when you do kind of bring people into the fold and think actually that is us that is everybody you know.” (P10)

Participant eleven used metaphors when thinking about his experience of the media in increasing or reducing fear and stigma and said:

“…the media and our experiences will lead us to sort of stamp somebody with a certain title or heading and sometimes we have got to see past that.” (P11)

I wrote the poem ‘Otherness’ written in response to the words of participant ten and eleven. Their experiences led them to recognise the importance of speaking up and challenging the stigma of dementia

Poem 12

Otherness

Living well or living in hell
It’s up to you
To act
Let’s end the silence
The stigma, the fear
No longer otherness
But us

5.4 Experiences and insights

Subordinate theme	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10	P11	Total
Personal experience and motivation	✓	✓		✓	✓	✓	✓	✓	✓	✓	✓	10
Storytelling and sharing	✓		✓	✓	✓	✓	✓	✓	✓	✓	✓	10
Challenges experienced		✓			✓			✓		✓	✓	5
Changed by the experience	✓	✓		✓		✓	✓	✓			✓	7

The superordinate theme captures the experiences and insights participants gained from being a champion. The table shows the four related subordinate themes and the prevalence of these across the participants.

Champions gained greater insight into their own situations, a deeper understanding of dementia, and felt part of a shared encounter. Some champions experienced dissonance when delivering the message that you can live well with dementia which conflicted with their own experiences. The message was also challenged by some people attending sessions. Being a champion had resulted in a different life and different roles.

5.4.1 Personal experience and motivation

Ten of the eleven participants shared their experiences of family members living with dementia. Participant four, eight and eleven all discussed how their personal experiences influenced their decisions to become a dementia friends champion:

"… I came into the Alzheimer Society because I was a carer, I still am a carer, and my loved one is in residential care now. So, I was a carer, I was interested in the area." (P4)

Participant eleven was motivated by wanting to help others and the desire to have a better understanding of dementia. He shared the challenges and how he did not feel prepared for the caring role:

"…it is close to me because my mother suffered from dementia and I never knew how to deal with it to be quite honest." (P11)

Participant two shared how her husband's dementia had been influential in her taking the step to becoming a dementia friends champion. She was one of the early champions and did not know what the role entailed, what the experience would be like, or whether she was ready for the changes. Her experience of making the decision to become a champion and how the experience resulted in a new journey in her life, is reflected in my poem "Bridge to understanding":

Poem 13

Bridge to Understanding

Step onto the bridge
To find the footprints of others
Who have gone before

You may feel nervous
Tread slowly and carefully
To find your way there

A new life for you
From carer to champion
Footprints shaped by you

During the interview participant two shared how being a champion had helped her to understand what mattered in a new way. She explained it as:

…I often say, forget everything else just remember this, emotional memories last and I have got a personal illustration of that you see. But I mean I think it is something I didn't know when I was caring for X and I can look back now on things (P2)

I wrote the poem 'As memories fall away' to capture what Smith (2011b) describes as a gem of meaning that had previously been hidden. Memories, times, and events may be lost but participant two came to recognise the importance of emotional memories.

Poem 14

As Memories Fall Away

Just remember this
As memories fall away
What he feels will stay

Participant three did not share personal experiences but conveyed the emotional connection and engagement with people attending sessions:

"one person actually also came up to me and said I may not be able to stay for the whole session, I've got something personal going on with someone with dementia, a family member and I may find this too upsetting to stay and I said of course that's absolutely, you know up to you how long you stay and I think she did go halfway through." (P3)

The words of the participants reflected the emotional impact of delivering sessions on hearing the struggles faced by people attending sessions.

Champions spoke of the positive reinforcement from the audiences and the letters and contacts after the sessions. These were meaningful to them and shared in the interviews as an important source of encouragement. The level of engagement with the people attending sessions was not an expectation but reflected their personalities and commitment:

“I did actually have an e-mail from somebody afterwards you know basically thanking me and just saying that you know the examples mirrored her examples and she, you know was interested in finding out much more.” (P1)

The changes champion’s experienced included beliefs, attitudes, knowledge and understanding reflected in the ‘I’ poem ‘I changed’:

Poem 15

I Changed

I say dementia is important
I see carers can be isolated
I find it emotional sometimes
I understand what it means
I changed

5.4.2 Storytelling and sharing

Storytelling and sharing were evident throughout the interviews and highlighted how aware and engaged participants were with their audiences. Ten of the eleven participants shared how it had increased their own understanding and insights into dementia, had an impact on them emotionally, and further increased their belief in what they were doing. Reflecting on the storytelling and sharing led to writing the poem “Connecting with stories”. The words, the voices and the experiences brought to the fore the champions own experiences.

Poem 16

Connecting With Stories

Behind the words
Voices are heard
Feelings rise
Relived anew
Thinking through
A different time
Finding meaning
In what you do

Participant seven was touched by the openness with which attendees shared their stories and said:

"..I think it's been very humbling, that people are willing to share their personal experiences of perhaps someone in their family and willingly share that in a classroom setting so it has been very humbling." (P7)

5.4.3 Challenges experienced

Champions witnessed needs beyond the scope of the dementia friends sessions and wanted to do more. Five of the participants shared examples of challenges they experienced in the role. Participant two discussed the difficulty in keeping to the guidance on occasions:

"Sometimes people come up to me afterwards wanting to talk and I personally find it difficult to obey the rule of, you know, I'm not the person, I will direct you to so and so because I often have the answers. So, I do find that one very difficult because you want to help, you know." (P2)

Being a champion meant being prepared for the unexpected and recognising people came to the sessions for different reasons.

Participant 6 shared someone attending a Dementia Friends session who he knew but had not seen for many years. He shared feelings of shock when hearing she had dementia but also realised that her experiences were challenging his own beliefs about dementia and how he was changed by the experience

“I find this one quite upsetting…… and suddenly I recognised her and the shock, my initial response was shock, sadness, perhaps even pity and in the few moments of her relating her experience…. I have suddenly gone the other way, but I use that relationship …. As an example of it’s possible to live well with Dementia.” (P6).
From the words came the poem, ‘stories shared’:
Poem 17

Stories shared

Stories told and shared
Moments that matter
Etched in faces
Shaped by time

The interviews and examples brought to the fore the level of communication skills required in the role and the ability to reflect in and on situations. These included dealing with distress and anger in attendees:

Participant four gave an example of a personal experience of managing a difficult situation and how it motivated him to get information about dementia out to the public:

“…yesterday was a bit of a challenge because there were a couple of people there that were very clear about dementia is this because it was that for their immediate family. Everyone is aggressive, they all get violent, no they don’t, well they did for me so therefore they must for everybody.” (P4)

Being a champion meant confronting the dissonance in delivering a key message that you can live well with dementia when their own experiences were not positive. This was linked particularly to end of life care. End of life care was explored in many of the interviews and participant two shared:

“It’s very difficult when somebody with dementia reaches the severe cognitive stage.” (P2)

Participant eleven explained how he felt when delivering the message:

“I think the hardest key message is that it’s possible to live with dementia, alright, people can live well with dementia …..even from my own personal experiences, my mother wasn’t living well with dementia.” (P11)

The key message, the words, and the ability to live well at the advanced stage of dementia were also picked up by participant five who said:

“..there is still a need for better quality of care at the end stages of dementia because until that is resolved, people would still fear dementia and there will still be quite a negative attitude to dementia and that would then prevent people from getting early diagnosis.” (P5)

People attending the sessions also challenged the message as expressed by participant eight:

“I’ve had people say to me yeah you say living well with dementia you know it is a living hell coping with somebody with dementia.” (P8)

Participant ten found the message that you can live well with dementia challenging when she looked back to her own experiences and the people she encountered in the role. She was able to come to terms with this conflict by recognising that each person is different and the importance of considering the positives as well as the challenges. She goes on to say:

“I can see how it can be a struggle, but I think to only focus on the negative then misses all those many, many thousands of people who do have aspects of their life that are still positive.” (P10)

Reflective box 4: Personal challenges: Living well with dementia

A moment of significance emerged as it became evident how five participants were trying to manage feelings of dissonance in delivering one of the five key messages that you can live well with dementia. Returning to their own experiences of caring for a relative with dementia, particularly end of life care, they shared their inner conflict in expressing words that did not reflect their own experiences or in some instances their beliefs. They also shared examples of how people attending sessions had confronted and challenged them as they delivered the message. One participant was able to reconcile the difficulty in delivering the message by reflecting on how information could be helpful in managing the situation while still acknowledging the hardship particularly during the later stages of dementia. Living well with dementia meant physical and psychological care, freedom from fear or stigma of diagnosis, being accepted and having an identity. They spoke of the importance of being able to talk about dementia and social inclusion. There were differing views about whether changing attitudes was enough or whether action was required to promote inclusion and dementia friendly communities.

I reflected on my own experiences of end of life care and what it meant to live well with dementia. Like the participants I felt it was important not to negate the difficulties, to recognise the effects of impairment and the different stages of the disease. Being disabled by dementia was not the responsibility of the individual but society’s understandings and response to dementia. Like the participants I did not feel creating dementia friendly environments would address all the challenges and living well meant recognising impairment as well as disability

5.4.4 Changed by the experience

Seven participants shared how they had been changed from their experiences of being champion. Their passion had not been diminished but there was an emotional cost. Delivering sessions brought to the fore how they felt when family members were living with dementia. There were also moments of regret as they came to recognise how they could have dealt with situations differently. Participant eight discussed having greater insight into dementia and participant eleven said.

“I’ll say well my mum died of it and if I’d known this, I would have been able to deal with it better. I couldn’t stop her dying but I could deal with it better.” (P11)

From the words of participant eight and eleven ‘Journey to understanding’ was written.

Poem 18

Journey to Understanding

I stumbled across dementia
I wasn’t looking for it
I couldn’t stop her dying
I could have dealt with it better
I think it was my motivation
I can empathise
I think understanding outweighs action
I have my badge on

Attitudes also changed for participant six who shared how he now felt comfortable relating to people with dementia. He explained how he had felt awkward in the past but recognised he had changed and found a ‘better side of me’. He was emotionally moved when recalling the change, he saw in himself and said:

“During that time [pause] I recognised my bad attitude towards disabled people and not only did something about it but also found a pleasure in relating.” (P6**)**

The words from the interview with participant six are reflected in the poem entitled ‘A better side of me’.

Poem 19

A Better Side of Me

I am finding a better side of me
I wonder when change will come
I hear your stories
I see your struggles
I want a future without dementia
I am finding a better side of me

I pretend to be confident
I feel upset by your tears
I touch your hand
I worry at your distress
I cry you are so young
I am finding a better side of me

I understand in a deeper way
I say there is more to the person than dementia
I try to make a difference
I hope in possibility
I am finding a better side of me

The demands of the role and the resilience required were evident in the interviews. Participants shared how they engaged with other champions and the Alzheimer’s Society, but these did not address the lived experiences or deeper impact of the role. Interviews provided the space and opportunity to speak from a personal perspective, reflect on past and present events, and explore what it meant to be a dementia friends champion. Champions expressed enjoyment at the opportunity to be interviewed and participant ten said:

“It’s been great having an opportunity to talk about it because I don’t think I’ve ever talked about it in any other capacity really because it’s not as you say it’s not really something that is talked about.” (P10)

5.5 Dementia friendly communities

Subordinate theme	**P1**	**P2**	**P3**	**P4**	**P5**	**P6**	**P7**	**P8**	**P9**	**P10**	**P11**	**Total**
Communities that care		✓	✓	✓					✓	✓		5
Making a difference	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	11
Workplace challenges				✓		✓					✓	3
Sustainability		✓		✓	✓	✓				✓	✓	6
Promoting understanding and action	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	11

The superordinate theme captures champion’s insights and understanding of dementia friendly communities. The table captures the four related subordinate themes and the prevalence of these across the participants.

The dementia friends initiative was designed to raise awareness and turn understanding into action. Champions shared what was happening in communities, what they perceived as priorities and the challenges of accessing some organisations. They expressed feelings of hope that change would come but were also concerned about sustainability.

5.5.1 Communities that care

Five participants discussed how they felt about policy and initiatives and what they had witnessed. They shared how their sessions motivated others to fund raise or take other positive action such as visiting and campaigning for services. They were actively involved in youth groups and organisations in their local communities. Participant four shared his feelings:

“You know Cameron’s Big Society annoys the hell out of me because it is an assumption that the Big Society didn't exist beforehand. It did. It has done for tens of thousands of years.” (P4).

5.5.2 Making a difference

Being a champion and making a difference meant being proactive. The research participants were connected to London and South East region of the Alzheimer’s Society and engaged with a diverse range of communities in a wide range of settings. These are outlined in appendix 10.9.

As they revisited events it became apparent how they had developed in the role. They did not come into the role with the same skill set but developed and changed as they engaged in a wide variety of settings. Participant two and six shared how they developed their communication styles for different audiences and settings. Participant four shared how he felt nervous before delivering a session but how he had gained in confidence. He shared the experience in the following way:

“So, I do think it takes a bit of courage to do what we are doing. I don’t know whether people acknowledge that” (P4)

The research identified that champions mainly sought out opportunities or were contacted directly by organisations. Participant three and nine discussed working collaboratively with charities and organisation such as the Dementia Action Alliance to promote sessions and become part of a bigger group. Champions recognised their personal motivation, commitment and how outreach was important:

“I think delivering the message is really important. I also think the fact that you are self-advertising if that makes sense of what you can do and what you are able to deliver is really important as well. There is still a big drive for you to self-motivate yourself.” (P9)

5.5.3 Workplace challenges

Being a champion meant networking and negotiating to gain access to organisations. Time and money had a big influence in reaching some businesses and organisations. Schools were identified as an area for outreach but there were limited opportunities. Three participants

outlined how some organisations were reluctant to participate.
Participant 11 shared some of the dilemmas he experienced and how he had developed a range of skills in the role and said:

“But trying to get a session even a 45-minute session when you are dealing with staff members who only get 45-minute break for lunch and then they have got to be back at their desks, hitting the phones or doing what their job is, that becomes difficult.” (P11)

This was also shared by participant six:

“And then of course it starts coming to time and money. Anyway, the upshot was they did not do it, they couldn't find the commercial reason for doing it.” (P6)

During the interviews what emerged was the range of communication skills they used and developed, the level of commitment to meet the challenges, and determination to break down the barriers that confronted them.
From the words of participant six and eleven the poem ‘Time and money’ was written:

Poem 20

Time and Money

Time is money you say
Don’t want to see
What dementia is, what dementia does

Time is money you say
Don’t want to see
What you can know
What you can do

I say- not true
Someday, some time
It could be you

Time is money well spent

5.5.4 Sustainability

Champions shared experiences from the past and present. The insights gained led them to question the sustainability of the initiative. They explored why they believed it was making a difference, getting people to talk about dementia and bringing about change. All research participants had delivered sessions to adult groups and some to youth groups. Participant, two, four and ten explored experiences of working with young people and youth groups and how they could be influential in changing attitudes, reducing stigma, and changing the dementia landscape. Participant two shared:

“I think that we should be educating children and young people about dementia so that they take that information right the way through their lives, you see.” (P2)

Participants four and ten discussed concerns and said:

“I think there is an issue around how do we keep the momentum going because dementia is flavour of the month at the moment. How do we keep that going? My worry is that if we are not careful at some point something else will take over and that sounds terribly awful...” (P4)

5.5.5 Promoting understanding and action

Universally champions shared the importance of promoting understanding and action. Their experiences led them to question understanding and action. Participant ten considered understanding to be more important than action leading to a ‘more positive relationship with people with Dementia within our communities’ This was also reiterated by participant eleven who explained:

“I would rather have the whole population understand Dementia and choose to do nothing about it than I've got seventy percent of people taking an action, but they don't really understand why they are doing it.” (P11)

Participant ten used metaphors and discussed raising awareness as ‘planting a seed’ with the aim that it would lead to growth and development. She said:

“I think it's the awareness….like a seed that kind of comes out elsewhere really and is generally I think when people come across someone with Dementia their way of understanding what that person is going through and the attitude towards them may be different.” (P10).

Reflecting on the goal of changing the way people think about dementia and the metaphor of a ‘seed’ led to writing the poem ‘The flower of understanding’.

Poem 21

The Flower of Understanding

The seed is planted

Watered with knowledge and care

Stronger than stigma

It grows bigger and brighter

No flower more beautiful

Hearing the voice of people living with dementia was identified by participant ten as needing attention and a force to bring about change. The poem ‘Side by side’ was written to reflect the collaboration:

Poem 22

Side by Side

I am

Standing with

Not standing for

Speaking up

Not speaking more

Seeing you

Not seeing past

Stepping up

For change that lasts

Asking what

I can do

Not what could be done

For you

Champions expressed determination and drive to develop communities that are informed, caring and dementia friendly and the belief that:

“Basically, people are good and if you go under that precept then we can make our society a more dementia friendly society.” (P11)

The philosophy of being a dementia friends champion was expressed by participant eleven as:

“The whole idea of a Dementia Champion giving a session is it is a human being portraying his or her concern for another human being.” (P11).

From the words of participant 11 the poem ‘Being a friend’ was written:

Poem 23

Being a Friend

Remembering you
The stranger who stops to ask
Will lighten the load

The beliefs and hope for the future were captured in the words of participant four:

“…if we are going to change the world, which I think we are intending to do aren’t we, you've got to believe it’s possible.” (P4)

‘The champion’s message’ was written to convey the belief that change, and transformation is possible captured in the words of participant four and eleven:

Poem 24

The Champion's Message

I stand here today
Delivering a message of hope
For a community that cares
That listens, that shares
Together we can change the world

Look and see
It's you, it's me
There is no shame
We are all the same
Together we can change the world

Don't turn your back on Dementia

5.6 Summary

The experiences of dementia friends champions were captured in four superordinate themes. These included being a champion, knowledge and understanding in communities, experience and insights and dementia friendly communities.

Being a volunteer champion represented passion, commitment, and a new identity.

Their motivation and the meaning of the role was influenced by the positive feedback they received, their own experiences and desire to make a difference. They worked autonomously but felt they belonged to a bigger movement. They were happy with the design and content of the sessions and developed a range of skills, insights, and understandings about dementia. There was an emotional impact and the need for resilience as they heard stories of hardship, reflected on events in their own lives, and managed situations that challenged them. Through this, some came to understand their experiences in a new way. They developed a connection with the people they met and were confronted with the fear of dementia. Some participants faced challenges in delivering the message that you can live well with dementia particularly in relation to end of life care. Champions identified positive action in communities but also encountered organisations who were reluctant to engage, due to the financial impact and the time required. They identified the need to reach younger generations to bring about change in attitudes to dementia. They were changed by the experience of being a champion and came to understand themselves, their situations, and experiences differently.

6 Discussion

6.1 Introduction

The research explored the lived experiences of dementia friends champions who are volunteers delivering information sessions to raise awareness about dementia and turn understanding into action (Alzheimer's Society, 2017d)

In this chapter I consider the research findings in the context of current thinking about champions. I incorporate how these studies illuminate and build on previous research including new topics that emerged through the interpretative analysis. New literature will be introduced here that is relevant to the discussion.

The discussion is organised under the four superordinate themes developed from the interpretative phenomenological analysis. These are being a champion, knowledge and understanding in communities, experiences and insights and dementia friendly communities.

Research poetry (found and generated) is discussed in relation to the literature and the role it played in providing an alternative form of representation to express the human experience in a creative, condensed, and meaningful way.

The strengths and limitations of the study are included.

6.2 Being a dementia friends champion

Wilcock (2006) and Hitch et al. (2014) describe being as the way we understand ourselves incorporating motivation and self-efficacy that directs action. It includes self-discovery, thinking, reflection and lived experience. These concepts were evident as participants explored what being a dementia friends champion meant to them.

6.2.1 Being a volunteer

The literature review highlighted a diversity of champion roles with many linked to paid employment in health or social care professions and settings (Brown et al., 2017; Mayrhofer et al., 2016; Miech et al., 2018). This differed from the dementia friends champions who shared the meaning associated with being a volunteer. Champions spoke passionately about the importance of volunteering and how it represented commitment to the cause which was not influenced by payment or linked to any specific profession, job title or seniority in a workplace.

This research highlighted how, for many, their motivation arose as they experienced the challenges of dementia first-hand, their desire to make a difference and to bring about change in understanding and action. Ten of the eleven champions had experienced a relative living with dementia, and one knew someone from his workplace. Scott et al. (2017) and Soderhamn et al. (2017) found the motivations and meaning of volunteering in bereavement and palliative care were influenced by personal experience and brought fulfilment, development, and connection with others. Champions in this study had not all experienced bereavement but many had witnessed change, challenges, and feelings of loss, as they encountered a deterioration in their relatives living with dementia. In line with the literature champions all expressed a sense of fulfilment from undertaking the role.

6.2.2 Skills and knowledge

The literature review identified a diverse range of training provided for champions which was often designed, organised, and delivered at a local level. Only one paper included an Alzheimer’s Society dementia friends session which had been adapted for the needs of people with a learning disability and their carers (Alzheimer’s Society, 2018). Many of the papers in the literature review outlined how the training was designed for staff who has practical experience of working with people with dementia in a health or social care setting (Banks el al., 2014; Brooke et al., 2017; Ellison et al., 2014; Wilkinson et al., 2016). This differed considerably from the dementia friends champions who were not required to be experts in the field of dementia or employed in health or social care. Dementia friends champions were delivering a structured one-hour session that had been informed and developed from the work undertaken in Japan (Hayashi, 2017).

Dementia friends champions receive a one-day training and updates from the Alzheimer’s Society. During the interviews it became apparent that they used and developed wide ranging skills and knowledge in the role. Unlike the literature review these were not just skills and knowledge linked to care but also included a range of transferable skills. Champions organised, publicised sessions, delivered sessions, managed the allocated time, and uploaded evaluations. They discussed requisite performance and presentation skills and some shared feelings of trepidation before starting a session. Champions all developed familiarity and confidence in using the resources and engaging with diverse audiences over time. Wilcock (2006) discussed the importance of personal capabilities in 'being' including underdeveloped aptitude, abilities, and traits. Self-motivation was evident as champions shared how they engaged with communities and instigated new opportunities to deliver sessions. It also became evident from their experiences that the changes went beyond the practical skills and knowledge incorporating communication skills, emotional intelligence, and resilience. Participants spoke of feeling welcomed and encouraged by feedback received from the audiences but also being confronted with different views and beliefs and limited knowledge and understanding about dementia. Champions were aware of the emotions in the groups and their own emotions. They were sensitive to how the messages might be received and considered their responses carefully.

The literature review highlighted how some champions felt empowered by the role (Wilkinson et al.,2016; Philipson et al., 2018; Bartlett, 2015) but others identified challenges due to workload, working in isolation or lack of stakeholder engagement (Ellison et al., 2014, Fossey et al., 2018; Heward et al., 2017). Dementia friends champions also described feeling empowered and able to face the challenges of time and working autonomously. Participants also faced fear, anger and distress from people attending sessions and shared the skills and strategies as well as demonstrating empathy in their responses. The ability to manage complex situations came from their personal experience of dementia, developing in the role and attributes acquired in their working lives. What emerged from this research was that the challenges experienced also came from the emotional impact of the role. Champions felt an emotional connection with the people they met and were affected by the fear of dementia and witnessing unmet need and at times distress. All the participants shared the many ways they had developed since becoming a champion.

Information about becoming a dementia friends champion did not reflect the complex nature of the role or the skills and abilities required (Alzheimer's Society, 2017d). The lived experience of being a champion was not reflected in the training they received and did not recognise the emotional impact of the role.

6.2.3 Understanding in a new way

The champions understanding of dementia was shaped by their past experiences, the content and delivery of the dementia friends sessions, the people they met and the stories they heard. Most champions developed a deeper knowledge of dementia and many gained answers or new understandings into their own experiences. For one participant it gave her new insights into her aunt's behaviour. Another champion reflected on caring for her husband in a new way. She found she could focus on their relationship and how they felt, and not what had been diminished because of dementia. New understandings and meanings that champions developed in the role differed from that found in the literature. A number of papers reviewed focussed on being a change agent and action but did not capture whether champions experienced changes in attitude, insights or understanding about dementia (Banks et al., 2014; Ellison et al., 2014; Mayrhofer et al., 2016; Wilkinson et al., 2016). Findings from the research undertaken by Wilkinson et al. (2016) showed that junior doctor's level of empathy and decision to become a dementia champion was influenced by their personal experience of a relative living with dementia. The findings also identified how junior doctors who became dementia champions developed a better understanding of their role, improved patient care, leadership, and career development. The study did not however incorporate whether they had developed a deeper understanding of their experience of a relative living with dementia.

Champions described how they had been changed and therefore understood their past experiences in a new way. Some experienced moments of regret that things could have been different but also recognised that they were less informed at the time. One participant shared how becoming a champion had enabled him to recognise his own poor attitude and behaviour and described having found ‘a better side of himself’. Being a champion was an evolving process of becoming as they experiences changes in themselves and others. (Hitch et al., 2014). Champions in this study perceived becoming a champion as an ongoing process of personal development over time.

6.3 Knowledge and understanding in communities

6.3.1 Limited knowledge in communities

As participants delivered sessions to different groups, they expressed surprise at the limited knowledge and understanding about dementia. Champions identified how the information session resources were helping people to construct new ways of understanding dementia. One participant shared how some people were going away from a session no longer believing dementia was associated with evil spirits and how another had been challenged to reconsider her view that everyone with dementia is aggressive. Another champion shared a memorable time when a person felt empowered to stand up and share her diagnosis with the group for the first time. He spoke of how this affected him, challenged his beliefs, and reinforced the view that you can live well with dementia. Gergen (2009) and Burr (2015) discuss social construction as being shaped through ongoing dialogue, social relationships, questioning and doubting what has been accepted as true. Champions were witnessing transformation through their interactions but also recognised that changing beliefs and attitudes to dementia takes time. They described the sessions as providing time and space to talk about dementia and creating opportunity to challenge previously held ideas.

6.3.2 Engaging people with dementia as champions

Meeting people living with dementia and engaging on a personal level was identified in the literature as having a major influence in changing attitudes and practice (Sheaff et al., 2018; Wilkinson et al., 2016;

Gilmour and Brannelly, 2010; Parker, 2005). The literature review also highlighted a binary perspective and division between people with and without dementia (Bosco et al., 2019; Goodley, 2017; Lester and Nusbaum, 2018; Grue, 2017). Hearing the voice of people living with dementia was also highlighted by champions in this study. Two participants reflected on how more needed to be done to hear the voice of people living with dementia in the dementia friends sessions. They also gave examples of ‘us’ and ‘them’ situations particularly when trying to access some organisations.

Bartlett (2015), Phillipson et al. (2018) and Crampton and Eley (2013) all used a variety of approaches to actively engage people living with dementia in research. They did not however identify how different needs were addressed or whether changes were made to engage those at the later stages of dementia. Chaplin et al. (2009) discuss the barriers to user involvement in mental health services which also informs engaging people living with dementia as champions. They view user involvement as an essential part of delivery and service development but also outline the importance of tailoring the provision to the needs of users.

The importance of hearing the voice of people living with dementia and seeing them as activists, change agents and influential in reducing stigma was captured by champions and evident in the literature (Andrew et al., 2019; Reynold et al.,2017; Sheaff et al., 2018, Miech et al., 2018; Bartlett, 2015; Banks et al., 2014). ADI (2020) reported that more groups of people living with dementia and carers are being established giving voice to all aspects of dementia.

Enabling people living with dementia to become champions means recognising different needs at different stages of the disease and using different approaches to engage in a meaningful way (Phillipson et al., 2018)

6.3.3 Fear and stigma

None of the champions said they were personally fearful of dementia, but they were confronted with the fear and stigma as they engaged with people in dementia friends sessions. Goffman (1963) referred to stigma as a devalued identity and Page et al. (2018) and Aihara et al. (2016) described the fear of dementia as threatening identity and sense of self and creating feelings of shame. Champions witnessed the fear of being diagnosed with dementia, fear of telling anyone, fear that they would be treated differently and fear of dependence. They also encountered carers attending sessions expressing fear for the future, fear that relatives with dementia would forget who they were and fear about managing the physical and emotional challenges. Champions reflected on how they responded to the fears and how the resources and key messages in the sessions helped them. They shared past and present situations and experienced the challenge of seeing and hearing the struggles and unmet needs of carers. The vividness and detail captured in the interviews demonstrated the emotional connection that had with the people they met.

Being confronted by fear during dementia friends sessions brought champions back to their own experiences. One champion was taken back to a time in her life when a member of her family was diagnosed with dementia. She was able to remember the fear and anxiety felt by her mother and how she felt in that situation. Other participants recognised how the fear of dementia affected carers mental health. Some participants felt that fear and stigma was a result of a lack of knowledge and providing the space to get people talking about dementia was influential in bringing about change. The idea that knowledge can reduce the fear of dementia was supported by Werner (2002) but some literature found that an increase in knowledge increased the level of concern (Hodgson and Cutler, 2004). Other research identified that knowledge of dementia was beneficial as it addressed misunderstanding and encouraged people to contact a health professional (Corner and Bond, 2004). Lack of awareness and understanding of dementia can lead to stigma and has been recognised as an ongoing issue for people living with dementia and carers (ADI, 2019; WHO, 2017). Champions recognised that a dementia friends session would not necessarily remove fear and stigma but found being better informed addressed some misunderstanding and misinformation.

Participants expressed concern for the people they met in the sessions and a sense of duty as they delivered the five key messages. There was an emotional connection and cost as they listened, acknowledged, and responded to the fears of others, and returned to their own experiences.

6.4 Experiences and insights

6.4.1 Motivations and meanings

Research undertaken by Wilkinson et al. (2016) and Mayne et al. (2014) outlined the advantages of becoming a champion linked to personal interests and the potential for career development in the medical profession. Participants in this research were not motivated by opportunities for career development or other aspirations but shared the many ways in which the role had meaning for them. One expressed guilt that her husband's dementia had given her a new and rewarding life. Others said they found answers and understood their own experiences in a new way. Another champion felt that he had become a better person and engaged with people in a different way.

They all felt they had developed in knowledge and understanding about dementia and many saw their own situations in a new light.

6.4.2 Challenges to living well with dementia: end of life care

Many of the champions discussed the conflict they felt when delivering one of the five key messages that 'It is possible live well with dementia". The statement was interpreted in the resource pack (Appendix 10.6.1, Appendix 10.6.2, Appendix 10.6.3, Appendix 10.6.5) as focussing on what the person with dementia can do. Despite the explanation they found themselves challenged when reflecting on their own experiences of caring and particularly end of life care. They also shared examples of people questioning and angered by the statement during the sessions as it did not reflect their lived experience or the hardship they faced. Participants identified different ways of managing feelings of dissonance. These included recognising different stages of dementia and that it may be possible to live well during the early stages but harder during end of life care. Others managed the conflict of delivering the message by focussing on managing well rather than living well. For others they addressed the dilemma by recognising that each person is different and that their experiences did not necessarily reflect other people's situations. Although participants found ways to come to terms with the statement it raised questions about disability and impairment. Some champions identified that even with an inclusive environment and society it was important to acknowledge the impact and difficulties faced by people living with dementia and their carers. Shakespeare et al. (2019) explored whether dementia should be considered a disability and the importance of recognising how the biological, psychological, environmental, social, and legal implications interact to produce the experience of disability. Living well with dementia and good end of life care requires planning at an early stage to continuing care after death (Bamford et al., 2018; WHO, 2017c).

Champions also returned to their experiences and questioned if they could have done better or handled situations differently when caring for a relative living with dementia. Several explained how they managed these feelings of sadness or guilt by recognising they were doing the best they could at the time.

Support available through the Alzheimer's Society did not address the emotional impact, or at times conflict that was evident from the participants' experiences or provide strategies to promote resilience.

6.5 Dementia friendly communities

6.5.1 Belonging

Participants had agency, choice and responsibility for organising and delivering sessions. They worked alone but expressed a sense of belonging to something bigger than themselves. Being known in their community was important and they saw changes taking place to promote inclusion for people living with dementia. They also recognised the needs of people with dementia and carers were far bigger than could be met through a dementia friends sessions or local initiatives.

Understanding and action

Some champions began to question combining understanding and action. One felt that raising awareness was far more important than action if people did not understand the meaning behind the action. Other champions focussed on the importance of removing ‘us and them’ attitudes and ‘otherness’ and recognising that each person is an individual with a life and a history not defined by a disease. Their beliefs, and the meanings of the messages they were delivering, resonated with the philosophy of personhood and the importance of recognition and respect for people with dementia (Kitwood, 2019; 1997; Milne, 2010). The literature review incorporated understanding and action but many of the papers were focussed on healthcare (Banks et al., 2014; Brook et al., 2017; Ellison et al., 2014). This differed from the dementia friends champions who worked with a wide range of groups and different settings (appendix 10.9).

Experiences during the sessions led champions to believe that the metaphors used (the brain as a bookcase and fairy lights as a metaphor for the brain, 10.6.4) created moments when understanding changed in the audience. One participant also shared how meaningful this had been to her as she thought about how dementia had affected her aunt. The study undertaken by Aihara et al. (2016) study looked at attitudes to dementia in Japan used a variety of approaches to change attitudes but concluded that it was not possible to know what had been the most influential. All champions experienced unmet needs and shared how they were affected and found it difficult to keep to the remit. Some went beyond the role by providing information and acting as navigators for services when experiencing the distress of people who were attending sessions and struggling to cope.

6.5.2 Sustainability

Many of the champions expressed concerns about the sustainability of the provision and the feeling that action at a local level was variable and depended on interest, costs, and benefits to organisations. Stakeholder involvement and sustainability was also highlighted as a concern in the literature and reinforced the importance of policy, government and global action plans (ADI, 2019; ADI, 2020; Heward et al., 2017).

The value of networking was expressed by participants who felt that being known in the community led to greater opportunity to deliver sessions and access organisations. Not everyone was welcoming, and they experienced challenges in gaining access to organisations affected by staff time and cost implications. Heward et al. (2017) discussed the need for strategies to maintain stakeholder involvement and identified challenges in gaining commitment from organisations. Champions were sometimes faced with having to explain to employers why it was relevant and how it could be beneficial for staff. There were also occasions where staff were instructed to attend a session and champions needed to gain their interest and participation. They gave examples of the skills they used to interact and engage different groups.

Many participants had delivered sessions to young people in addition to adult groups and noted their receptiveness. Challenges were described as balanced with uplifts for example experiencing the openness and acceptance of young people. The need to target schools, youth groups and the younger generations was highlighted in most interviews but not evident in the literature. Milne (2010) identified the need to look to future generations to find ways to reduce the stigma associated with dementia and thereby improve the lives and care of affected people and their families.

Champions all showed perseverance, determination, and resilience but a number talked about not having enough time and having to work at maintaining self-motivation. Dementia friends and the role of champions continues to be supported in policy and best practice but there is also the need for legislation and research to bring about positive change (ADI, 2019; ADI, 2020, Heward et al., 2017).

6.6 Research Poetry

Bartlett (2015) was the only one of the eighteen papers in the literature review that used arts-based approaches to communicate research findings using a range of formats such as banners, film, and an exhibition. Research poetry to express the experiences of dementia champions was not evident from the literature review.

Parsons et al. (2017) found that arts-based research, including interventions and disseminations, could engage audiences and evoke emotional reactions. I produced found poetry from the words of the participants to capture their voices, the emotion, feelings, and the meanings of their experiences. The integration of creative research approaches has been advocated to cultivate empathy and challenge audiences to engage with complex and difficult social issues (Chamberlain et al., 2018). Dementia is a complex social issue with calls for change in relation to the extra cost of providing care, training provided to staff and access to services (Alzheimer's Society, 2018a; WHO, 2017c). Bringing about change requires the dissemination of research and information in an accessible way. Langer and Furman (2004) support the effectiveness of poetry in compressing the narrative, communicating the lived experience, and disseminating research. Simile and metaphor have been identified as an effective way to capture affect, emotion and feeling that may not be so readily available through words (Willis and Cromby, 2020)

Generated poetry was produced from my insights as the researcher, with the aim of capturing the essence of the work and bringing together the perspective of the participants and the researcher.

Research poetry provided another layer to the analysis as I continually returned to the words of the participants in the recordings and transcripts to analyse and interpret the meaning of their experiences. It also served as a method of reflection and reflexivity as I considered each interview, looked across cases and explored my position as the researcher.

Researchers are recognising the benefits of creating space to incorporate academic and alternative forms of representation to capture lived experience (Segalo, 2018).

6.7 Strengths and limitations of the research

The strengths and limitations are summarised below and outlined in a table.

Strengths

No other research was identified that explored the lived experience of dementia friends champions and this highlighted a gap in knowledge. The research provided insight into what influenced their decisions to become a volunteer, their experiences, and the meaning of the role. How they were affected and changed by the experience brings new knowledge and understanding. Combining an academic and arts-based approach created greater opportunity to capture participant's voices, mood, and the emotion of their experiences. Expressing the findings in an academic and creative way also provides opportunity to disseminate to a wider audience.

Limitations

It cannot be assumed that the participant's experiences reflect those of other champions. Participants were from London, Outer London and the South East and the research captures one period. It was not possible to recruit champions who were themselves living with dementia or that fully reflect ethnic diversity. It is hoped that the knowledge and insights gained will be transferable to other settings and inform the design and development of the dementia friends provision.

Table - summary of strengths and limitations

Strengths
New knowledge No other research was identified that explored the lived experience of champions Provides a review of the available research into the experiences of dementia champions, research methods, models, and approaches Participants include women and men, some ethnic diversity, employed and retired Champions had wide ranging experience in the role and had delivered sessions in diverse settings Provides greater insight into the role of the dementia friends champions incorporating the strengths, weakness, opportunities, and threats to sustainability Informs the recruitment, design and delivery of the dementia friends information sessions and the resource pack Provides insight into action being undertaken in a range of settings and communities to promote dementia friendly communities

Identifies needs in relation to information and support available to people living with dementia and carers Captures a picture of what is happening in relation to dementia awareness at an individual and societal level
Limitations Specifically, about dementia friends champions which is an Alzheimer Society initiative Includes champions from London and the South East and may not represent the work being undertaken in other parts of the UK or internationally It was not possible to recruit champions living with dementia Captures one period Represents the views, meanings and experiences of the champions interviewed which may not represent the wider population The research participants only included two people who self-identified as “other” ethnicity.

6.8 Summary

This chapter considered the research findings in relation to the literature and highlighted new knowledge and understanding, insights and meanings from the lived experience of dementia friends champion.

Arts based approaches were discussed in relation to the literature. The use of research poetry was considered as an alternative form of representation to express the human experience and add a further layer to the analysis.

The strengths and limitations of the study were included.

The next chapter presents the main conclusions from the research and recommendations for future research.

7 Conclusions

7.1 Introduction

In this chapter, I present the main conclusions from this study, outline arising recommendations, and identify areas for future research.

The chapter incorporates my motivations in undertaking the research and the rationale for incorporating research poetry. I also include my reflections on the experience of undertaking the doctoral study.

7.2 Background

In this study I aimed to explore the lived experience of dementia friends champions. I identified the roles undertaken by champions and reviewed, discussed, and critically appraised the research. I undertook analysis and synthesis of the findings to reveal what was already understood and what remained unanswered about the experiences of dementia champions. In doing so I identified the gap in knowledge to which this study could contribute new understandings. The use of arts-based approaches and research poetry represented a novel way of looking at this area of enquiry.

7.3 Summary

7.3.1 Being a dementia friends champion

Being a volunteer

The study revealed that being a volunteer was perceived to be very important by all the participants. They articulated their commitment to making a difference to the lives of people living with dementia and those caring for loved ones in this situation. For some champion's, the role provided a new direction and identity. All talked about enjoying social interaction associated with the champion role and deriving a sense of purpose and satisfaction arising from feeling that they were making a difference. Most champions identified how their personal experiences of dementia were influential in the decision to become a champion.

Skills and knowledge

It became apparent from the findings that wide ranging skills and knowledge were required to fulfil the role of champion effectively.

Examples of necessary competences included networking purposefully, organising and delivering purposeful sessions and communicating clearly with groups in a variety of settings. Participants appeared to develop emotional intelligence as they encountered anger and distress in others and emotionally connected with their own experiences. The wide range of skills and knowledge associated with the role was not reflected in the definition of a dementia friends champion or covered in any real depth by training provided by the Alzheimer's Society.

Understanding in a new way

Participants talked about gaining a more subtle and nuanced understanding of dementia. Some said they found answers to questions that had been troubling them through their role and many felt they had gained valuable insights into their own experiences around dementia as well as those of others.

7.3.2 Knowledge and understanding in communities

Limited knowledge in communities

Through delivering sessions, champions encountered limited knowledge about dementia. Delivering the five key messages was a contested terrain for some who felt that doing so was challenging and impacted on their beliefs and conceptualisation of dementia. Participants talked in terms of constructing new understandings through exposure to experiences associated with their role.

Engaging people with dementia as champions

As they reflected on their experiences some champions identified the need to do more to capture the voice of people living with dementia with a view to bringing about change in attitudes. Some shared examples of ‘us and them’ situations and a sense of ‘otherness’ in the people they encountered. Othering related to seeing someone with dementia in a negative light. Brown et al. (2017) asks why we need dementia champions and goes on to say they will continue to be needed until people with dementia are fully accepted in society and not labelled as ‘other’. Having undertaken my study, I concur with this view. My motivation was at least in part informed by a desire to bring new understandings about dementia into the light through the novel employment of creative approaches exemplified by my use of research poetry.

Fear and stigma

None of the champions expressed a fear of dementia but witnessed this reaction in people attending sessions. As well as being of benefit to others, champions found delivering the sessions personally beneficial. They found the information and resources useful and were able to reflect upon their own experiences of dementia with the benefit of increased knowledge. These tools and reflections helped them in finding ways to respond to and manage challenging situations

Experiences and insights

Changed

As participants met people living with dementia and their carers, who were often struggling, they felt emotionally affected by these interactions. In part this was due to the realisation that the people they were working with had needs that were greater than could be met through a dementia friends session. Champions recognised the necessity for personal resilience when people in distress attended sessions. They discussed feelings of having been changed in a wide range of different ways by these interactions. These changes included revising previously held beliefs about dementia, revising previously held attitudes and finding new ways of understanding their own experiences.

Challenges to living well with dementia: End of life

Some champions were personally challenged and conflicted when delivering the message that you can live well with dementia as they reflected on their own experiences, particularly end of life care. Their encounters with attendees who shared life experiences which contradicted this message were experienced as challenging and further dissonance arose when they could also relate to these stories on a personal level. The negatives related to being expected to cope alone without adequate levels of appropriate services. This understanding resonates with social model thinking and a practical take home message is that better services are necessary to have a chance of living well with dementia particularly near the end of life.

7.3.3 Dementia friendly communities

Belonging

Perceptions shared by champions revealed them to be self-motivated and able to work relatively autonomously, within limits. They talked about feeling a sense of belonging to a bigger movement aimed at raising awareness, getting people to talk about dementia and promoting inclusion. This was something which participants valued highly for themselves and they also felt that a sense of belonging was vital to people with dementia and their carers. Living well with dementia is hard to attain within environments which lack empathic and inclusive support structures built on the idea of belonging.

Understanding and action

Champions were encouraged and motivated by positive action taking place in some communities. They also experienced reluctance to engage on the part of some organisations and were quite despondent when time and money appeared, on the surface, to be the main barriers to engagement. Some champions articulated the view that in some ways understanding was more important than action as an initial step. Intervening without understanding was felt to be a limited response unlikely to make any real sustained difference.

Sustainability

The sustainability of the provision was a concern when set against other competing health priorities. Participants, many of whom were not young themselves, talked about the need to reach the next generation. They articulated the hope that things might be better for people with dementia and their cares in the future. Unfortunately, this hope was often juxtaposed with the fear that this would not happen mainly because of socially constructed obstacles such as resource limitations and being low on a list of competing priorities.

7.3.4 Phenomenology: Interpretative Phenomenological Analysis

I concluded that my choice of a qualitative phenomenological approach was an appropriate methodology to capture lived experience. IPA provided me with the opportunity to facilitate participant’s exploration of what it meant to be a dementia friends champion. The approach provided me, as the researcher, with a lens through which to analyse and interpret the experiences and understandings of participating champions (Smith et al., 2009; Finlay, 2011; Biggerstaff and Thompson, 2008).

7.3.5 Research poetry

There is an ethical obligation to ensure research is accessible and disseminated broadly to promote social justice (Foster, 2012). Writing found and generated research poetry provided a further layer of analysis and interpretation and an alternative approach to presenting the work (Prendergast, 2016).

The research poetry book (Appendix 10.1.1) and poem cards (10.1.2) aim to capture what it meant to be a dementia friends champion and express the emotional dimension of their lived experience in a creative way (Furman, 2006). The commentary in the poetry book provides some context to each poem. Condensing information into the form of a poem aims to provide a succinct way to capture the essence of experience. The poetry book and poem cards will be freely available online or can be printed. This approach represents an original means of engaging with the area of enquiry and offers a novel means which may be useful to other researchers and practitioners.

7.3.6 Moving forward/ recommendations

This research illuminates the reality that the number of people living with dementia is increasing worldwide. The findings underpin the contention that action is needed to ensure that people affected by dementia have access to adequate support and services, which locate their views and experiences centre stage (ADI, 2019). ADI (2020) outline seven key areas including dementia awareness to promote inclusion, respect and supportive attitudes in the community, workplaces, and services and in all healthcare settings. These ideas are built on foundations of belonging rather than othering where stigma may be felt or enacted (Fletcher, 2019). The sustainability of the provision requires the ongoing commitment at a worldwide as well as local and national level action.

New knowledge and understanding about the lived experience of being a dementia friends champion, have been generated by this research. It provides insights into who is delivering dementia friends sessions and their motivations. In general terms participants were motivated, often because of personal experience of dementia in the family, to raise awareness and turn understanding into action bringing together the desire to improve services

Recommendations outlined below summarise key understandings which emerged from this work:

Continue to recruit highly motivated dementia friends champions in a voluntary capacity rather than part of paid employment.

Consider ways to enable people living with dementia at different stages of the disease to become champions or contribute to the delivery of dementia friends sessions

Incorporate in the content opportunities to discuss beliefs about dementia from different ethnic, religious, or cultural perspectives.

Review the language used in the key messages to be sensitive to the challenges of both living with and caring for someone living with dementia.

Revise the definition of dementia friends champions to accurately reflect the skills, knowledge and the personal attributes required to engage effectively.

Update the training to incorporate not only the hard skill of delivering the session but also the soft skills of managing the challenges.

Offer ongoing training, support, and supervision to address the emotional impact and demands of the role.

Develop a wider range of inclusive and culturally sensitive session designs and creative approaches

Undertake further research to capture the lived experience of champions in other parts of the United Kingdom and ensure it represents cultural and ethnic diversity.

Reiterate the aims of the Dementia Friends initiative to raise public awareness and promote positive action. It is important that the Dementia Friends one-hour session is not seen as a short cut or a cheaper alternative for more detailed training that might be provided to staff in health and social care.

7.3.7 Reflection

Motivations to undertake the research

My professional and personal experience of dementia influenced my decision to undertake the research. As an occupational therapist I saw the various challenges faced by people living with dementia and their carers. These ranged from complex needs of younger people with HIV cognitive impairment/ dementia and older adults experiencing changes due to age and dementia. I gained a personal perspective as I cared for a relative living with dementia and experienced the impact from a physical, psychological, social, and environmental viewpoint. My experiences led me to become a dementia friends champion in October 2014. Over a six-year period, I delivered sessions resulting in one thousand and sixteen people making the decision to become a dementia friend. Becoming a dementia champion regional committee member with the Alzheimer's Society in 2017 provided further opportunity to contribute to the development of the provision. During that time, I became aware of the limited research about dementia friends champions and particularly their lived experiences. This led to the decision to undertake qualitative phenomenological research to provide new knowledge and insights into their lived experiences. My motivations for this study had much in common with those of the participant champions in that I wanted to do something useful which would make a positive difference to services for people with dementia and their carers. I took this a step further and was able to add to the existing evidence base and build on understandings in creative and novel ways.

7.3.8 Reflective practice

I engaged in reflective practice throughout the undertaking of the doctoral study using a variety of models and approaches (Gibbs, 1988; Driscoll, 2007; Schon, 2016; Wareing, 2016; Zannini et al., 2011). Presenting at conferences and networking provided many opportunities to reflect on the experience of undertaking the research but this was only part of the story. I have lived with this study for three years and I am acutely aware of the personal impact of developing my understanding and deepening my engagement with an area of enquiry which has real potential to do some good in the world. One of the key purposes of a practice doctorate is to impact on practice and I am very aware that during this doctorate I have reflexively engaged with the process and constantly and self critically questioned and developed my practice accordingly.

Mapping

Throughout the research process organisational and mind maps helped me to formulate ideas and organise my thoughts (Buzan and Buzan, 2006; Whiting and Sines, 2012). They were also incorporated to capture information in a succinct way. Mind mapping is something I plan to incorporate into future research.

Kawa Model

The Kawa model (Teoh and Iwama, 2015; Iwama et al., 2009) was a useful tool to reflect on the research participant's experiences and my doctoral journey (Appendix 10.2.2; 10.2.3). I delivered poster presentations at the LSBU doctoral research conference and the staff conference in 2019 (Appendix 10.2.4). These opportunities subjected my enquiry to peer scrutiny which enabled me to develop my critical thinking.

Write a letter to yourself

Writing a letter to myself was a free form narrative approach to express thoughts, feelings, insights and understanding (Zanini, 2011). Writing, reading, and sharing with others helped to express the content, emotion and meaning of experiences. Feedback from peers, supervisors and others enabled me to pin-point key messages arising from the evidence generated by the study.

What, so what, now what

The reflective account and questioning included in Appendix 10.2.1 represents the transition from the taught phase to the research phase of the doctorate (Driscoll, 2007).

Reflecting using arts-based approaches

I used various creative tools to reflect alone and with others (Brown and Collins, 2018). This included using Lego bricks with a group of doctoral students to capture patterns or threads in the doctoral journey (Appendix 10.2.5). Many avenues opened in relation to the potential for future research.

Poetry writing

I engaged in poetry writing throughout my doctoral journey and found it particularly helpful to capture the mood, emotion and meaning of experiences (Moore, 2005).

I use the metaphor of a puzzle to make a personal statement describing my doctoral journey (Appendix 10.2.6).

During the doctorate we were often challenged to explain the whole thing in as few words as possible. The three-minute thesis competition honed my thinking in this regard. If I were asked to summarise my doctoral study in twenty words, I would say:

“Through the lens of dementia friends champions experiences, we gain insights and understanding to promote change in individuals and society.”

8 Dissemination and Impact

8.1 Introduction

This chapter outlines the process and action taken to share information and knowledge. Attention was given to different audiences and styles of dissemination throughout the undertaking of the thesis. The impact of the research is expressed in relation to education and training, knowledge and understanding, practice, and collaborations. Future plans are explained.

8.2 Dissemination

Rivas and Pandya-Wood (2014) discuss dissemination as a moral, ethical, and professional responsibility to ensure the results are relevant and to enable other researchers to build on the work. They highlight the importance of a dissemination strategy to ensure information reaches the intended audience in a meaningful way. Disseminating information demonstrates value and respect for the participants who have given up their time and shared so much of their lives and experiences in taking part in the research.

8.2.1 Research participants

A meeting was organised for research participants in December 2017 to share the research findings and obtain their feedback (Appendix 10.3.5; 10.3.6).Research updates were also provided at the Alzheimer's Society London and the South East Regional meetings and included in the minutes.

Conference presentations

Information was shared at conferences, research forums**,** networking events, committee meetings, in publications and through poetry writing. The goal was to reach as wide an audience as possible in accessible ways including researchers, champions, service users, carers, clinicians, charities, organisations, and students.

Networking at champions meetings, conferences and forums provided further opportunities to share my research and helped me to reflect on the language, content, and presentation style, to convey information and obtain feedback. Undertaking the three-minute thesis (3MT) provided valuable skills in condensing and sharing information (Appendix 10.7.1). The 3MT was recorded to share with fellow doctoral students at London South Bank University (LSBU) to encourage them to take part in the yearly events and gain from the experience. Posters and abstracts in conference handbooks enabled interested parties to get in contact and researchers to locate information.

Publications

Publications are often judged by the impact factor showing the frequency with which they have been cited in a particular year. Having a strong or marked effect can mean more than having papers published in journals with the highest impact factors. The benefits of presentations and consulting in disseminating research to ensure it reaches the intended audience and not just those in an academic arena (Ironside, 2007). Publishing a reflective piece about the experience of research poetry in Occupational Therapy News generated emails and interest in the approach (Appendix 10.8), despite not being a high impact journal (Woods, 2017).

Having poems accepted for publication in anthologies (Carers UK 2016, p77; 2018 p65) and the annual Haiku International Conference (2019, p63) reached a different audience and generated discussion and interaction with charities, poets, and carers.

8.2.2 Education

I developed a greater knowledge and understanding of research skills arts-based approaches while undertaking the doctorate and implemented these in practice. For example, through the delivery of a post graduate workshop at LSBU on creative approaches to working with older adults using poetry writing.

Engaging with academics, artists, people with dementia and carers brought new insights to presenting research findings and ways of engaging in reflective practice. For example, attending study days at the Society for Research in Higher Education (SRHE) provided space, time, and techniques to reflect using creative methods (Appendix 10.2.5). Using visual approaches, such as the doctoral journey as a river, were used during a study day at SRHE and influential in later using the Kawa model to reflect on the doctoral journey (Appendix 10.2.2; 10.2.3; 10.2.4)

Hearing about the use of installations to convey research (Brown, 2018) led to reflecting on how the writing of the thesis could be captured in an image. Attending a Dementia Engagement and Empowerment Project (DEEP) meeting was an opportunity to hear from people with dementia, carers, researchers, and artists. They shared how they were using arts-based approaches to capture lived experience and provided examples of ‘chap books’ they produced (British Library, 2014). The chapbooks included poems, photographs, storytelling, and reflections representing a collaboration between people with dementia, carers, researchers, and artists. Insights gained from attending the meeting were influential in the design of the research poetry book (Appendix 10.1.1) and poem cards (10.1.2).

I have taken every opportunity to disseminate information about the research, to share the skills and knowledge gained, and to mentor, support and develop others.

8.3 Impact

8.3.1 Alzheimer’s Society education and development

The findings and recommendations from the research into the lived experiences of dementia friends champions will be shared with participants who engaged in the research and presented to the Alzheimer’s Society UK. All participants who engaged in the research and the regional officer will receive a poetry book and set of poem cards upon completion. Research papers will be submitted to peer reviewed journals following the completion of the research.

8.3.2 Knowledge understanding and action

The research brings new knowledge from the lived experiences of dementia friends champions to shape the future provision and captures how research can be presented in academic and arts-based ways.

8.3.3 Collaborative poetics

The collaborations that took places as a result of engaging in research poetry led to the creation of the collaborative poetics toolkit, the collaborative poetics website, the first collaborative poetics conference and the subsequent paper about the event (Fennessy et al., 2019).

8.3.4 Education provision

The knowledge, skills, and insights I gained from undertaking the research were shared with students undertaking undergraduate and post graduate studies (Appendix 10.1.3). These included teaching qualitative research methods to postgraduate students and undertaking the role of dissertation supervisor. Other developments included providing taught sessions to students on a post graduate multidisciplinary module entitled 'Best Practice in Dementia Care' at LSBU.

As a result of undertaking the research and dissemination I was contacted by Skills for Health and reviewed the development of the Skills for Health online Dementia site.

Through engaging with researchers, artists, people with dementia and carers I created and designed a new post graduate study day entitled 'Creative approaches to dementia care'.

Networking and collaborations also led to my securing funding for theatre productions for students and staff at LSBU. The included 'Grandma remember me' and 'What do you see' by the theatre company Az2B https://az2btheatre.com/

Other developments have included my work with the School of Engineering at LSBU to teach and support the development of the module 'Designing for Dementia' and undertaking the role of module coordinator for the VLE Dementia Moodle site. This has included keeping the site up to date, engaging with staff and students, sending announcements and alerts about recent developments, publications, arts-based information, and conferences

In addition to the thesis, two other research projects were undertaken with fellow researchers and an expert by experience. The research into students understanding following a Dementia Friends session was undertaken (Baillie et al., 2015) and mixed method research into whether Occupational Therapy students had turned their understanding into action following a dementia friends session is being written up for publication. The research included co- production with an expert by experience at every stage following funding approval.

8.4 Summary

This research brings new knowledge about the lived experience of dementia friends champions to inform the existing and future provision of the service.

The findings and recommendations from the research will be shared widely through academic publication, the free distribution of the online poetry book (Appendix 10.1.1) and poem cards (10.1.2), conferences, forums, and ongoing collaborative working. The aim is to also encourage others to incorporate arts-based approaches into research and scholarly activity. Bringing together experts by experience, carers, academics, and artists provides the greatest opportunity to develop new and innovative ways to shape the future for people living with dementia.

9 References

Aihara, Y. Kato, H. Sugiyama, T. Ishi, K. and Goto, Y. (2016) Public attitudes towards people living with dementia: A cross- sectional study in urban Japan (innovative practice), *Dementia*, 0 (0), 1-9 DOI: 10.1177/1471301216682118

Alden, S. Wigfield, A.D. Kispeter, E. Karania, V. (2019) Changing the narrative: The role of frontline worker attitudes and beliefs in shaping dementia friendly services in England, *Disability & Society*. ISSN 0968-7599

Aldridge, H. Fisher, P. and Laidlaw, K. (2017) Experience of shame for people with dementia: An interpretative phenomenological analysis, *Dementia*, 0 (0), 1-6

https://0-doi-org.lispac.lsbu.ac.uk/10.1177/1471301217732430

All Party Parliamentary Group on Dementia (2011) *The £20 billion question: An inquiry into improving lives through cost-effective dementia services*. Version 1.05, London: Alzheimer's Society. https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/the20_billion_question_an_inquiry_into_improving_lives_through_cost_effective_dementia_services_from_the_all party_parliamentary_group_on_dementia.pdf

Alzheimer's Disease International (2019) *World Alzheimer Report 2019 Survey: Your attitudes around Dementia.* https://www.alz.co.uk/research/world-report-2019 last accessed 12/07/19

Alzheimer's Disease International (2019a) *From plan to impact 11*, London: ADI https://www.alz.co.uk/adi/pdf/from-plan-to-impact-2019.pdf last accessed 13/07/19

Alzheimer's Disease International (2017). *Dementia friendly communities global developments*. 2nd ed. ADI: London. https://www.alz.co.uk/adi/pdf/dfc-developments.pdf last accessed 12/07/19

Alzheimer's Disease International (2015) *World Alzheimer Report 2015, The global impact of Dementia An analysis of prevalence, Incidence, cost and trends: Executive summary*. London: ADI https://www.alz.co.uk/research/worldalzheimerreport2015summary.pdf last accessed 12/07/19

Alzheimer's Research UK (2019e) *Dementia Attitudes Monitor: Wave 1* (2018) https://www.alzheimersresearchuk.org/about-us/our-influence/policy-work/reports/dementia-attitudes-monitor-wave-1-2018/ last accessed 12/07/19

Alzheimer’s Research UK (2018) *Dementia Statistics* https://www.dementiastatistics.org/statistics/global-prevalence/ last accessed 12/07/19

Alzheimer’s Society (2019) *About us/ who we are.* https://www.alzheimers.org.uk/about-us/who-we-are last accessed 12/07/19

Alzheimer’s Society (2019a) *Types of dementia.*

https://www.alzheimersresearchuk.org/about-dementia/types-of-dementia/ last accessed 12/07/19

Alzheimer’s Society (2018) *Learning disability and dementia project evaluation.* UK: Alzheimer’s Society. https://www.alzheimers.org.uk/sites/default/files/2018-08/Learning%20disability%20and%20dementia%20final%20evaluation_2018_07.pdf last accessed 13/07/19

Alzheimer’s Society (2018a) *Dementia- the true cost: Fixing the care crisis.* London: Alzheimer’s Society https://www.alzheimers.org.uk/sites/default/files/201805/Dementia%20the%20true%20cost%20-%20Alzheimers%20Society%20report.pdf

Alzheimer’s Society (2018c). *The dementia statements*. London: Alzheimer’s Society https://www.alzheimers.org.uk/about-us/policy-and-influencing/what-we-think/dementia-statements-and-rights

Last accessed 13/07/19

Alzheimer’s Society (2018d) *Positive language: An Alzheimer’s Society guide to talking about dementia*. London: Alzheimer’s Society. Publication code: PLExt https://www.alzheimers.org.uk/sites/default/files/2018-09/Positive%20language%20guide_0.pdf

Alzheimer’s Society (2017) *Dementia Friends.*

https://www.dementiafriends.org.uk/ last accessed 12/07/19

Alzheimer’s Society (2017d) *What is a champion?*

https://www.dementiafriends.org.uk/WEBArticle?page=what-is-a-champion#.XShcuP57nIU last accessed 12/07/19

Alzheimer’s Society (2017f) *New deal on dementia.*

https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/alzheimers_society_2017-2022_the_new_deal_on_dementia.pdf last accessed 12/07/19

Aveyard, H. Pyne, S. and Preston, N. (2016) *A post-graduates guide to doing a literature review*. England: Open University Press

Baillie, L. Beecraft, S. Woods, S. (2015) Dementia Friends sessions for nursing students, *Nursing Older People*, 27(9), 34-38. DOI:10.7748/nop.27.9.34.s20

Baldwin, C. and Capstick, A. (eds) (2007) *Tom Kitwood on dementia*. Berkshire: Open University Press.

Bamford, C. Lee, R. McLellan, E. Poole, M. Harrison- Denning, K. Hughes, J. Robinson, L. and Exley, C. (2018) What enables good end of life care for people with dementia? A multi-method qualitative study with key stakeholders, *BMC Geriatrics*, 18 (302), 1-15 https://doi.org/10.1186/s12877-018-0983-0

Banks, P. Waugh, A. Henderson, J. Sharp, Brown, M. Oliver, J. and Marland, G. (2014) Enriching the care of patients with dementia in acute hospital settings. The Dementia Champions programme in Scotland, *Dementia*, 13 (6), 717-736 DOI: 10.1177/1471301213485084

Barnes, C. and Mercer, G. (eds) (2004) *Implementing the social model of disability: Theory and research*. Leeds: The Disability Press

Barnett- Page, E. and Thomas, J. (2009) *Methods for the synthesis of qualitative research: a critical review*. London: ESRC http://eprints.ncrm.ac.uk/690/1/0109%2520Qualitative%2520synthesis%2520methods%2520paper%2520NCRM.pdf

Barone, T. and Eisner, E. W. (2012) *Arts based research*. London: Sage

Bartlett, R. (2014) Citizenship in action: the lived experiences of citizens with dementia who campaign for social change, *Disability and Society*, 29 (8), 1291-1304 DOI:10.1080/09687599.2014.924905

Bartlett, R. (2015) Visualising dementia activism: using the arts to communicate research findings, *Qualitative Research*, 15 (6), 755-768 https://doi.org/10.1177/1468794114567493

Beard, R. L. Knauss, J. and Moyer, D. (2009) Managing disability and enjoying life: How to reframe dementia through personal narratives, *Journal of Ageing Studies*, 23 (4), 227-235 https://doi.org/10.1016/j.jaging.2008.01.002

Berry, P. Davies, T. Fordyce, C. Gordon, H. Hare, P. Houston, A. Litherland, R. McLintock, M. Mitchell, W. Shorthouse, T. (2020) Dementia Enquirers – People with dementia in the driving seat of research, *Dementia*, 19(1) 68–73 DOI: 10.1177/1471301219876506

Bettany- Saltikov, J. (2012) *How to do a systematic literature review in nursing*, London: Open University Press.

Bettany- Saltikov, J. and McSherry, R. (2016) *How to do a systematic literature review in nursing*. 2nd ed. London: Open University Press.

Bhattacharya, K. (2018) *Designing an arts- based qualitative research study*, London: Sage https://methods.sagepub.com/video/designing-an-arts-based-qualitative-research-study last accessed 12/07/19

Biggerstaff, D. and Thompson, A. R. (2008) Interpretative phenomenological analysis (IPA): A qualitative methodology of choice in healthcare research, *Qualitative Research in Psychology*, 5 (3), 214-224 DOI: 10.1080/14780880802314304

Bolton, G. (2010) *Reflective practice: Writing and professional development*. 3rd ed. London: Sage

Bond, J. Peace, S. Dittmann- Kohli, F. and Westerhof, G. (2007) (eds) *Ageing in Society*. 3rd ed. London: Sage Publications

Booth, A. Papaioannou, D. Sutton, A. (2012) *Systematic approaches to a successful literature review*. London: Sage

Bosco, A. Schneider, J. Coleston- Shields, D.M. Higgs, P. Orrell, M. (2019) The social construction of dementia: Systematic review and metacognitive model of enculturation, *Maturitas*, 120, 12-22 DOI: 10.1016/j.maturitas.2018.11.009

Boyle, G. (2014) Recognising the agency of people with dementia, *Disability and Society*, 29 (7), 1130-1144 DOI: 10.1080/09687599.2014.910108

Braun, V. and Clarke, V. (2013) *Successful qualitative research: a practical guide for beginners*. London: Sage Publications Ltd

Brett, S. (2016) Future selves: Listening carefully to the voice of a Key Stage 5 pupil in a special school, in: Milton, D. and Martin, M. (eds) *Autism and Intellectual Disability in Adults*. Hove: Pavilion Publishing and Media Ltd, 1, 55-59

Breheny, M. (2012) “We’ve had our lives, we’ve had our lives”: a poetic representation of ageing, *Creative Approaches to Research*, 5 (2), 156-170

Brinkmann, S. and Kvale, S. (2015) *Interviews: Learning the craft of qualitative research interviewing*. 3rd ed. London: Sage

British Library (2014) Chapbooks.

https://www.bl.uk/romantics-and-victorians/articles/chapbooks last accessed 12/07/19

British Medical Journal (2016) *Qualitative research and the BMJ*, 352, j641, 1-2, doi: https://doi.org/10.1136/bmj.i641

Brooke, J. and Semlyen, J. (2017) Exploring the impact of dementia-friendly ward environments on the provision of care: A qualitative thematic analysis, *Dementia*, 18 (2), 685-700 DOI: 10.1177/1471301216689402

Brown, M. Waugh, A. Sharp, B. Duffy, R. F. J. and MacRae, R. (2017) What are dementia champions and why do we need them?,, *Dementia*, 0 (0), 1-4 https://doi.org/10.1177/1471301217743413

Brown, N. (2018) Exploring the lived experience of fibromyalgia using creative data collection methods, *Cogent Social Sciences*, 4, 1447759

https://doi.org/10.1080/23311886.2018.1447759

Brown, N. and Collins, J. (2018) Using Lego to understand emotion work in doctoral education, *International Journal of Management and Applied Research*, 5(4), 193-209 https://doi.org/10.18646/2056.54.18-014

Bryman, A. (2012) *Social Research Methods*. 4th ed. Oxford: Oxford University Press

Buckner, S. Mattocks, C. Rimmer, M, and Lafortune, L. (2018) An evaluation tool for Age-Friendly and Dementia Friendly Communities, *Working with Older People*, 22 (1),48-58 DOI: 10.1108/WWOP-11-2017-0032

Bulpit, H. and Martin, P.J. (2010) Who am I and what am I doing? Becoming a qualitative research interviewer, *Nurse Researcher*, 17 (3), 7-16 URI: http://eprints.soton.ac.uk/id/eprint/80136

Burgener, S. C. Buckwalter, K. Perkhounkova, Y. Liu, M.F. Riley, R. Einhorn, C. J. Fitzsimmons, S. Hahn-Swanson, C. (2015) Perceived stigma in persons with early stage dementia: Longitudinal findings: Part 1, *Dementia*, 14 (5) 589-608 https://doi.org/10.1177/1471301213508399

Burke, C. and Charlesworth, P. (2018) *Need 2 know: Hidden in plain sight- dementia and learning disability*, London: Foundation for People with Learning Disabilities

Burr, V. (2015) *Social Constructionism*. 3rd ed. Hove; East Sussex: Routledge

British Haiku Society (2019) *Where silence becomes song*. P63. Essex: The British Haiku Society

Butler- Kisber, L. (2010) *Qualitative Inquiry: Thematic, narrative and arts- informed perspectives*. London: Sage Publications

Buzan, T. and Buzan, B. (2006) *The mind map book*. 3rd ed. Harlow: BBC Active Publications

Campbell, M. Srinivasa, V. K. Sowden, A. McKenzie, J. E. Thomson, H. (2018) Improving conduct and reporting of narrative synthesis of quantitative data (ICONS-Quant): protocol for a mixed methods study to develop a reporting guideline. *BMJ Open*; 8:e020064. doi:10.1136/bmjopen-2017-020064

Carers UK (2018) *Keep well, keep connected: An anthology of poems* and stories. Vol.5. p65. Wellingborough: Carers UK

Carers UK (2016) *I belong here: An anthology of poems and stories*. Vol. 3. P77.Wellingborough: Carers UK

Cavalli- Sforza, L. L. Feldman, M. W. Chen, K. H. Dornbusch, S. M. (1982) Theory and observation in cultural transmission, *Science*, 218 (4567), 19-27 DOI: 10.1126/science.7123211

Chadwick, R. (2017) Embodied methodologies: challenges, reflections and strategies, *Qualitative Research*, 17 (1), 54-74 https://doi.org/10.1177/1468794116656035

Chalk, A. and Page, S. (2014) Dementia RED (Respect, Empathy, Dignity): Collaborating to build dementia supportive communities in North Wales- reporting on a pilot project (innovative practice), *Dementia*, 0 (0) 1-6 DOI: 10.1177/1471301214563203

Chamberlain, K. McGuigan, K. Antiss, D. and Marshall, K. (2018) A change of view: arts-based research and psychology, *Qualitative Research in Psychology*, 15 (2-3), 131-139. https://doi.org/10.1080/14780887.2018.1456590

Chaplin, E. Halls, S. Carlile, G. Hardy, S. and Joyce, T. (2009) Barriers to user involvement in mental health services for people with learning disability, *Advances in Mental Health and Learning Disabilities*, 3 (2), 28- 33 https://doi.org/10.1108/17530180200900028

Cipriani, G. and Borin, G. (2014) Understanding in the sociocultural context: A review, International Journal of Social Psychiatry, 1-7, DOI:10.1177/0020764014560357

Converse, M. (2012) Philosophy of phenomenology: how understanding aids research, *Nurse Researcher*, 20 (1), 28-32 DOI: 10.7748/nr2012.09.20.1.28.c9305

Crampton, J. and Eley, R. (2013) dementia- friendly communities: what the project" creating a dementia friendly York" can tell us, *Working with Older People*, 17 (2), 49-57 doi:10.1108/13663661311325463

Dementia Engagement and Empowerment Project (2014) *Dementia words matter: Guidelines on language about dementia.* http://dementiavoices.org.uk/wp-content/uploads/2015/03/DEEP-Guide-Language.pdf

Department of Health (2015) Prime Ministers Challenge on Dementia 2020https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/414344/pm-dementia2020.pdf

last accessed 12/07/19

Department of Health (2012) *Prime Ministers Challenge on Dementia.* London: DoH https://www.gov.uk/government/news/prime-minister-s-challenge-on-dementia last accessed 12/07/19

Department of Health (2009) Living Well with Dementia: A national dementia strategy. https://www.gov.uk/government/publications/living-well-with-dementia-a-national-dementia-strategy

Last accessed 12/07/19

Dewey, J. (1997) *How we think*. Mineola; NY: Dover Publications

Dewsbury, G. Clarke, K. Randall, D. Rouncefield, M. and Sommerville, I. (2004) The anti-social model of disability, *Disability and Society*, 19 (2), pp. 145-148 DOI:10.1080/0968759042000181776

Dowling, M. (2007) From Husserl to van Manen: A review of different phenomenological approaches, *International Journal of Nursing Studies,* 44(1):131-42. DOI:10.1016/j.ijnurstu.2005.11.026

Drach, G. W. (2017) Improving Specialty Care of Older Adults: Creating Champions, Supporting Research, Fostering Partnerships, *Journal of the American Geriatrics Society,* 65 (10), 2151- 2152 https://doi.org/10.1111/jgs.14975

Driscoll, J. (2007) *Practising clinical supervision: A reflective approach for healthcare professionals.* 2nd ed. Edinburgh: Bailliere Tindall

Ebert, A. R. Kulibert, D. and McFadden, S. H. (2019) Effects of dementia knowledge and dementia fear on comfort with people with dementia: Implications for dementia friendly communities, *Dementia* 0(0), 1-13 DOI: 10.1177/1471301219827708

Eisner, E. W. (1997) The promise and perils of alternative forms of data representation, *Educational Researcher*, 26 (4) 4-9. https://doi.org/10.3102/0013189X026006004

Ellison, S. Watt, G. and Christie, I. (2014) *Evaluating the impact of the Alzheimer's Scotland dementia nurse consultants/ specialists and dementia champions in bringing about improvements in dementia care in acute general hospital*. Edinburgh: Blake Stevenson https://www.nes.scot.nhs.uk/media/2711493/impact_evaluation_-_final_report.pdf

Engel, G. L. (1977) The need for a new medical model: a challenge for biomedicine, *Science*, 196 (4286), 129-136 DOI: 10.1126/science.847460

Equality Act (2010) https://www.legislation.gov.uk/ukpga/2010/15/contents last accessed 12/07/19

Faulkner, S. L. (2016) *Poetry as method: Reporting research through verse.* 2nd ed. Abingdon; Oxon: Routledge

Faulkner, S. L. (2009) *Poetry as method: Reporting research through verse.* Walnut Creek; CA: Left Coast Press Inc.

Faulkner, S. L. (2007) Concern with craft: Using arts poetics as criteria for reading research poetry, *Qualitative Inquiry*, 13 (2), 218-234 https://doi.org/10.1177/1077800406295636

Fennessy, J. Woods, S. Johnson, H. Rivas, C. Norbury, D. Almeida-Harvey, I. Moriarty, J. Wimpenny, K. Bushell, K. and Blake, P. (2019). Conference Report: Carnival of Invention, *Forum: Qualitative Social Research*, 20 (2), Art. 3, http://dx.doi.org/10.17169/fqs-19.2.3260

Ferguson, P. M. and Nusbaum, E. (2012) Disability studies: What is it and what difference does it make? *Research and Practice for Persons with Severe Disabilities*, 37 (2), 70-80 https://doi.org/10.1177/154079691203700202

Fink, A. (2019) *Conducting research literature reviews: From the internet to paper*. 5th ed. London: Sage

Finlay, L. (2014) Engaging phenomenological analysis, *Qualitative Research in Psychology*, 11 (2), 121-141 https://doi.org/10.1080/14780887.2013.807899

Finlay, L. (2011) *Phenomenology for therapists: Researching the lived world.* West Sussex: Wiley Blackwell

Fletcher, J. R. (2019) Destigmatising dementia: The dangers of felt stigma and benevolent othering, *Dementia*, 0(0) 1–10 https://doi.org/10.1177/1471301219884821

Fossey, J. Garrod, L. Guzman, A. and Testad, I. (2018) A qualitative analysis of trainer/ coach experiences of changing home practice in the Well- being and health in Dementia randomised control trial, *Dementia*, 0 (0) , 1-6 DOI: 10.1177/1471301218772178

Foster, V (2012) What if? The use of poetry to promote social justice, *Social Work Education*, 31 (6), 742-755 https://doi.org/10.1080/02615479.2012.695936

Furman, R. (2006) Poetic forms and structures in Qualitative Health Research, *Qualitative Health Research*, 16 (4), 560-566 https://doi.org/10.1177/1049732306286819

Furman, R. Enterline, M. Thompson, R. and Shukraft, A. (2012) Poetry matters, A case poetry in social work, *Journal of Social Intervention: Theory and Practice,* 21 (1), 5-17 DOI: http://doi.org/10.18352/jsi.283

Gabel, S. and Peters, S. (2004) Presage of a paradigm shift? Beyond the social model of disability toward resistance theories of disability, *Disability and Society*, 19 (6), 585-600 DOI:10.1080/0968759042000252515

Gaudet, S. and Robert, D. (2018) *A journey through qualitative research. From design to reporting*. London: Sage

GBD 2016 Dementia Collaborators (2019) Global, regional, and national burden of Alzheimer's disease and other dementia 1990-2016: a systematic analysis for the global burden of disease study 2016, *The Lancet Neurology*, 18 (1), 88-106 https://www.thelancet.com/action/showPdf?pii=S1474-4422%2818%2930403-4

DOI:https://doi.org/10.1016/S1474-4422(18)30403-4

Gergen, K. J. (2009) *An invitation to social construction*. 2nd ed. London: Sage

Gerritsen, D. L. Oyebode, J. and Gove, D. (2018) Ethical implications of the perceptions and portrayal of dementia, *Dementia*, 17 (5), 596-608 DOI: 10.1177/1471301216654036

Gibbs, G. (1988) *Learning by doing: A guide to teaching and learning methods*. Further Education Unit. Oxford: Oxford Brookes University.

Gill, M. J. (2014) The possibilities of phenomenology for organizational research, *Organizational Research Methods*, 17 (2), 118-137 https://doi.org/10.1177/1094428113518348

Gilliard, J. Means, R. Beattie, A. and Daker- White, G. (2005) Dementia care in England and the social model of disability: lessons and issues, *Dementia*, 4 (4), 571-586 https://doi.org/10.1177/1471301205058312

Gilmour, J. A. and Brannelly, T. (2010) Representations of people with dementia- subaltern, person, citizen, *Nursing Inquiry*, 17 (3) 240-247 https://doi.org/10.1111/j.1440-1800.2009.00475.x

Goffman, E. (1963). *Stigma; notes on the management of spoiled identity*. Englewood Cliffs; N.J.: Prentice-Hall.

Goldblatt, Patricia (2006) "How John Dewey's Theories Underpin Art and Art Education," *Education and Culture*, 22 (1), Article 4. https://docs.lib.purdue.edu/eandc/vol22/iss1/art4

Goodley, D. (2017) *Disability Studies: An interdisciplinary introduction*. 2nd ed. London: Sage

Gove, D. Downs, M. Vernooij- Dassen, M. Small, N. (2016) Stigma and GPs' perceptions of dementia, *Ageing and Mental Health*, 20 (4) 391-400. doi: 10.1080/13607863.2015.1015962.

Gov.UK (2019) *The Dementia 2020 Challenge: 2018 Review Phase 1*

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/780777/dementia-2020-challenge-2018-review.pdf last accessed 12/07/19

Gov.UK (2016) *Prime ministers challenge on dementia: Implementation plan.*https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/507981/PM_Dementia-main_acc.pdf last accessed 12/07/19

Gov. UK (2015) *Prime Minister's challenge on dementia 2020*: *Policy Paper. https://www.gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020/prime-ministers-challenge-on-dementia-2020* Last accessed 12/07/19

Gov. UK (2012*) Prime Minister's challenge on dementia 2020*. https://www.gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020/prime-ministers-challenge-on-dementia-2020

Last accessed 12/07/19

Greenwood, N. Mezey, G. and Smith, R. (2018) Social exclusion in adult informal carers: A systematic narrative review of the experiences of informal carers of people with dementia and mental illness, *Maturitus*, 112, 39-45 DOI:10.1016/j.maturitas.2018.03.011

Grønmo, S. (2020) *Social Research Methods: Qualitative, quantitative and mixed methods approaches*. London: Sage

Grossoehme, D. H. (2014) Research methodology: Overview of qualitative research, *Journal of Health Care Chaplaincy*, 20 (3), 109-122 DOI: 10.1080/08854726.2014.925660

Grue, J. (2017) Now you see it, now you don't: A discourse view of disability and multidisciplinarity, *ALTER, European Journal of Disability Research*, 11 (3), 168-178 https://doi.org/10.1016/j.alter.2017.05.002

Haegele, J. A. and Hodge, S. (2016) Disability discourse: overview and critiques of the medical and social models, *QUEST*, 68 (2), 193-206 DOI: 10.1080/00336297.2016.1143849

Havelka, M. Lucanin, J. D. Lucanin, D. (2009) Biopsychosocial Model- the integrated approach to health and disease, *Collegium Antrpologicum*, 33 (1), 303-310

Hampson, C. and Morris, K. (2017) Dementia: Normal ageing, political cause or social construction? *OAJ Gerontology and Geriatric Medicine*. 1 (4), 001-004

Hart, C. (1998) *Doing a literature review: Releasing the social science research imagination*. London: Sage

Hayashi, M. (2017) The dementia friends initiative- supporting people with dementia and their carers: reflections from Japan, I*nternational Journal of Care and Caring*, 1 (2), 281-287 https://doi.org/10.1332/239788217X14951898377524

Hayes, C. and Fulton, J. (2014) Framing interpretative phenomenological approaches to educational research, Innovations, *British Journal of Mental Health Nursing*, 3 (2), 76-79

Heidegger, M. (2010) *Being and time*. New York: Harper and Row

Herrmann, L. K. Welter, E. Leverenz, J. Lerner, A.J. Udelson, N. Kanetsky, C. Sajatovic, M. (2018) A Systematic Review of Dementia-related Stigma Research: Can We Move the Stigma Dial? *The American Journal of Geriatric Psychiatry* https://doi.org/10.1016/j.jagp.2017.09.006

Heward, M. Innes, A. Cutler, C. Hambridge, S. (2017) Dementia-friendly communities: challenges and strategies for achieving stakeholder involvement, *Health and Social Care in the Community*, 25 (3), 858-867 https://doi.org/10.1111/hsc.12371

Hitch, D. Pépin, G. and Stagnitti, K. (2014) In the footsteps of Wilcock, part 1: The evolving of doing, being, becoming and belonging, *Occupational Therapy in Healthcare*, 28 (3), 231-246 DOI:10.3109/07380577.2014.898114

Horrigan- Kelly, M. Millar, M. and Dowling, M. (2016) Understanding the key tenets of Heidegger's philosophy for interpretive phenomenological research*, International Journal of Qualitative Methods,* 1-8 *https://doi.org/10.1177/1609406916680634*

Howitt, D. and Cramer, D. (2014) *Introduction to research methods in psychology*. 4th ed. London: Pearson

Howitt, D. and Cramer, D. (2017) *Research methods in psychology*. 5th ed. London: Pearson

Hughes, B. (2009) Disability Activisms; social model stalwarts and biological citizens, *Disability and Society*, 26 (6), 677-688 https://www.researchgate.net/deref/http%3A%2F%2Fdx.doi.org%2F10.1080%2F09687590903160118

Johnson, H. Carson-Apstein, E. Banderob, S. and Macualay-Rettino, X. (2017). 'You Kind of Have to Listen to Me': Researching Discrimination through Poetry. *Forum Qualitative Social Research*, 18 (2). Doi: http://dx.doi.org/10.17169/fqs-18.3.2864.

Koelsch, L. E. (2016) The use of I poems to better understand complex subjectivities, In: Galvin, K. T. and Prendergast, M. (Eds) *Poetic inquiry 11- seeing, caring, understanding: Using poetry as and for inquiry*. Rotterdam; The Netherlands: Sense Publishers

Langer, C. L. and Furman, R. (2004) Exploring identity and assimilation: Research and interpretive poems, *Forum Qualitative Social Research*, last accessed 5 (2), Art 5, ISSN 1438 5627 file:///C:/Users/User/AppData/Local/Temp/609-1978-2-PB.pdf 12/07/19

Larkin, M. Eatough, V. and Osborn, M. (2011) Interpretative phenomenological analysis and embodied, active, situated cognition, *Theory and Psychology*, 21 (3), 318- 337 https://doi.org/10.1177%2F0959354310377544

Iliffe, S. and Manthorpe, J. (2017) Dementia: Is the biopsychosocial model vindicated, *British Journal of General Practice*, 67 (661), 344-345 DOI: https://doi.org/10.3399/bjgp17X691781

Inclusion London (2015) The social model of disability factsheet. https://www.inclusionlondon.org.uk/wp-content/uploads/2015/05/FactSheets_TheSocialModel_Easy-Read.pdf last accessed 04/01/19

Innes, A. Manthorpe, J. (2012) Developing theoretical understandings of dementia and their application to dementia care policy in the UK, *Dementia*, 12 (6), 682-696 DOI: 10.1177/1471301212442583

Iwama, M. K. Thomson, N. A. Macdonald, R. M. (2009) The Kawa model: The power of culturally responsive occupational therapy, *Disability and Rehabilitation*, 31 (14), 1125-1135 https://doi.org/10.1080/09638280902773711

Johnson, H. (2019) The Collaborative Poetics project: developing methodological resources for collaborative arts-based research, *National Centre for Research Methods* https://www.ncrm.ac.uk/news/show.php?article=5562

Kitwood, T. (1997) *Dementia reconsidered: The person comes first.* Buckingham: Open University Press:

Kitwood, T. (2019) *Dementia reconsidered, revisited: The person still comes first*. 2nd ed. London: Open University Press

Kravitz, M. S. Schmeidler, J. Schnaider, M. (2012) Cognitive decline and dementia in the oldest-old, *Rambam Maimonides Medical Journal*, 3 (4), 1-15 file:///C:/Users/User/Downloads/rmmj-3-4-e0026.pdf

Lahman, M.K.E. and Richard, V. M. (2014) Appropriated poetry: Archival poetry in research, *Qualitative Inquiry*, 20 (3), 344-355 https://doi.org/10.1177%2F1077800413489272

Lahman, M. K. E. Rodriguez, K. L. Richard, V. M. Geist, M. R. Schendel, R. K. and Graglia, P. E. (2011) Forming research poetry, *Qualitative Inquiry*, 17 (9), 887-896 https://doi.org/10.1177%2F1077800411423219

Lane, H.P., McLachlan, S., & Philip, J. (2013). The war against dementia: are we battle weary yet? *Age and Ageing*, 42 (3), 281-283 https://doi.org/10.1093/ageing/aft011

Langdridge, D. (2007) *Phenomenological psychology: Theory, research and method*. Harlow; Essex: Pearson

Lapum, L. Liu, L. Church, K. Yau, T. M. Ruttonsha, P. Matthews David, A. and Retta, B. (2014) Arts- informed research dissemination in the health sciences: An evaluation of peoples responses to “The 7,024th patient” art installation, *Sage Open*, 1-14 https://doi.org/10.1177/2158244014524211

Launer, J. (2018) *Narrative based practice in health and social care*. 2nd ed. Abingdon; Oxon: Routledge

Lautarescu, B. A. Holland, A. J. and Zaman, S. H, (2017) The Early Presentation of Dementia in People with Down Syndrome: a Systematic Review of Longitudinal Studies, *Neuropsychological Review*, 27 (1), 31–45 https://dx.doi.org/10.1007%2Fs11065-017-9341-9

Leggo, C. (2005) The heart of pedagogy: On poetic knowing and living, *Teachers and Teaching*, 11 (5), 439-445 https://doi.org/10.1080/13450600500238436

Lester, J. N. and Nusbaum, E. A. (2018) “Reclaiming” disability in qualitative research: Introduction to the special issue, *Qualitative Inquiry*, 24 (1) 3-7 https://doi.org/10.1177%2F1077800417727761

Levitt, J. M. (2017) Exploring how the social model of disability can be re-invigorated: in response to Mike Oliver, *Disability and Society*, 32 (4), 589-594 DOI:10.1080/09687599.2017.1300390

Lin, S. Y. and Lewis, F.M. (2015) Dementia friendly, dementia capable and dementia positive: concepts to prepare for the future, *The Gerontologist*, 55 (2), 237-244 https://dx.doi.org/10.1093%2Fgeront%2Fgnu122

Lucas, P.J. Baird, J. Arai, L. Law C. Roberts H. M. (2007) Worked examples of alternative methods for the synthesis of qualitative and quantitative research in systematic reviews. *BMC Medical Research Methodology,* 7(4) 1-7 doi:10.1186/1471-2288-7-4

Mantovani, N. Pizzolati, M. Gillard, S. (2017) Engaging communities to improve mental health in African and African Caribbean groups: a qualitative study evaluating the role of community well-being champions, *Health and Social Care in the Community*, 25(1), 167–176 doi: 10.1111/hsc.12288

Mayne, D. J. F. Allan, L. Reynish, E. MacLullich, A. M. J. Cunningham Vardy, E. R. L. (2014) Experience and opinions on post-graduate dementia training in the UK: a survey of selected consultant geriatricians, *Age and Ageing*, 43 (2), 263-266 https://doi.org/10.1093/ageing/aft205

Mayrhofer, A. Goodman, C. and Smeeton, N. (2016) The role of dementia champions in dementia care: Its aspirations, development and training needs (innovative practice), *Dementia*, 15 (5) 1306-1312 DOI: 10.1177/1471301216631448

Mayrhofer, A. Goodman, C. and Smeeton, N. (2015) Establishing a community of practice for dementia champions (innovative practice), *Dementia*, 14 (2), 259-266 DOI: 10.1177/1471301214542534

Mays, N. and Pope, C. (2000) Assessing quality in qualitative research, *British Medical Journal*, 320, 50-52 https://doi.org/10.1136/bmj.320.7226.50

McInerney, F. (2017) Dementia discourse- A rethink? *Dementia*, 16 (4), 409-412 DOI: 10.1177/1471301217700535

Mental Health Foundation (2015) *Dementia, rights, and the social model of disability*. London: Mental Health Foundation. https://www.mentalhealth.org.uk/sites/default/files/dementia-rights-policy-discussion.pdf

Micallef, R. Grewal, J. S. Khan, S. Wells, J. and Kayyali, R. (2019) Health champions in South London: evaluation of training and impact on public health, *International Journal of Pharmacy Practice,* 27, pp. 71–79 doi: 10.1111/ijpp.12464

Miech, E. J. Rattray, N. A. Flanagan, M. E. Damschroder, L. Schmid, A. A. Damush, T. M. (2018) Inside help: An integrative review of champions in healthcare- related implementation, *Sage Open Medicine*, 6, 1-11 https://doi.org/10.1177/2050312118773261

Miles, M. and Huberman, M. (1994) *Qualitative Data Analysis*. 2nd ed. Thousand Oaks: Sage

Milne, A. (2010) The ‘D’ word: Reflections on the relationship between stigma, discrimination and dementia, *Journal of Mental Health*, 19 (3), 227-223. https://doi.org/10.3109/09638231003728166

Miyawaki, C. E. Belza, B. Marlana, J. Petrscu- Prahova, M. (2018) Champions of an Older Adult Exercise Program: Believers, Promoters, and Recruiters, *Journal of Applied Gerontology*, 37 (6), 728-744 ISSN: 0733-4648 AN: 129632303

Moore, T. (2005) Poetry in education: a way to deepen understanding of the experience of families, *Dementia*, 4 (1), 139-143 https://doi.org/10.1177%2F1471301205004001O9

Morris, K. J. (2012) *Starting with Merleau–Ponty'*. London: Bloomsbury Publishing Plc

Morrison, M. (2019) New doctors in Scotland are being given a book of poetry to help them deal with the stresses of the job. https://inews.co.uk/news/education/scotland-doctors-tools-of-the-trade-poetry/ last accessed 12/07/19

Nedland, A. and Bartlett, R. (2017) Citizenship-in-and-as- practice: a framework for improving life with dementia, in: Hyden, L and Antelius, E. (eds) *Living with dementia*. London: Palgrave 49-67

Oliver, M. (1996) *Understanding disability: from theory to practice*. Basingstoke: Palgrave Macmillan

Oliver, M. (2013) The social model of disability: thirty years on, *Disability and Society*, 28 (7), 1024-1026 DOI: 10.1080/09687599.2013.818773

Office for National Statistics (2019) *Deaths registered in England and Wales 2018*, England: ONS

https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsregistrationsummarytables/2018

Owens, J. (2015) Exploring the critiques of the social model of disability: the transformative possibility of Arendt's notion of power, *Sociology of Health and Illness*, 37 (3), 385-403 https://doi.org/10.1111/1467-9566.12199

Oxley, L. (2016) An examination of interpretative phenomenological analysis (IPA), *Educational and Child Psychology*, 33 (3), 55- 62

Page, K. S. Hayslip Jnr, B. Wadsworth, D. and Allen, P. A. (2019) Development of a multidimensional measure to examine fear of dementia, *The International Journal of Ageing and Human Development*, 89 (2), 187- 205 https://doi.org/10.1177/0091415018784737

Parker, J. (2005) Constructing dementia and dementia care, *Journal of Social Work*, 5 (3), 261-278 https://doi.org/10.1177%2F1468017305058935

Parsons, J. A. Gladstone, B. M. Gray, J. and Kontos, P. (2017) Re-conceptualising “impact” in arts- based health research, *Journal of Applied Arts and Health*, 8, 155-173. doi:10.1386/jaah.8.2.155_1

Patrick, L. D. (2016) Found poetry: Creating space for imaginative art-based literacy research writing, *Literary Research: Theory, method, and practice*, 65 (1), 384- 403 DOI: 10.1177/2381336916661530

Pelleboer- Gunnink, H. A. van Weeghel, J. Embregts, C. M. (2019) Public stigmatisation of people with intellectual disabilities: a mixed-method population survey into stereotypes and their relationship with familiarity and discrimination, *Disability and Rehabilitation*, DOI: doi: 10.1080/09638288.2019.1630678

Percer, L. H. (2002) Going Beyond the Demonstrable Range in Educational Scholarship: Exploring the Intersections of Poetry and Research, *The Qualitative Report*,7(2), 1-13. Retrieved from https://nsuworks.nova.edu/tqr/vol7/iss2/6

Phillipson, L. Hall, D. Cridland, E. Fleming, R. Brennan- Horley, C. Guggisberg,, N. Frost, D. and Hasan, H. (2018), Involvement of people with dementia in raising awareness and changing attitudes in a dementia friendly community pilot study, *Dementia*, 0 (0), 1-6 https://doi.org/10.1177/1471301218754455

Pinderup, P. (2018) Improving the Knowledge, Attitudes, and Practices of Mental Health Professionals Regarding Dual Diagnosis Treatment - a Mixed Methods Study of an Intervention, *Issues in Mental Health Nursing*, 39 (4), 292-303 DOI: http://0-dx.doi.org.lispac.lsbu.ac.uk/10.1080/01612840.2017.1398791

Ploeg, J. Skelly, J. Rowan, M.Edwards, N. Davies, B. Grinspun, D. Bajnok, I. Downey, A. (2010) The Role of Nursing Best Practice Champions in Diffusing Practice Guidelines: A Mixed Methods Study, *World Views on Evidence-Based Nursing: Linking Evidence to Action*, 7 (4), 238-251 https://doi.org/10.1111/j.1741-6787.2010.00202.x

Popay, J. Roberts, H. Sowden, A. Petticrew, M. Arai, L. Rogers, M. Britton, N. Roen, K. Duffy, S. (2006) Guidance on the conduct of narrative synthesis in systematic reviews: A product from the ESRC methods programme file:///C:/Users/User/AppData/Local/Temp/download-1.pdf

last accessed 12/07/19

Popay, J. Roberts, H. Sowden, A. Petticrew, Britten, M. Arai, L. Roen, K. Rodgers, , K. (2005) Developing guidance on the conduct of narrative synthesis in systematic reviews, *Journal of Epidemiological Community Health*, 59 (Suppl 1), A7 http://jech.bmj.com/content/vol59/suppl_1/

Potash, S (2018) Tackling the growing, global burden of dementia, 17 (5) *Global Health Matters Newsletter*. https://www.fic.nih.gov/News/GlobalHealthMatters/Documents/fogarty-nih-global-health-matters-newsletter-september-october-2018.pdf

last accessed 12/07/19

Prendergast, M. (2016) *Poetic inquiry 11- seeing, caring, understanding: using poetry as and for inquiry*. Rotterdam: Sense Publishers

Prendergast, M. Leggo, C. and Sameshima, P. (Eds) (2009) *Poetic Inquiry: Vibrant voices in the Social Sciences*. Rotterdam: Sense Publishers

Pringle, J. Hendry, C. and McLafferty, E. (2011) Phenomenological approaches: challenges and choices, *Nurse Researcher*, 18 (2), 7-18

https://doi.org/10.7748/nr2011.01.18.2.7.c8280

Rahman, E. (2016). I wear a badge that says: if you have dementia I'm your friend. The Guardian, 19th May, Available from: https://www.theguardian.com/voluntary-sector-network/2016/may/19/dementia-alzheimers-friend last accessed 30/12/18

Rahman, S. and Swaffer, K. (2018) Assets-based approaches and dementia friendly communities, *Dementia*, 17 (2), 131-137 DOI: 10.1177/1471301217751533

Reynolds, L. Innes, A. Poyner, C. and Hambridge, S. (2017) ‘The stigma attached isn’t true of real life’: Challenging public perception of dementia through a participatory approach involving people with dementia (Innovative Practice), *Dementia*, 16 (2), 219-225 DOI: 10.1177/1471301216635828

Richardson, L. (1993) Poetics, dramatics and transgressive validity: The case of the skipped line, *The Sociological Quarterly*, 34 (4), 695-710

Ridout, S. (2016) Well- being and creative methodologies as a tool for communicating with health and social care practitioners, in: Milton, D. and Martin, M. (eds), *Autism and Intellectual Disability in Adults*. Hove: Pavilion Publishing and Media Ltd, 1, 45-47

Rivas, C and Pandya- Wood, R. (2014) Dissemination, in: Walker, D. *An introduction to health service research* (ed), London: Sage, 343-355

Robinson, U. Tilford, S. Branney, P. and Kinsella, K. (2013) Championing mental health at work: Emerging practice for innovative projects in the UK, *Health Promotion International*, 29 (3), 583-595, doi:10.1093/heapro/das074

Ryan, F. Coughlan, M. and Cronin, P. (2007) Step-by-step guide to critiquing research. Part 2: qualitative research, *British Journal of Nursing*, 16 (12), 738- 744

Schon, D. A. (2016) *The reflective practitioner: How professionals think in action*. Abingdon; Oxon: Routledge

Scott, K.R. and Barrett, A. M. (2007) Dementia syndromes: evaluation and treatment, *Expert Review Neurotherapeutics*, 7 (4), 407-422 doi:10.1586/14737175.7.4.407

Segal, L. (2015) Portraying ageing: its contradictions and paradoxes, *Working with Older People*, 19 (1) 3-11, DOI 10.1108/WWOP-12-2014-0040

Segalo, P. (2018) Women speaking through embroidery: using visual methods and poetry to narrate lived experiences, *Qualitative Research in Psychology*, 15 (2-3), 298-304. https://doi.org/10.1080/14780887.2018.1430013

Shakespeare, T. Zeilig, H. and Mittler, P. (2019) “Rights in mind: Thinking differently about dementia and disability, *Dementia*, 1, 1-14 DOI: 10.1177/1471301217701506

Shakespeare, T. Zeilig, H. and Mitler, P. (2017) Rights in mind: Thinking differently about dementia and disability, *Dementia*, 18 (3), 1075-1088. doi:10.1177/1471301217701506

Shakespeare, T. (2006) *Disability rights and wrongs*. London: Routledge

Shakespeare, T. and Watson, N. (2002) The social model of disability: an outdated ideology? *Research in Social Science and Disability*, 2, 9-28 DOI: 10.1016/S1479-3547(01)80018-X

Sheaff, R. Sherriff, I. and Hennessy, H. (2018) Evaluating a dementia learning community: exploratory study and research implications, *BMC Health Services Research*, 18:83, 1-13 https://dx.doi.org/10.1186%2Fs12913-018-2894-3

Shih-Yin, L. Becker, M. and Belza, B. (2014) From dementia fearful to dementia friendly: Be a champion in your community, *Journal of Gerontological Nursing*, 40 (12) 3-5 https://doi.org/10.3928/00989134-20141114-01

Smith, J. A. (2019) Participants and researchers searching for meaning: Conceptual developments for interpretative phenomenological analysis, *Qualitative Research in Psychology*, 16 (2), 166-181 https://doi.org/10.1080/14780887.2018.1540648

Smith, J. A. (2018) “Yes it is phenomenological”: A reply to Max Van Manen’s critique of Interpretative Phenomenological Analysis, *Qualitative Health Research*, 28 (12) 1955-1958 https://doi.org/10.1177%2F1049732318799577

Smith, J. A (2011) Evaluating the contribution of interpretative phenomenological analysis, *Health Psychology Review*, 5 (1), 9-27 https://doi.org/10.1080/17437199.2010.510659

Smith, J. A. (2011b) ‘We could be diving for pearls’ The value of the gem in experiential qualitative psychology, *Qualitative Methods in Psychology Bulletin*, 12, 6-15 ISSN 2044-0820

Smith, J.A. (2007) Hermeneutics, human sciences and health: Linking theory to practice. *International Journal of Qualitative Studies on Health and Well-Being*, 2 (1), 3-11 https://doi.org/10.1080/17482620601016120

Smith, J. A. (2004) Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology, *Qualitative Research in Psychology*, 1 (1), 39-54

Smith, J. A. Flowers, P. and Larkin, M. (2009) *Interpretative Phenomenological Analysis: Theory, Method and Research*. London Sage

Sontag, S. (1991). *Illness as metaphor and Aids and its metaphors*. London: Penguin Books

Swaffer, K. (2014) Dementia: Stigma, language, and dementia friendly, *Dementia*, 13 (6), 709-716 DOI: 10.1177/1471301214548143

Swift, J. and Steeden, B. (2020) *Literature review: Exploring representations of old age and ageing*, London: Centre for Ageing Better, 1-62 https://www.ageing-better.org.uk/sites/default/files/2020-03/Exploring-representations-of-old-age.pdf

Teoh, J. Y. and Iwama, M. K. (2015) *The Kawa Model Made Easy: A guide to applying the Kawa Model in occupational therapy practice.* 2nd ed. Retrieved from: www.kawamodel.com

Thomas, J. and Harden, A. (2008) Methods for thematic synthesis of qualitative research in systematic reviews, *MC Medical Research Methodology*, 8 (45) doi:10.1186/1471-2288-8-45 http://www.biomedcentral.com/1471-2288/8/45 last accessed 12/07/19

Thomas and Milligan (2015) *How can and should UK society adjust to dementia?* York: Joseph Rowntree Foundation https://www.jrf.org.uk/report/how-can-and-should-uk-society-adjust-dementia

Thomas, C. and Milligan, C. (2018) Dementia, disability rights and disablism: understanding the social position of people living with dementia, *Disability and Society*, 33 (1), 115-131 DOI: 10.1080/09687599.2017.1379952

Todres, L. (2007) *Embodied enquiry: phenomenological touchstones for research*, *psychotherapy and spirituality*. Basingstoke; England: Palgrave Macmillan

Trekaskis, C. (2002) Social Model Theory: the story so far, *Disability and Society*, 17 (4), 457-470 DOI: 10.1080/09687590220140377

Tuffour, I. (2017) A Critical Overview of Interpretative Phenomenological Analysis: A Contemporary Qualitative Research Approach, *Journal of Healthcare Communications*, 2, No. 4.52, 1-5. DOI: 10.4172/2472-1654.100093

Turner, N. Cannon, S. (2018) Aligning age- friendly and dementia-friendly communities in the UK, *Working with Older People*, 22 (1), 9-19

van Manen, M. (2019) Rebuttal: Doing phenomenology on the things, *Qualitative Health Research*, 29 (6), 908-925 https://doi.org/10.1177/1049732319827293

van Manen, M. (2018a) Rebuttal rejoinder: Present IPA for what it is- Interpretative Psychological Analysis, *Qualitative Health Research*, 28 (12), 1959-1968 https://doi.org/10.1177/1049732318795474

van Manen, M. (2017a) But is it phenomenology? *Qualitative Health Research*, 27 (6), 775-779 https://doi.org/10.1177/1049732317699570

van Manen, M. (2017b) Phenomenology its original sense *Qualitative Health Research*, 27, 775-779 https://doi.org/10.1177/1049732317699381

van Manen, M. (1997) ‘From meaning to method’, Qualitative Health Research: *An International Interdisciplinary Journal*, 7 (3), 345-369 https://doi.org/10.1177%2F104973239700700303

van Manen, M. (1990) ‘From meaning to method’, *Qualitative Health Research*: An *International Interdisciplinary Journal*, 7, 345-69

Wade, D. T. and Halligan, P. W. (2017) The biopsychosocial model of illness: a model whose time has come, *Clinical Rehabilitation*, 31 (8), 995-1004 https://doi.org/10.1177/0269215517709890

Waggstaff, C. and Williams, B (2014) Specific design features of an interpretative phenomenological analysis study, *Nurse Researcher*, 21 (3), 8-12 DOI: 10.7748/nr2014.01.21.3.8.e1226

Wakeman, B. E. (2015) Poetry as research and as therapy, *Transformation*, 32 (1), 50-68 https://www.jstor.org/stable/90010960

Waldschmidt, A. (2018) Disability- culture- society: Strengths and weaknesses of a cultural model of dis/ability, *ALTER, European Journal of Disability Research*, 12, 67-80 https://doi.org/10.1177/1471301218754455

Walker, W. (2011) Hermeneutic inquiry: insights into the process of interviewing, *Nurse Researcher*, 18 (2),19-27 https://doi.org/10.7748/nr2011.01.18.2.19.c8281

Wareing, M. (2016) Using the 'me, my, more, must' approach to learning, *British Journal of Healthcare Assistants*, 10 (09), 446- 452

Watson, J. (2016) Is it possible to live well with dementia? *Dementia*, 15 (1), 4-5 DOI: 10.1177/1471301215616324

Whiting, M. and Sines, D. (2012) Mind maps: establishing 'trustworthiness' in qualitative research, *Nurse Researcher*, 20 (1), 21-27 DOI: 10.7748/nr2012.09.20.1.21.c9304

Wilkinson, I. Coates, A. Merrick, S. and Lee, C. (2016) Junior doctor champions in a district general hospital (innovative practice), *Dementia*, 15 (2), 263-272 https://doi.org/10.1177/1471301215584083

Willis, M. and Cromby, J. (2020) Bodies, representation, situations, practices: Qualitative research on affect, emotion and feeling, *Qualitative Research in Psychology*, 17(1), 1-12. DOI: 10.1080/14780887.2019.1656361. (*AN: 140252463*)

Willis, P. (2001) The "things themselves" in phenomenology, *Indo-Pacific Journal of Phenomenology*, 1 (1), 1-12 https://doi.org/10.1080/20797222.2001.11433860

Wisnewski, J. (2013) *Heidegger: An introduction*. Lanham, Md: Rowan and Littlefield

Woods, S. (2018) Reflection through poetry writing, *OT News*, 3, 22-23

World Alzheimer Report (2018) *The state of the art of dementia research:* New frontiers https://www.alz.co.uk/research/WorldAlzheimerReport2018.pdf

World Health Organisation (2019) *Dementia Factsheet*.

https://www.who.int/news-room/fact-sheets/detail/dementia last accessed 12/0719

WHO and ADI (2019) *Dementia: a public health priority*.

https://www.who.int/mental_health/publications/dementia_report_2012/en/ last accessed 12/07/19

WHO (2019g) *Disabilities*.

https://www.who.int/topics/disabilities/en/ last accessed 12/07/19

WHO (2002) *Towards a common language for functioning, disability and health* ICF: Geneva: World Health Organization: http://www.who.int/classifications/icf/icfbeginnersguide.pdf

last accessed 12/07/19

World Health Organisation (2018) *Dementia*. https://www.who.int/news-room/facts-in-pictures/detail/dementia

World Health Organisation (2017) *Disabilities.* http://www.who.int/topics/disabilities/en/

World Health Organisation (2017). Dementia.

http://www.who.int/news-room/fact-sheets/detail/dementia

(Accessed 30/12/18)

World Health Organisation and Alzheimer's Disease International (2012) *Dementia: A public health priority* https://www.emeraldinsight.com/doi/pdfplus/10.1108/WWOP-12-2017-0036

World Health Organisation (2017c) Global action plan on the public health response to dementia 2017 – 2025. https://apps.who.int/iris/bitstream/handle/10665/259615/9789241513487-eng.pdf?sequence=1

Yardley, L. (2000) Dilemmas in qualitative research, *Psychology and Health*, 15 (2), 215-228 https://doi.org/10.1080/08870440008400302

Yilmaz, K. (2013) Comparison of quantitative and qualitative research traditions: Epistemological, theoretical, and methodological differences, European Journal of Education, 48(2), 311-325 https://doi.org/10.1111/ejed.12014

Yin, R. K. (2003) *Case study research: design and methods*. 3rd ed. Tjousand Oaks, CA: Sage

Young, J. A. Lind, C. Orange, J. B. and Savundranayagam, M. Y. (2019) Expanding current understandings of epistemic injustice and dementia: learning from stigma theory, *Journal of Ageing Studies*, 48, 76-84 DOI: 10.1016/j.jaging.2019.01.003

Zahavi, D. (2019) *Phenomenology: The basics*. London: Routledge

Zahavi, D. (2018) Getting it quite wrong: Van Manen and Smith on phenomenology, *Qualitative Health Research*, 1-8

https://doi.org/10.1177/1049732318817547

Zannini, L. Cattaneo, C. Brugnolli, A and Saiani, L. (2011) How do healthcare professionals perceive themselves after a mentoring programme? A qualitative study based on the reflective exercise of ‘write a letter to yourself’, *Journal of Advanced Nursing*, 67 (8), 1800-1810 https://doi.org/10.1111/j.1365-2648.2011.05615.x

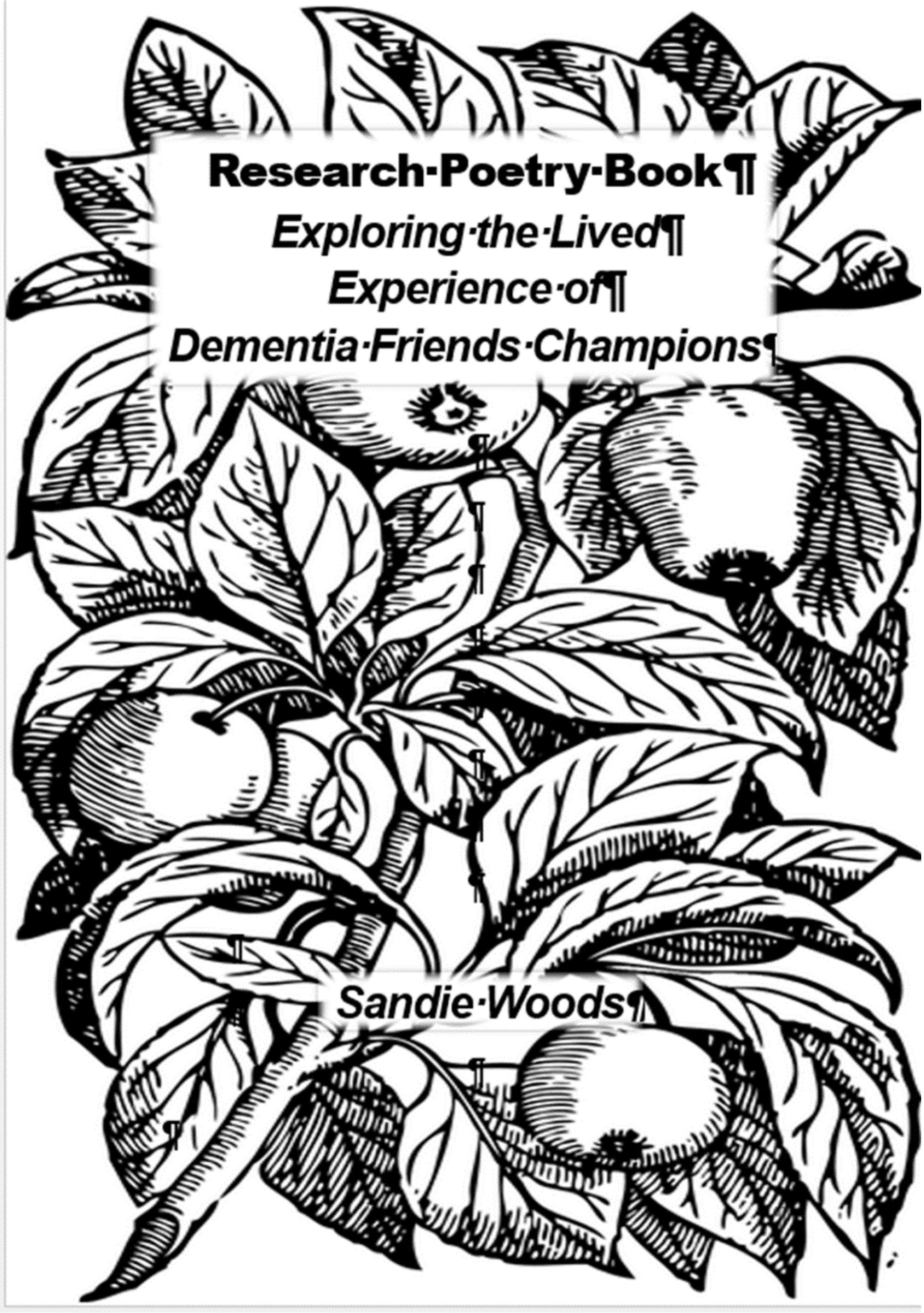
Zeilig, H. (2013) Dementia as a cultural metaphor, *The Gerontologist*, 54 (2) pp. 258-267 https://doi.org/10.1093/geront/gns203

Zimmerman, M. (2017). Alzheimer’s Disease: metaphors as mirror and lens to the stigma of dementia, *Literature and Medicine*, 35 (1), 71-97 DOI: 10.1353/lm.2017.0003

10 Appendices

10.1 Research Poetry

10.1.1 Research Poetry Book



Research Poetry Book

Exploring the Lived
Experience of
Dementia Friends Champions

Sandie Woods

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Introduction

This book represents research into the lived experiences of eleven dementia friends champions, presented in the form of research poetry. It incorporates ‘found poetry’ from the interviews with the dementia friends champions and ‘generated poetry’ from researcher insights from undertaking the research (Butler- Kisber, 2010; Faulkner, 2016). The poems are presented in a variety of formats, with a commentary to highlight aspects of the research and support discussion and reflection.

Background

The Alzheimer’s Society’s launched the Dementia Friends initiative in 2013 influenced by the Japanese initiative which started in 2004 (Alzheimer’s Disease International, 2016), to change people’s perceptions of dementia and turn understanding into action. Dementia friends champions are volunteers trained to deliver Dementia Friends information sessions. There is limited research into the lived experience of being a Dementia Friends Champion.

Terminology

Dementia

Dementia is a syndrome caused by a variety of brain illnesses that affect memory, thinking, behaviour and ability to perform everyday activities. Worldwide there are currently an estimated 47 million people living with dementia; it is projected to increase to 75 million by 2030 and almost triple by 2050. A lack of awareness and understanding of dementia can result in stigmatization and barriers to diagnosis and care; it impacts on carers, families, and societies physically, psychologically, and economically (World Health Organisation, 2018).

Dementia Friends

Dementia Friends is an Alzheimer's Society initiative, started in 2013, to raise awareness about living with dementia with the goal of turning understanding in action. The latest figures show there are 2.5 million Dementia Friends in England, Wales and Northern Ireland including people living with Dementia. The sessions can be delivered face to face or via on online version (Alzheimer's Society UK, 2017).

Dementia Friends Champions

A dementia friends champion is a volunteer, who may also have dementia, who encourages others to make a positive difference to people living with dementia in their community. They do this by giving them information about the personal impact of dementia, and what can be done to help.

The word ‘champion(s)’ will be used throughout to represent the dementia friends champions (Alzheimer’s Society UK, 2017(a)).

Dementia Friendly Communities

A dementia friendly community can be defined as: a place or culture in which people with dementia and their carers are empowered, supported and included in society, understand their rights and recognise their full potential (Alzheimer’s Disease International, 2016).

Research Poetry

Poetic inquiry is a way of knowing through poetic language and devices (Prendergast, 2016). Butler-Kisber (2010) highlights how in poetry so much can be revealed in compelling and contracted forms; it is an artful way of being a researcher, requiring careful attention to people, places, events, and contexts. It requires engagement in the pursuit of aesthetic craft and needs to be undertaken with a social conscience. Research poetry is written to represent data and stay true to the essence of the participant’s experience (Patrick, 2016). Leggo (2005) highlights how poetry can inform research and research can inform poetry. Furman et al. (2012) supports the view that research poetry can give voice to the participant’s experience.

Aim

Explore the lived experience of dementia friends champions: poetic representation.

Objectives

- Define and identify the roles undertaken by dementia champions
- Review, discuss and analyse the experiences of dementia champions
- Critically appraise the research undertaken into the experiences of dementia champions
- Synthesize the findings to reveal what is understood from various perspectives, or unanswered about the experiences of dementia champions.
- Examine the use of arts-based approaches and research poetry.

Data collection

Semi structured interviews were undertaken with eleven Champions to explore their experiences, meanings, and insights from undertaking the role. Poetry was produced from the transcripts, and insights from the researcher, with the goal of disseminating to a broader audience in an accessible way.

Analysis

Interpretative phenomenological analysis was undertaken (Smith et al., 2009) and four themes were developed. These included:

- Being a Champion
- Knowledge and understanding in communities
- Experiences and insights
- Dementia friendly communities

Findings and discussion

The findings and discussion are presented in a thematic format in the thesis and in the form of research poetry under the four headings.

Being a dementia friends champion

Being a volunteer

Being a volunteer was very important to all the participants representing their commitment to making a difference to the lives of people living with dementia and carers. For some champion's, the role provided a new direction and identity. They all enjoyed the social interaction, a sense of purpose and satisfaction that they were making a difference. Most champions identified how their personal experiences of dementia were influential in the decision to become a champion.

Skills and knowledge

Wide ranging skills and knowledge were required in the role. They networked, organised, and delivered sessions and communicated with groups in different settings. They developed emotional intelligence as they encountered anger and distress in some people attending and emotionally connected with their own experiences. The skills and knowledge gained and deployed, were not reflected in the definition of a dementia friends champion or the training provided by the Alzheimer's Society.

Understanding in a new way

They gained a better understanding of dementia, some found answers and many gained insights into their own and other experiences.

Knowledge and understanding in communities

Limited knowledge in communities

They encountered limited knowledge about dementia and found delivering the five key messages had an impact on beliefs and the construction of new understandings.

Engaging people with dementia as champions

As they reflected on their experiences some champions identified the need to do more to capture the voice of people living with dementia and to bring about change in attitudes. Some champions shared examples of ‘us and them’ situations and a sense of ‘otherness’. Brown et al. (2017) asks why we need dementia champions and goes on to say they will continue to be needed until people with dementia are fully accepted in society and not labelled as ‘other’.

Fear and stigma

None of the champions expressed a fear of dementia but witnessed the fear of dementia in people attending sessions. They found the information provided in the session resources and their own personal experiences helped them in finding ways to respond to and manage challenging situations.

Experiences and insights

Changed

As they met people living with dementia and struggling carers, they felt emotionally affected. These people experienced needs that were greater than could be met through a dementia friends session. Champions recognised the need for resilience when people in distress attended sessions. Champions found they had been changed in different ways including their beliefs and attitudes and finding new ways of understanding their own experiences.

Challenges to living well with dementia: End of life

Some champions were personally challenged and conflicted when delivering the message that you can live well with dementia as they reflected on their own experiences, particularly end of life care. They also encountered attendees challenging the message, when it did not represent their own experiences or reflect the difficulties they encountered.

Dementia friendly communities

Belonging

Champions were self-motivated and worked autonomously but felt a sense of belonging to a bigger movement aimed at raising awareness, getting people to talk about dementia and promoting inclusion.

Understanding and action

They were encouraged and motivated by positive action taking place in communities but also experienced reluctance to engage by some organisations which seemed influenced by time and money. Some champions believed understanding was more important than action.

Sustainability

The sustainability of the provision was a concern when set against other competing health priorities and the need to reach the next generation.

Research poetry book

The research poetry book uses an arts-based approach to present the research findings with the goal of disseminating information to a wider audience in an accessible format. It is freely available in an electronic format for use by individuals or groups to promote exploration, reflection and critique of research poetry and the use of arts-based approaches in research.

How this book may be used

It is hoped that the reader will speak it, hear it, discuss it, reflect on it, learn from it, and share it with others.

It should encourage the reading and writing of poetry to capture experiences and develop new understandings.

It will provide researchers with the opportunity to reflect on the use of arts-based approaches, and specifically research poetry, in qualitative research.

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Section 1: Being a Dementia Friends Champion

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The Champion’s Hat

Commentary

The poem reflects taking on a different role when becoming a champion. The reasons for taking on the role were different for each champion who participated in the research, but they were all influenced by personal experiences. Participants described delivering Dementia Friends sessions as positive, rewarding, and exciting but also challenging and emotionally demanding. In many cases the role had created new interests, opportunities, and a life they had not expected. They expressed how they were changed by the experience, saw a different side of themselves, were proud to be volunteers and represent the movement. There were also expressions of guilt and reflections on what could have been different. The metaphor of the hat also reflected taking on different roles and seeing things differently at different times in our lives or in different situations.

The Champion’s Hat

Put on a new hat
A different shape and colour
Try it on for size

Look in the mirror
See yourself differently
Wear the hat with pride

The Champion’s Tale

Commentary

During the interviews, the champions shared their own experience of dementia within their families or communities, the people they met in the role, and the impact of the experiences. They all discussed how being a champion increased their knowledge and understanding of dementia and they reflected on how they had been changed by their experiences. For some participants there were moments or experiences that were influential, but others over time, came to understand their experiences in a new light. They found meaning and purpose in the role and came to understand themselves better. One participant shared how it was the first time reflecting on and exploring experiences in depth.

The Champion’s Tale

Telling my story
The champion’s tale
Feeling, revealing
Who I am now
Who I was then
Sending me back in time
A flash of light
Or gradual insight
Finding meaning
Finding me

The Champion’s Message

Commentary

The commitment and belief in the Dementia Friends initiative was evident from all the participants and they explored the importance of bringing a message of hope, that there is more to the person than dementia, and you can live well with dementia. The champions shared a common goal to get out into communities, to talk about dementia, and reduce the fear and stigma associated with the condition. They hoped the sessions would motivate others to start taking action to support people living with dementia. They acknowledged the difficulties and challenges faced by people living with dementia and those providing care, but there was a sense of positivity for the future. They all believed in the importance of what they were doing and were confident it would make a difference in attitudes, knowledge, and action to promote dementia friendly communities.

The Champion’s Message

I stand here today
Delivering a message of hope
For a community that cares
That listens, that shares
Together we can change the world

Look and see
It’s you, it’s me
There is no shame
We are all the same
Together we can change the world

Don’t turn your back on Dementia

Wearing The Badge

Commentary

Champions spoke positively about their experiences and the encouragement and positive feedback they received from people attending the sessions. They delivered information sessions to large and small groups in diverse settings for example, firefighters, charity workers, security staff, community groups, faith groups, health and social care groups, government ministers and youth groups. Sessions were delivered in lecture theatres, primary care centres, community halls and shopping centres. They expressed feelings of excitement, anticipation and showmanship when delivering sessions, but also trepidation about how they would be received. Being a volunteer was identified as a demonstration of their commitment to the cause and the badge was an important statement about being dementia friendly. They spoke of change occurring in attendees and in themselves as they listened, learnt, and shared together.

Wearing The Badge

Delivering the session
A bit of showmanship mixed with fear
A partnership, in it together
I share stories, they share lives
Touched by dementia
Asking questions, finding answers
Change is possible, not impossible
And in that moment
I find a better side of me

Your Presence

Commentary

Ten of the eleven champions interviewed had experience of family members who had lived or were living with dementia. When delivering the sessions, they had to keep to the format in the resource handbook and not introduce their own examples and experiences. However, the stories they heard from people attending, and the emotional aspects of their interaction, were often powerful and led to their own experiences and feelings being brought to the fore. It created challenges at times, due to the need to stay composed and deliver the session. They reflected on these moments and how they managed the emotional aspects of the role. A word, a story or a look could trigger memories and experiences. The emotional connection, whilst challenging, was important in the role.

Your Presence

In her eyes I see
What you were to me
I check myself, stand tall
I wasn't expecting you

Who You Are

Commentary

Participants in the study spoke about the importance of seeing each person for who they are and not being defined by a diagnosis. As they shared stories, there was engagement at a personal level and the drive to move away from an ‘us’ and ‘them’ situation to all working together to promote inclusion. In the poem the clouds represent the way someone may feel overshadowed by a diagnosis of dementia and not seen for the unique person they are. It also represents society moving from distancing and lack of clarity, to a greater understanding of dementia.

Who You Are

I saw you from a distance
The clouds disappear
I know you for who you are

Stories Shared

Commentary

The stories shared during the interviews reflected the champions own experiences of dementia and the people they met. The interviews highlighted the level of engagement with the audiences, the relationship, connection, empathy, rapport, and trust developed with the people they met. Non-verbal communication conveyed feelings about past and present experiences.

Stories Shared

Stories told and shared
Moments that matter
Etched in faces
Shaped by time

Exploring Meanings

Commentary

For many champions it was the first time they had spoken in depth about becoming a champion, their lived experiences, insights they gained and their commitment to raising awareness about dementia. Being a champion had personal meaning for each of them. Poetry provides a way to engage in a different way to condense and capture the essence of the experience. Poetry also provides shape and space on the page moving from the bigger picture and going deeper to capture meaning.

Exploring Meanings

Images appear
Creating shapes and stories
A different way of seeing
Finding meaning
Reflecting light
On you

The Interview

Commentary

The poem reflects undertaking an in-depth interview for the research.

The first stage represented meeting with the person, being focussed and actively engaged. It meant being attentive to their comfort and respecting and valuing their contribution.

The second stage involved creating a relaxed atmosphere allowing the person to tell their story. It could be described as wandering through life events and experiences together, creating opportunities for the person to explore and make connections. It required time and space to wait as thoughts, ideas and insights fell into place.

The third stage represented the emotional connection and empathy between the researcher and participant. There was an emotional component to sharing experiences and expression of feelings that may not have previously been revealed or surfaced anew.

The fourth stage is the move from interview to writing up. It represented the researcher's responsibility to stay true to the interviewee's words whilst capturing the meanings behind the lived experience of being a dementia friends champion.

The Interview

See
Hear
Me

Wander
Wait
Make

Feel
Reveal
More

Write
Reflect
Meaning

Section 2: Knowledge and understanding in communities

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Placed In The Past

Commentary

During the interviews one of the champions reflected on her own experiences and understandings. She talked about being in the person's reality and how it did not matter that her aunt thought she was her neighbour rather than her niece but what was importance was they continued to have a positive relationship. Rather than trying to reinforce the present time she could engage in the person's reality, time, and place. The Dementia Friends information session highlights the impact of dementia and responding in a way that is meaningful for the person.

Placed In The Past

The present was gone
Drawing me into her past
When she was a teenager
I became her neighbour
In a little village
In the west of Ireland

Invisible

Commentary

One of the champions had been a carer for many years. During the interviews, the experience of caring for someone living with dementia was described as ‘being under the radar’, ‘not noticed’ and a feeling that the needs of carers and the challenges of caring were not recognised. As the person living with dementia changed or deteriorated the carer faced the challenge of continuing trying to find a way to meet their needs. It also reflected the way relationships changed and how caring for someone with dementia could create challenges. Champions shared how many of the people attending the information sessions were carers who were seeking help and support.

Invisible

Under the radar
Not noticed, not detected
Finding a new way
To care for you

Patience

Commentary

The poem represents a woman’s name and a quality required in dementia care. The word ‘fear’ came through strongly in many of the interviews. Champions shared how many people attending the sessions were fearful of being diagnosed with dementia, did not know how to care for someone with dementia or how to handle challenging situations. They also recognised how information was changing perceptions, attitudes and promoting positive action. One champion said many people attending the sessions had stated they felt less fearful and having a better understanding would lead them to be more patient. The role of the champions is supporting people to move from being dementia fearful to dementia friendly was also highlighted in the paper by Shih-Yin et al. (2014). Another champion, who delivered sessions to health and social care students, shared the impact of the session on providing care, taking time to listen, and getting to know each person. For another champion it was opportunity to reflect on being a carer and insights and understanding gained in relation to challenging behaviours experienced.

Patience

You don’t need to fear
Be patient, listen and care
She has dementia

Memories

Commentary

Champions reflected on fears expressed about the impact of dementia on memory, relationships, and identity. For many it was the fear that the person living with dementia would no longer know or remember them. The messages delivered were helpful in recognising that although short term memory may be affected, earlier memories and emotional memories can last.

Memories

Memories
Present and past
Who knows
What stays, what goes
Lost slowly, unknowingly
Forever

Danny

Commentary

One participant shared his experiences of seeing someone he knew and met on a regular basis in his place of work. Danny's (pseudonym) personality, mood and behaviour had changed by the impact of dementia. Although he spoke in the interview about the effects of dementia he started and ended the story by remembering the positives about the person. He remembered him as one of life's gentleman, with always a good word to say. He had not lost contact with the essence of the person. It highlighted the uniqueness of the person, the life lived, and not seeing just the impact of the disease.

Danny

He was one of life’s gentleman
Always a good word to say
Until today
No smile on his face
He paces back and forth
Not recognising his friends
He ends the visit
Without a word
I heard
He had Dementia
He was one of life’s gentleman

Feelings Remembered

Commentary

When delivering a dementia friends session, one of the champions noticing someone in the audience that he recognised. He acknowledged her and continued with the session. As the session was ending, she stood up and said she wanted to share with the group that she had dementia. She went on to talk about all the things she had been doing and all the plans she had for the coming months. The champion described the initial shock at hearing the news then went on to say the positive impact it had on him and the group. It had reinforced the message that you can live well with dementia. Even if at a later stage facts or details are lost what will remain are the positive feelings experienced. There can be new learning, new opportunities and experiences and quality of life following the diagnosis.

Feelings Remembered

You and me together
Will live and laugh
Go dancing, sing songs
Enjoying all we have
Not what we’ve lost
We will make memories
From what we feel
As long as we can carry on
You and me together

My Friend

Commentary

The resources used in the information sessions include scenarios and stories that highlight the importance of emotional memory. Through storytelling, people are encouraged to recognise that even when memory is affected by dementia, what the person feels will remain. The scenarios highlight the importance of continuing to visit someone, even if the person forgets, and the benefits of connecting. People attending sessions identified actions they would take including visiting relatives living with dementia, and spending more time listening, because of new learning.

My Friend

Each day was the same
Until you came to see me
A light within you
That woke me from my darkness
Loneliness was all I knew
In you I found a future

May

Commentary

One of the champions discussed the experience of her grandmother living with Alzheimer’s. She recalled how her grandmother no longer recognised her daughter or the people around her and everyone became known as ‘May’ (pseudonym). The dementia impacted on her memory and ability to recognise people and faces. What had remained was the emotional connection and how she felt about her daughter. It highlighted that even when short- term memory is affected, how they feel and their connections with others persist. Her daughter represented peace of mind. Emotional connections are picked up in the content of the Dementia Friends sessions.

May

May is coming soon
I don’t remember her face
Or the place we met
But I feel safe when she’s here
And I don’t fear dementia

Purpose

Commentary

Becoming a champion had given one participant a new life and opportunities she had not anticipated. There was a period of bereavement and transition but through her work as a champion she found purpose and a new, rewarding, engaging and influential role.

Purpose

Sharing your stories
A lens to view dementia
From the inside out

Laughter comes with tears
Someone listening to you
Moments that matter

Time to fill the void
From sadness to something that
Will make a difference

The people you meet
Shine a new light
On past and present

A new beginning
From carer to champion
A time to move on
With life

Branches

Commentary

The branches of the tree reflect how many people want to reach out and engage but are fearful of dementia and seek to avoid rather than confront. One of the champions discussed how he had avoided people with dementia as he felt awkward and did not know what to say. Taking that first step in confronting doubts and fears brought people together and prevented an ‘us’ and ‘them’ situation.

Branches

Branches reaching out
Touching the edges of fear
That keep us apart

The Flower of Understanding

Commentary

People attending dementia friends sessions often came with limited knowledge about dementia but a desire to learn more. Through the delivery of the key messages they left with a greater understanding and confronted the fear and stigma associated with dementia. In a short space of time a seed had been planted that could grow and develop resulting in a change in attitude and perception about dementia.

The Flower of Understanding

The seed is planted
Watered with knowledge and care
Stronger than stigma
It grows bigger and brighter
No flower more beautiful

Section 3: Experiences and Insights

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Soldiering On

Commentary

The poem came from the story shared by one of the champions in the study highlighting the fear attached to dementia and the need for information and support. A mother and two daughters were in the audience and one of the daughters became upset during the session. He reflected on the possibility that the mother had dementia and they were coming to terms with the changes. It transpired the daughter had been diagnosed with early onset dementia and her sister and mother had come seeking information and support. The information session could not provide everything they needed but they felt in a safe and supportive space and came and spoke to the champion at the end of the session. Many of the champions interviewed shared how they brought additional information about services in the local area with them to pass on if needed. The conversations that took place at the end of the sessions were influential in the meanings and insights gained by the champions.

Soldiering On

I see you sitting there
And try not to stare
As your tears turn to sobbing
You leave the room
But soon return
Mouthing the words ‘so sorry’
Soldiering on as best you can
Your face shows the fear of dementia
Your sister looks sad
But glad to talk, to question, to hope
For a way to cope with life’s changes
The session ends
And time to go
You know you have found a friend

I Changed

Commentary

During the interview, one of the champions shared his experiences of caring for his mother living with dementia, how he wanted to learn and understand more about dementia, and the challenges he faced. Near the close of the interview, he shared how he had come to a better understanding of his own and others experiences and felt he had been changed by the experience of being a champion. Champions shared the emotional impact of delivering sessions, particularly hearing the struggles faced by people attending sessions.

I Changed

I say dementia is important
I see carers can be isolated
I find it emotional sometimes
I understand what it means
I changed

As Memories Fall Away

Commentary

One champion, with extensive experience, reflected on her experience of also being a carer, and the importance of an emotional connection with people living with dementia. The timeline and the detail of action may not be recalled but the emotional feeling and experience lasts. Delivering sessions and reflecting on experiences led to insights into the meaning of caring. Emotional memory and connection are key components in the dementia friends sessions.

As Memories Fall Away

Just remember this
As memories fall away
What he feels will stay

Journey To Understanding

Commentary

One champion shared how he came to understand dementia in a different way when his mother was diagnosed. He reflected on the experiences and events over a period of years, how he dealt with situations at the time, what they meant, and how they were influential in the decision to become a champion. He spoke about wearing the badge, what it represented to him, and the statement it made.

Journey To Understanding

I stumbled across dementia
I wasn’t looking for it
I couldn’t stop her dying
I could have dealt with it better
I think it was my motivation
I can empathise
I think understanding outweighs action
I have my badge on

Hope Finds A Way

Commentary

This poem reflects the importance of spirituality and meaning in life. Dementia can suddenly bring to the fore what it means to be human, the uniqueness of each person, what is important in life, and issues of mortality. Maintaining a sense of identity, meaning and purpose in life is important to well-being. During challenging times having hope that things can get better was very important. The messages delivered by the champions was one of hope and belief that everyone can make a difference.

Hope Finds A Way

The brightness had gone
And clouds covered her
Hiding your presence

When all appeared lost
Hope found a way through the dark
Bursting forth once more

As the sunflower
Turns towards the sun
She looks to you

Bridge To Understanding

Commentary

The poem represents the stories, experiences and events that shaped the decision to become a champion. Many of the champions interviewed were influenced by family members living with dementia and the desire for things to be better, particularly in relation to end of life care.

Bridge To Understanding

Step onto the bridge
To find the footprints of others
Who have gone before

You may feel nervous
Tread slowly and carefully
To find your way there

A new life for you
From carer to champion
Footprints shaped by you

A Better Side Of Me

Commentary

One champion wished it to be conveyed that he had become a better person because of his experiences as a Champion, which he described as ‘a better side of me’. During the interview he was tearful as he recounted the stories of the people, he met in the sessions who were living with dementia and their carers and was touched by their experiences. He described a lack of confidence and poor attitude in the past but described himself as a changed person.

A Better Side Of Me

I am finding a better side of me
I wonder when change will come
I hear your stories
I see your struggles
I want a future without dementia
I am finding a better side of me

I pretend to be confident
I feel upset by your tears
I touch your hand
I worry at your distress
I cry you are so young
I am finding a better side of me

I understand in a deeper way
I say there is more to the person than dementia
I try to make a difference
I hope in possibility
I am finding a better side of me

Connecting With stories

Commentary

There were many voices heard during the interviews with champions. The voices of people living with dementia and care givers attending sessions, the voices of the champion’s experiences, the voices of the communities they engaged with and the voice of society encompassing views, beliefs and interpretations of dementia in the 21st century. Voice reflects the words, the meanings, and the interpretation of the experiences of champions in the context of time and place.

Connecting With Stories

Behind the words
Voices are heard
Feelings rise
Relived anew
Thinking through
A different time
Finding meaning
In what you do

Picture Of You

Commentary

Champions shared the connection they felt with the people they met. At times it brought them back to their own experiences, people, times, and events, caring for someone living with dementia.

Picture Of You

Deep within his eyes
The picture of you appears
From a different time

Section 4: Dementia Friendly Communities

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- Time Is Money 86
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The Mire Of Dementia

Commentary

This poem uses metaphors to capture the complexities of dementia. Plaques and tangles are terms used to describe the changes in the brain associated with dementia but also represent trying to find a way through a boggy area with growth that can hinder or block the way forward. The emotional element is captured in the last verse with a focus on hope. Despite the difficulties, in navigating in the darkness of limited knowledge and understanding, there is always hope that it is possible to live well with dementia. Hope that one day it will be a condition that can be managed, if not cured, and viewed in the same way as other long-term conditions. Champions shared the belief that raising awareness about the condition could shape attitudes and understanding, help people manage situations better, and create a sense of hope.

The Mire Of Dementia

I walk in darkness
Through the mire of dementia
As I step forward
Plaques and tangles entrap me
Searching for the place called ‘Hope’

Strands And Stories

Commentary

The poem represents the way the Dementia Friends initiative has grown since 2013 and how connections are being made across organisations and communities. Case studies and examples show individual, organisational, and societal changes taking place to improve understanding of dementia, reduce stigma and turn understanding into action to promote dementia friendly communities.

Strands And Stories

The fragility
Of the spiders web is seen
In all its beauty

The first thread strengthened
Built quickly, purposively
Will not be broken

The web grows bigger
Creating new connections
Intricate and strong

Woven together
Individual parts are lost
A new form is found

Otherness

Commentary

One champion talked about negative attitudes expressed by some people, the view that dementia did not relate to them, and a fear and avoidance culture. She was passionate about changing the ‘us and them’ attitude and the need for people living with dementia to say what would make a difference in their lives.

Otherness

Living well
Or living in hell
It’s up to you
To act
Let’s end the silence
The stigma, the fear
No more otherness but us

Time Is Money

Commentary

Champions shared how some organisations were reluctant to release staff to attend Dementia Friends sessions. There were time and cost implications and organisations needed to see what was involved and how it was relevant to them. The examples shared reflected the skills required to be a champion to be able to discuss and negotiate at all levels within organisations as well as the skills to set up and deliver sessions in a variety of settings and locations.

Time Is Money

Time is money you say
Don’t want to see
What dementia is
What dementia does

Time is money you say
Don’t want to see
What you can know
What you can do

I say - not true
Someday, some time
It could be you

Time is money well spent

Inclusion

Commentary

The term Dementia “friendly” could be challenged as being patronising if thought to be directed at the individual. However, Dementia Friends aims to promote inclusive communities, where people living with dementia are not labelled or face discrimination because of their diagnosis. Although not yet achieved it will be extraordinary to see this in the future.

Inclusion

Ordinary me
In ordinary places
Extraordinary

Free Not Fearful

Commentary

Fear about attitudes to dementia, fear of disclosure and fear or being treated differently can result in people with dementia facing greater hardship. As a result, they may miss out on opportunities and not receive the support or services they need. Champions gave many examples of how the Dementia Friends sessions had enabled people attending sessions to share their diagnosis for the first time.

Free Not Fearful

Severing the link
That binds us to fear
Frees us to live

Seeing Me

Commentary

Goffman (1963) refers to spoilt identity as an identity that causes a person to experience stigma. How dementia affects identity was picked up by several champions. They discussed delivering the key messages including ‘there is more to the person than dementia’. Rather than being a series of losses, it can be a time to try new things, develop in new ways and take on new roles. This led to discussion about how a diagnosis of dementia could affect identity, roles, responsibilities, and lifestyle choices. Although there are many champions who have dementia, two of the champions shared the view that there need to be more champions with dementia who can be role models and show that it is possible to live well with dementia. However, they recognised that it may not be possible to undertake the role at the later stages of the disease.

Seeing Me

Spoilt identify
Unacceptability
Finding me once more

Being A Friend

Commentary

Champions shared their thoughts about the meaning attached to the dementia friends badge. They described feeling proud to wear the badge, being dementia friendly, and a commitment to changing attitudes, understanding and action. Two of the champions gave specific examples of how it had made a difference when they were out in their local communities.

Being A Friend

Remembering you
The stranger who stops to ask
Will lighten the load

Side By Side

Commentary

The poem reflects the role of the champion working side by side with people living with dementia listening and responding. It is not about speaking for the person but about each person taking responsibility to bring about change

Side By Side

I am

Standing with

Not standing for

Speaking up

Not speaking more

Seeing you

Not seeing past

Stepping up

For change that lasts

Asking what

I can do

Not what could be done

For you

Dementia

Commentary

Reflecting on the use of research poetry, one may ask what a viable poem is and what elements need to be present. Seeing the word ‘me’ in the word dementia reminds us of the person living with dementia at the centre, surrounded by carers and supporters, communities, and the bigger society. Working together we can all make a difference to the lives of people living with dementia. One word can capture many things.

Dementia

DeMEntia

References

Alzheimer’s Disease International (2016) *Dementia friendly communities*

https://www.alz.co.uk/dementia-friendly-communities last accessed 08/06/19

Alzheimer’s Society (2017) *Dementia friends* https://www.dementiafriends.org.uk/ last accessed 08/06/19

Alzheimer’s Society (2017) *Dementia friends champion*

https://www.dementiafriends.org.uk/ last accessed 08/06/19

Butler- Kisber, L. (2010) *Qualitative inquiry: Thematic, narrative an arts-informed perspectives*. London Sage

Faulkner, S. L. (2016) *Poetry as method: Reporting research through verse*. Abingdon; Oxon: Routledge

Furman, R. Enterline, M. Thompson, R. and Shukraft, A. (2012) Poetry matters, A case poetry in social work, *Journal of Social Intervention: Theory and Practice,* 21 (1), 5-17 DOI: http://doi.org/10.18352/jsi.283

Goffman, E. (1963). *Stigma; notes on the management of spoiled identity.* Englewood Cliffs; N.J.: Prentice-Hall.

Patrick, L. D. (2016) Found poetry: Creating space for imaginative art- based literacy research writing, *Literary Research: Theory, method, and practice*, 65 (1), 384- 403 DOI: 10.1177/2381336916661530

Leggo, C. (2005) The heart of pedagogy: On poetic knowing and living, *Teachers and Teaching*, 11 (5), 439-445 https://doi.org/10.1080/13450600500238436

Prendergast, M. (2016) *Poetic inquiry 11- seeing, caring, understanding: using poetry as and for inquiry*. Rotterdam: Sense Publishers

Smith, J. A. Flowers, P. and Larkin, M. (2009) *Interpretative phenomenological analysis: Theory, method, and research*. London: Sage.

World Health Organisation (2018) *Dementia*. https://www.who.int/news-room/facts-in-pictures/detail/dementia

10.1.2 Poem cards/ Exhibition

Quotes

I can relate back to certain things that have happened to me (Participant 4)

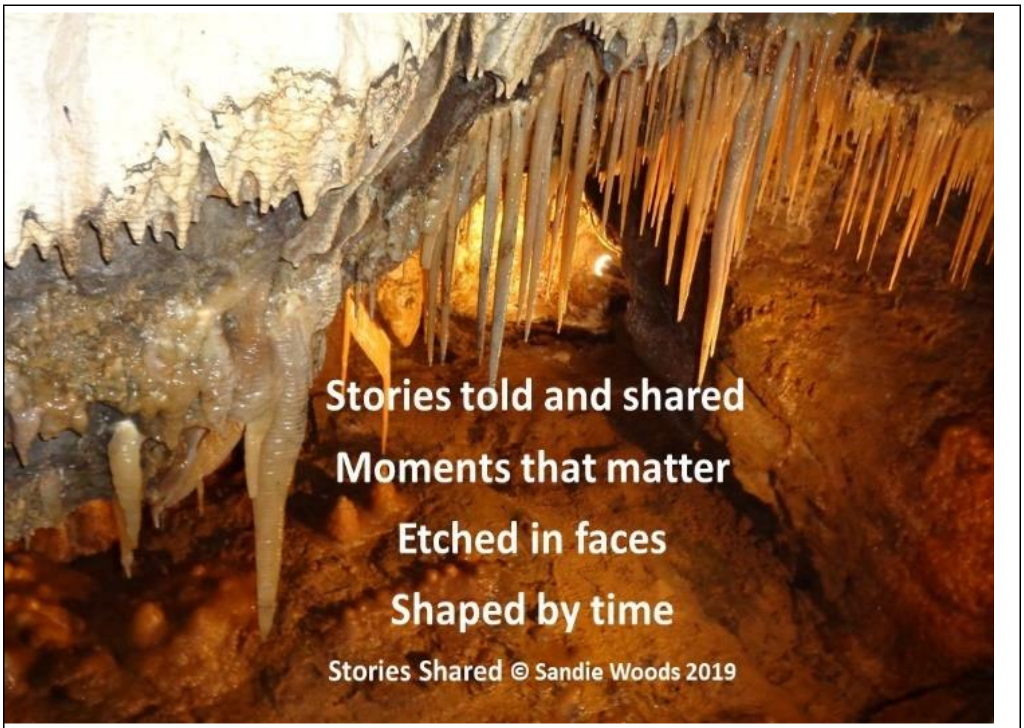
Look dementia can be a very emotive thing (Participant 6)

Telling them it can be an emotive topic actually then gives people the freedom to speak (Participant 9)

If you use your own examples, then sometimes your own emotion can kick in and then you think well this session isn't about me (Participant 9)

Commentary

Ten of the eleven champions interviewed had experience of family members who had lived or were living with dementia. When delivering the sessions, they had to keep to the format in the resource handbook and not introduce their own examples and experiences. However, the stories they heard from people attending, and the emotional aspects of their interaction, were often powerful and led to their own experiences and feelings being brought to the fore. It created challenges at times, due to the need to stay composed and deliver the session. They reflected on these moments and how they managed the emotional aspects of the role. A word, a story or a look could trigger memories and experiences. The emotional connection, whilst challenging, was important in the role.



Quotes

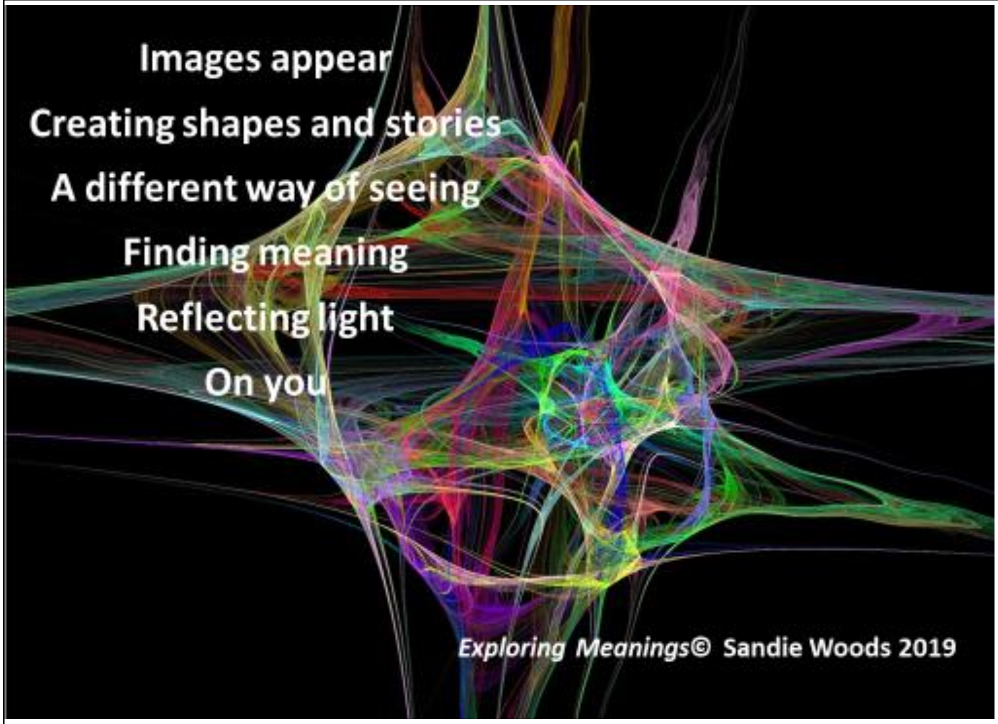
It has made me think of things that I could have done better but then I was doing the best I could at the time (Participant 2)

I perhaps had not anticipated quite how much people were just sort of desperate for support, you know there was one man in particular who was trying to support either his mum or his mother-in-law and really struggling (Participant 3)

I think it's important to talk about it in a way that doesn't negate the difficulties (Participant 10)

Commentary

The stories shared during the interviews reflected the champions own experiences of dementia and the people they encountered in the role. The interviews highlighted the level of engagement with the audiences, the relationship, connection, empathy, rapport, and trust developed with the people they met. Feelings of past and present experiences were often expressed non-verbally.



Images appear
Creating shapes and stories
A different way of seeing
Finding meaning
Reflecting light
On you

Exploring Meanings© Sandie Woods 2019

Quotes

My Aunt had died just before I did the dementia friends training, she had vascular dementia. The training actually gave me some answers as well (Participant 1)

It's altered my knowledge my belief and views (Participant 2)

By changing attitudes, it is possible to improve quality of life for people with dementia, particularly the early stages (Participant 5)

I would like to think that we have all got a bit more of an insight (Participant 8)

Commentary

For many, it was the first time of speaking in depth about becoming a champion, their lived experiences, the insights gained and their commitment to raising awareness about dementia. Being a champion had personal meaning for each of them. Poetry provides a way to engage in a different way to condense and capture the essence of the experience. Poetry also provides shape and space on the page, moving from the bigger picture and going deeper to capture meaning.

Quotes

A lot of those people sooner or later are going to experience it within their own family or within their close-knit friends. And so hopefully the Dementia Friends session will enable them to manage that better. So, I think that is a hope for the future (Participant 2)

I think it is about communities making a difference. It is a community focused approach (Participant 3)

Most of those people are picked up by the community and supported by the community and you hear some brilliant stories where people have stopped and they won't leave the person until their loved one has been contacted (Participant 4)

I think it's the awareness like a seed (Participant 10)

Commentary

People attending dementia friends sessions often came with limited knowledge about dementia but a desire to learn more. Through the delivery of the key messages they left with a greater understanding and confronted the fear and stigma associated with dementia. In a short space of time a seed had been planted that could grow and develop resulting in a change in attitude and perception about dementia. Understanding was turned into action.

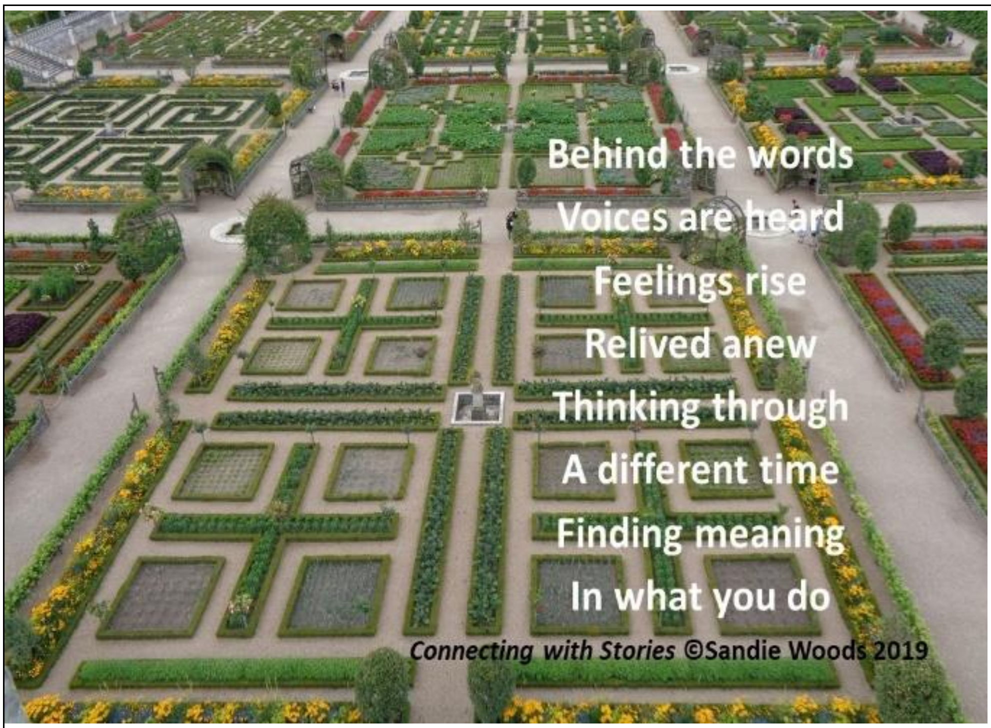
Quotes

I often say, forget everything else just remember this, emotional memories last and I've got a personal illustration of that you see (Participant 2)

Their emotions still exist, and they are who they were despite the changes in their cognition, so there is more to a person than just their memory (Participant 5)

Commentary

One champion, with extensive experience, reflected on gaining insights into the meaning of caring and the importance of emotional connections with people living with dementia. Emotional memory and connection are key components in the Dementia Friends sessions. It does not matter if the person cannot remember timelines or the detail of events, as the feelings and emotional connection remain.



Quotes

This is a sort of whole movement swell and I think it is hugely exciting because it has brought dementia out of the shadows. People have heard of it now. What they need though is a deeper understanding of the effects it has (Participant 2)

I think the personal experience gave me a completely different perspective in terms of the challenges for every day caring and being, and for someone with dementia to remain part of society (Participant 5)

The whole idea of a dementia champion giving a session is it is a human being portraying his or her concern for another human being (Participant 11)

Commentary

There were many voices heard during the interviews with champions. The voices of people living with dementia and care givers attending sessions, the voices of the champion's experiences, the voices of the communities they engaged with and the voice of society encompassing views, beliefs and interpretations of dementia in the 21st century. Voice reflects the words, the meanings, and the interpretation of the experiences of champions in the context of time and place.

Quotes

I can relate back to certain things that have happened to me (Participant 4)

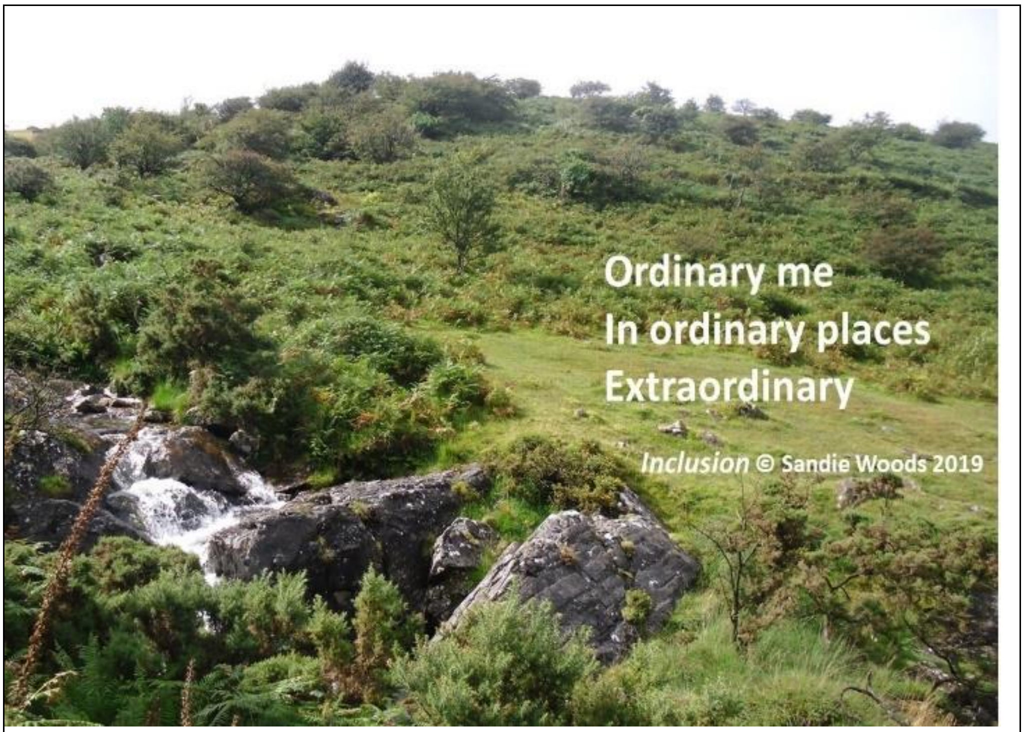
She had dementia and my mother took it very personally that her mother couldn't remember who she was. That really made me want to cry actually, that was very emotional (Participant 7)

It is close to me because my mother suffered from dementia and I never knew how to deal with it to be quite honest (Participant 11)

Commentary

Commentary

Champions shared the connection they felt with the people they met and how at times it brought them back to thinking about their own caring experiences, people, times, and events.



Quotes

Connection- connecting people together with society and their environment (Participant 5)

Ordinary human beings with a story with a life history that can with support live a normal life (Participant 7)

If we can talk about those people over there who are experiencing that then we can sort of distance it from us. So, it's difficult sometimes when you do kind of bring people into the fold and think actually that is us, that is everybody you know (Participant 10)

Commentary

The term Dementia “friendly” could be challenged as being patronising if thought to be directed at the individual. However, Dementia Friends aims to promote inclusive communities, where people living with dementia are not labelled or face discrimination because of their diagnosis. Although not yet achieved it will be extraordinary to see this in the future.

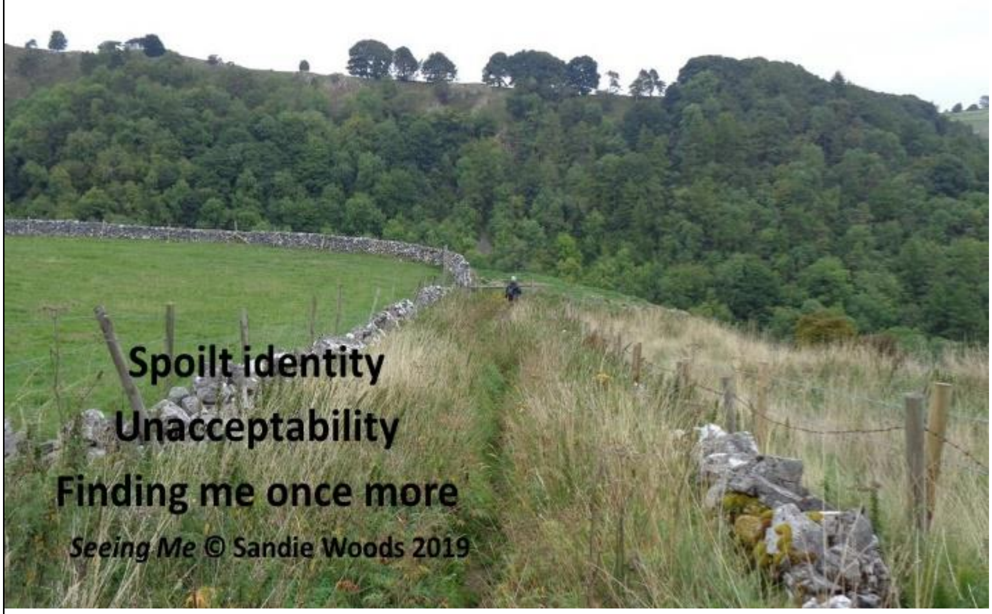
Quotes

People are terrified that you know their loved ones are going to forget who they are (Participant 4)

I think there is a fear, the fear kind of stops people seeking help or fear of you know having a relative that is diagnosed with dementia so I think to reduce that fear I think that would make a big difference for people with dementia (Participant 5)

Commentary

Fear about attitudes to dementia, fear of disclosure and fear or being treated differently can result in people with dementia facing greater hardship. They may miss out on opportunities and not receive the support or services they need. Champions gave many examples of how the Dementia Friends sessions had enabled people attending to share their diagnosis for the first time.



Quotes

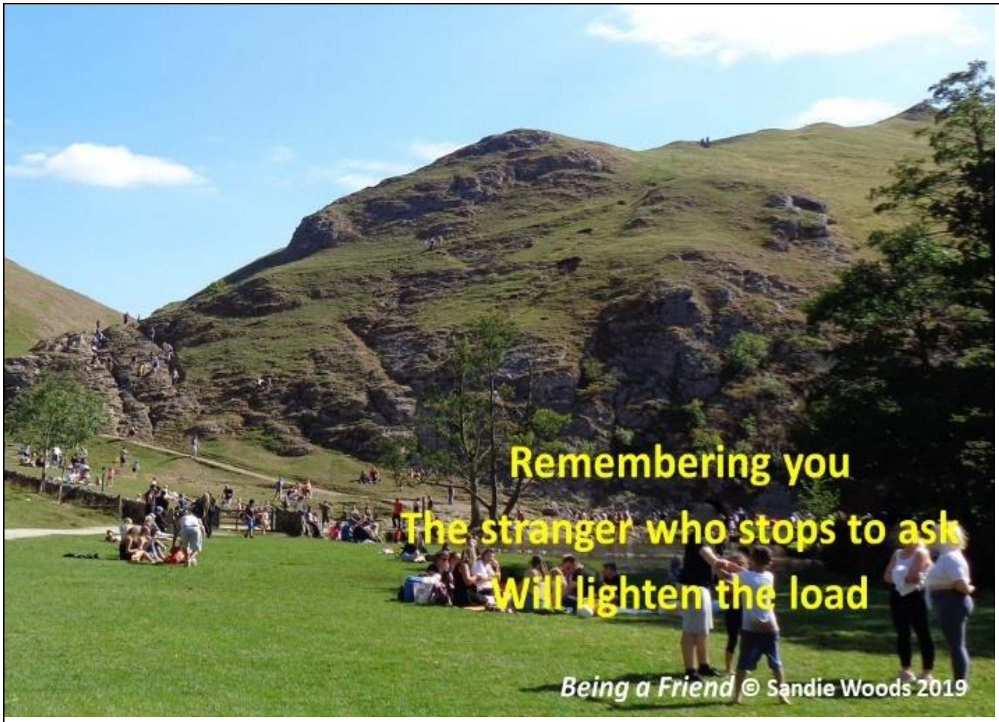
It's that's potential to counter stigma. I think that is probably my driving force in a way (Participant 10)

Embedding awareness or embedding understanding or helping people understand and helping people see people with dementia differently (Participant 10)

If you have met one person with dementia you have met one person with dementia (Participant 10)

Commentary

Goffman (1963) refers to spoilt identity as an identity that causes a person to experience stigma. How dementia affects identity was picked up by several champions. They discussed delivering the key messages including 'there is more to the person than dementia'. Rather than being a series of losses, it can be a time to try new things, develop in new ways and take on new roles. This led to discussion about how a diagnosis of dementia could affect identity, roles, responsibilities, and lifestyle choices. Although there are many champions who have dementia, two of the champions shared the view that there need to be more champions with dementia who can be role models and show that it is possible to live well with dementia. However, they recognised that it may not be possible to undertake the role at the later stages of the disease.



Quotes

Most people who wear the badge will wear the badge because they feel slightly more empowered (Participant 4)

I have had people give me a thumbs up and say I'm a champion you know (Participant 11)

If we are going to change the world which I think we are intending to do aren't we. You've got to believe it's possible (Participant 4)

I found a better side for myself. Let me relate this please (Participant 6)

Commentary

Champions shared their thoughts about the meaning attached to the dementia friends badge. They described feeling proud to wear the badge, being dementia friendly, and a commitment to changing attitudes, understanding and action. Two of the champions gave specific examples of how wearing the badge, and what it symbolises, had made a difference when they were out in their local communities.

Step onto the bridge
To find the footprints of others
Who have gone before

You may feel nervous
Tread slowly and carefully
To find your way there

A new life for you
From carer to champion
Footprints shaped by you

Bridge to Understanding© Sandie Woods 2019

Quote

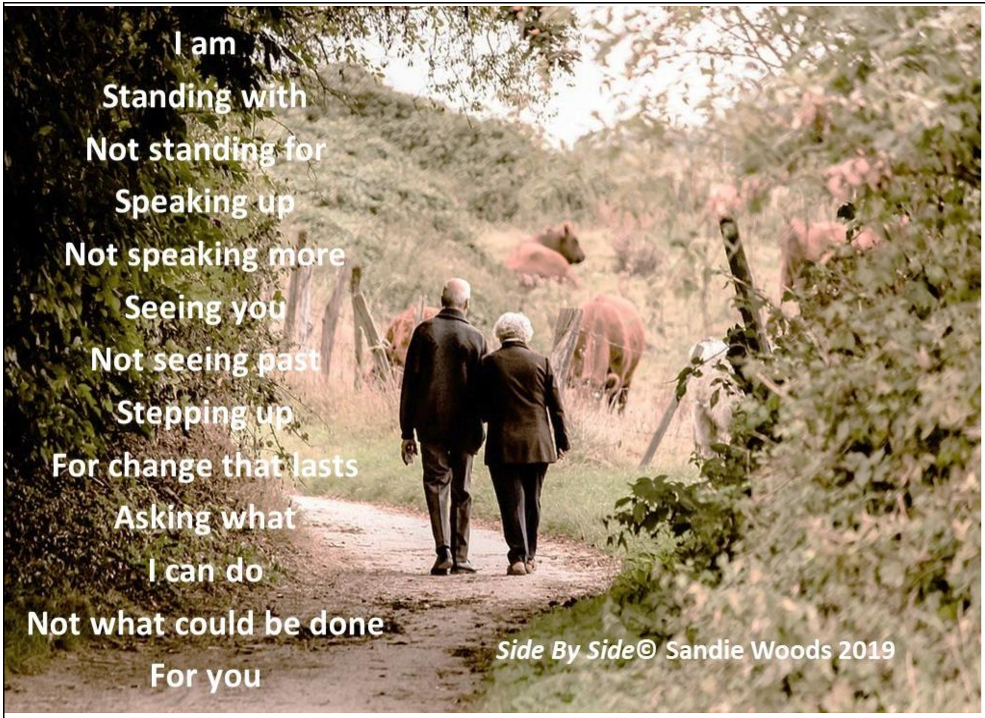
I came into the Alzheimer Society because I was a carer, I still am a carer (Participant 4).

There is still a need for better quality of care at the end stages of dementia because until that is not resolved, people would still fear dementia and there will still be quite a negative attitude to dementia and that would then prevent people from getting early diagnosis (Participant 5)

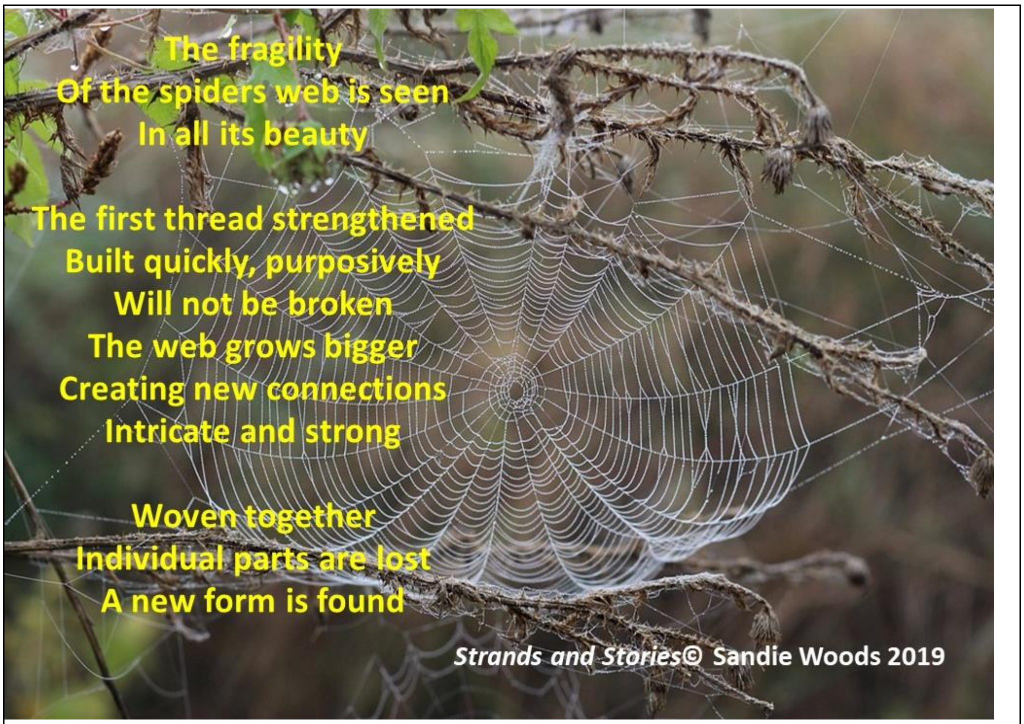
During that time, I recognised my bad attitude towards disabled people and not only did something about it but also found a pleasure in relating (Participant 6)

Commentary

The poem represents the stories, experiences and events that shaped the decision to become a champion. Many of the champions interviewed were influenced by family members living with dementia and the desire for things to be better, particularly in end of life care



Quote
Humbling, emotional, and I feel very proud to be involved in the movement really, because it is a social action movement and so I will proudly wear my badge and I proudly tell people about it and I feel very lucky to have been, to have found out about it and to have actively got involved with it really (Participant 7) It's that's potential to counter stigma. I think that is probably my driving force in a way (Participant 10) I suppose I would just like people to appreciate that we are all the same, we are all human beings and I would like people to just be open minded enough to not buy into all the ways that people get segregated you know (Participant 11).
Commentary
The poem reflects the role of the champion working side by side with people living with dementia, listening and responding, It is not about speaking for the person but about each person taking responsibility to bring about change and promoting inclusion



The fragility
Of the spiders web is seen
In all its beauty

The first thread strengthened
Built quickly, purposively
Will not be broken
The web grows bigger
Creating new connections
Intricate and strong

Woven together
Individual parts are lost
A new form is found

Strands and Stories© Sandie Woods 2019

Quote

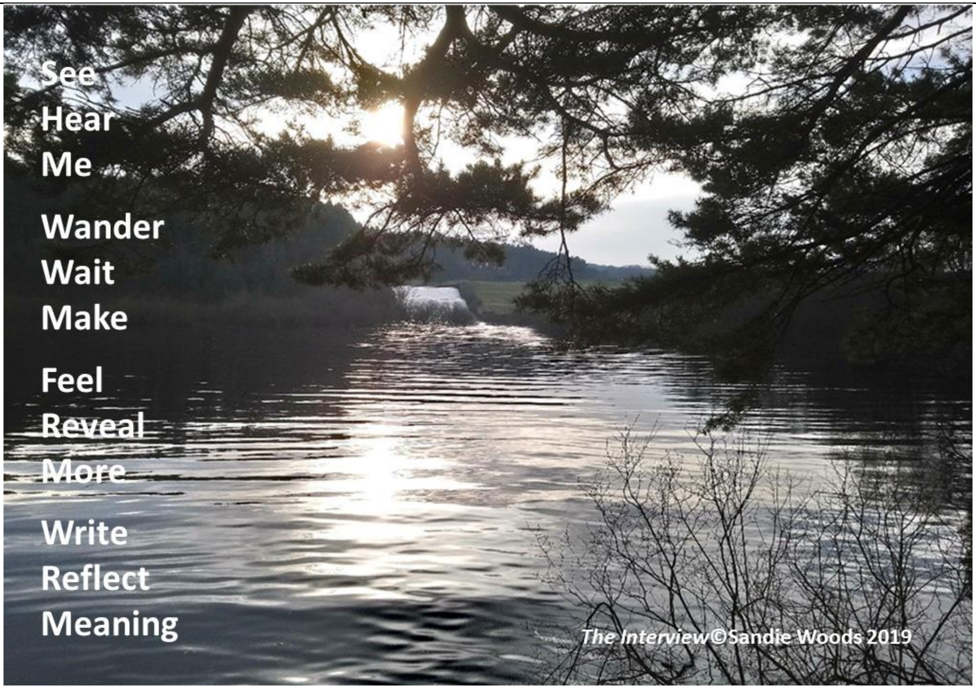
So I think it has been really taken up by so many of these organisations and I'm hoping you know it's really starting to make a difference (Participant 3)

It's about people actually thinking dementia is important (Participant 8)

They (Scouts) had actively as a group made a choice that was something they wanted to do and so then they tapped into the Alzheimer's Society (Scouts) (Participant 10).

Commentary

The poem represents the way the Dementia Friends initiative has grown since 2013 and how connections are being made across organisations and communities. Case studies and examples show individual, organisational and societal changes taking place to improve understanding of dementia, reduce stigma and turn understanding into action to promote dementia friendly communities



Quote

But in my own personal life, I've talked about it with my family, but I haven't really taken it any further (Participant 4)

It's been great having an opportunity to talk about it because I don't think I've ever talked about it in any other capacity really because it's not as you say it's not really something that is talked about (Participant 10)

Commentary

The poem reflects undertaking an in-depth interview for the research.

The first stage represented meeting with the person, being focussed and actively engaged. It meant being attentive to their comfort and respecting and valuing their contribution.

The second stage involved creating a relaxed atmosphere allowing the person to tell their story. It could be described as wandering through life events and experiences together and creating opportunities for the person to explore and make connections. It required time and space to wait as thoughts, ideas and insights fell into place.

The third stage represented the emotional connection and empathy between the researcher and participant. There was an emotional component to sharing experiences and expression of feelings that may not have previously been revealed or surfaced anew.

The fourth stage is the move from interview to writing up. It represented the researcher’s responsibility to stay true to the interviewee’s words whilst capturing the meanings behind the lived experience of being a dementia friends champion.

10.1.3 Student evaluation of poem cards (written consent given)

Person centred care

(Poem cards -poem and image “Being a friend”)

01/03/19

Activity:

- View and review the postcard with a poem and image conveying a message about person centred care.
- Work alone, or with a fellow student, and use the materials to represent person centred care in words, images, or symbols.
- Share the content and meaning of your work with the group.
- Reflect on arts-based approaches to convey a message.

No of feedback sheets: 18

Student evaluation:

- I enjoyed the activity. I liked the use of art and metaphor to convey an important message. It helped stimulate my own ability to share a belief or motivate others.
- Good way of reflecting what we have seen and learnt in practice and what can be improved.
- It was helpful to have the opportunity to reflect on this fundamental concept of person-centred care and to break it up into the component parts. I think these ideas will be at the forefront of my mind while on placement.
- Initially a bit daunting/ alarming. Positive to see everyone’s ideas. Good to think about it differently and break the ‘lecture format’. Also finding a word or symbol or image condenses and focuses the thoughts about what person-centred means.
- Sometimes it is too much information around with too many words and people just do not take the time to read it because it is just too much. So, it would be better to have less words but sharp straight to the point with images. My suggestion is staff wear a badge where you can read “with me you are safe”. Probably the effect on the patient is better rather than to read an

A4 poster with plenty of words stating how staff can make them safe.

- Makes us think about the importance of person- centred care. Sharing our posters allowed us to learn from our peers. Highlights the importance of the 6 C’s.
- An interesting way of learning about person centred care. Vital and important to learn and understand. A great way of fully appreciating the importance of dignity, care, supporting treatment “compassion in person centred care”.
- I enjoyed the activity. It helps with understanding what we believe is person centred care. The postcard can explain the 6 C’s to service users especially when you may not have had the same experience.
- The activity was very thought provoking and made me think deeply. Especially because I am on placement in an oncology ward and many patients are planning their last days/ funerals and then will go home/ hospice to pass away. As a student the activity has helped to think about quality of life and how people can live their last days in peace and without pain.
- The activity was an interesting way to think and visualise how we can represent person centred care.
- I quite liked that we could choose to work individually or with others but then had the opportunity to come together as a big group to share. There was a nice feeling of common purpose, warmth, and celebrating each other’s ideas and skills.
- The activities of the postcards regarding dignity is very interesting. It brings out the best in you regarding your heart and feelings towards others.
- It has been great to come back to uni from the placement and to emphasise the importance of person-centred approaches in practice. I’ve found the activity is warming the heart and inspiring to carry the values of dignity, respect and the appreciation of an individual.

- Person centred care puts the person at the heart of what we do.
- Different ways of ensuring person centred approach to care. It all revolves around the patient’s needs.
- The experience was important to realise that each person is an individual and needs to be in the middle and the head of care. Their views need to be valued so that the person feels valued, respected, and listened to.
- The activity was good, but I personally wasn’t clear what we were required to do, and I am not a creative type of person. I understood what was required when everyone else gave feedback to the group. I think you should continue with this activity in the future. Thank you.
- Very thought provoking and a good activity to allow for creativeness, also nice to see all the different work people in the class did and feedback to each other. Overall a nice activity.

10.2 Reflection

10.2.1 Reflection example 1 (Driscoll model)

A description of the event- **What**

An analysis of the event- **So what**

Proposed action following the event- **Now What** (Driscoll, 2007)

What?
Having completed the taught component of the EdD the time had come to commit to the research for the next three years. The first step was deciding on the research topic/ question. I had been focussed on investigating the experience of caring for an individual living with dementia. Moving from the topic to defining the question proved to be a far greater challenge. Sitting with pen and paper I started to write, each time recognising how changing one word in the research question was leading me to different theories, methods, and approaches I list below some of questions that I produced and reflected on in the process • How do carers use poetry writing to express the impact of caring for some with dementia? • How have carers used poetry to express the experience of caring for a relative with dementia • How have carers expressed the experience of caring for a relative with dementia • What are the experiences of caring for a relative with dementia: an analysis of poetry writing and reflection? • What are the experiences of caring for a relative with dementia: expressed through poetry writing? • How does poetry express the experience of caring for someone with dementia What does poetry tell us about the experience of dementia? • Learning about caring for someone with dementia through poetry

So what?

I began to question:

- How was poetry being used- would it be poetry produced from existing research, would it be current, and would that be suitable for a professional doctorate?
- Would I interview carers and produce poetry?
- How could I ensure it was participatory and how would I ensure that the poems reflected the experiences of carers?
- Would there be a poem for every interview, or would poems represent themes?
- Would I ask carers to write poetry to express their experiences?
- How would I access carers and what about the ethical issues?
- Could I do something purely based on my own experiences?
- Do I have the skills to produce poetry that would reflect meaning?

The more questions I asked the more uncertain I was. I found myself recognising that I was trying to make my desire to write poetry about the experience of caring for someone with dementia fit the requirements of a professional doctorate and it was not working. Feedback from one EdD supervisor highlighted that he was not convinced by my argument/ proposed study design.

I decided it was time to stop and rethink the research.

I began to recognise that there was nothing to stop me writing poetry about my experiences to share with others, but it would not be the EdD.

I began to think about other scholarly activity I could undertake in relation to caring for a person living with dementia. This included a literature review, systematic review, reflective account, or journal article based on personal experiences of writing poetry to express the experience

Now what?
Back to the beginning to reflect on: What aspects of Dementia have not been developed/ require further research? What do I want to study for the next three years? What matters to me and is an important area of investigation? How can my passion for poetry writing, poetic inquiry and arts-based approaches be used in research?

Driscoll, J. (2007) *Practising Clinical Supervision: A Reflective Approach for Healthcare Professionals*. 2nd ed. Edinburgh: Bailliere Tindall

10.2.2 Reflection example 2 (Kawa model)

Reflecting on the dementia friends champions experiences

Culture

In Westerns culture the self is socially constructed and situated in relation to the context or surroundings. In Western spheres independence, autonomy, equality, and self-determination are seen as ideals.

In the Kawa model the self is not central or unilaterally empowered but one of many parts of an inseparable whole. There is no need to gain control, but the self is part of the whole. There is an integration of self, nature, and the environment. The links between the self and the environment mean a change in one may result in a change in the other. In the metaphor of the river life is seen as a metaphor to represent the journey through time and space. Lives are shaped by surroundings, people, and circumstances.

Concepts

- A person’s bodily impairment becomes disabling when interfaced with the environment.
- Once the rocks are known, including the size and situation, intervention can be identified to improve the flow
- The river can be seen in a time and place
- Community assets and circumstances provide a real and potential impact
- Spaces represent the interrelationship between all the components
- Rhythms and cycles of change
- Harmony is seen as a state of individual or connective balance

How and why

Concept	Champions experiences
River flow  Past, present and future Priorities, driving force	• Experience and impact of dementia (family, friends) • Being a carer • Increasing numbers of people with dementia

Significant people	• Empathy, compassion
River banks  Environment, physical and social	• Alzheimer’s Society engagement • Access to communities • Communities becoming dementia friendly • Dementia Action Alliance and other charities helping • Media influence and high-profile advocates
Rocks  Obstacles and challenges Fears, concerns, circumstances	• ‘Us’ and ‘them’ mentality • Fear and stigma • Lack of knowledge • Time, money, and relevance issues for organisations • End of life care dissonance with messages (not living well with dementia) • Emotional impact and resilience • Energy and motivation • Need greater than provision • Other commitments • Sustainability
Driftwood  Influencing factors Personal traits, characteristics Skills, abilities, experiences Beliefs, values principles Social connections assets and circumstances	• Meeting other champions • Known in the community • Work roles/ contacts • Belief that change can happen • Personal passion • Hope for the future • Local, national, and worldwide action

Spaces Opportunities for enhancing flow New channels Rocks become smaller Riverbanks become wider New pieces of driftwood to push away the rocks	• Alzheimer's Society • Regional officers and networks • Known in the community • Individual action • Community action • Government action • Policy and practice • Family and friends

Links to the research

- Champions are spreading the messages that it is not us and them, but we are all responsible and have a role to play in raising awareness and taking action
- Reducing the physical and social barriers will improve well-being for all
- The research represents a specific time and place and change is not only possible but expected
- The champions are one way to reduce the rocks/ barriers, increase the driftwood/ assets and increase the flow/ dementia friendly communities

References

Iwama, M. K. Thomson, N. A. Macdonald, R. M. (2009) The Kawa model: The power of culturally responsive occupational therapy, *Disability and Rehabilitation*, 31 (14), 1125-1135

Teoh, J. Y. and Iwama, M. K. (2015) *The Kawa Model Made Easy: A guide to applying the Kawa Model in occupational therapy practice*, 2nd ed, Retrieved from: www.kawamodel.com

10.2.3 Reflection example 3 (Kawa model)

I used the Kawa Occupational Therapy model as a tool to reflect on the experience of undertaking the doctorate (Teoh and Iwama, 2015). ‘Kawa’ is the Japanese word for river and a metaphor to depict one’s life journey. There are five interrelated constructs including:

- River flow (life flow and priorities)
- Riverbanks (environments/ contexts, social and physical)
- Rocks (obstacles and challenges). Can also include ‘rocks’ as significant others in life
- Driftwood (influencing factors)

Spaces (opportunities to enhance flow)

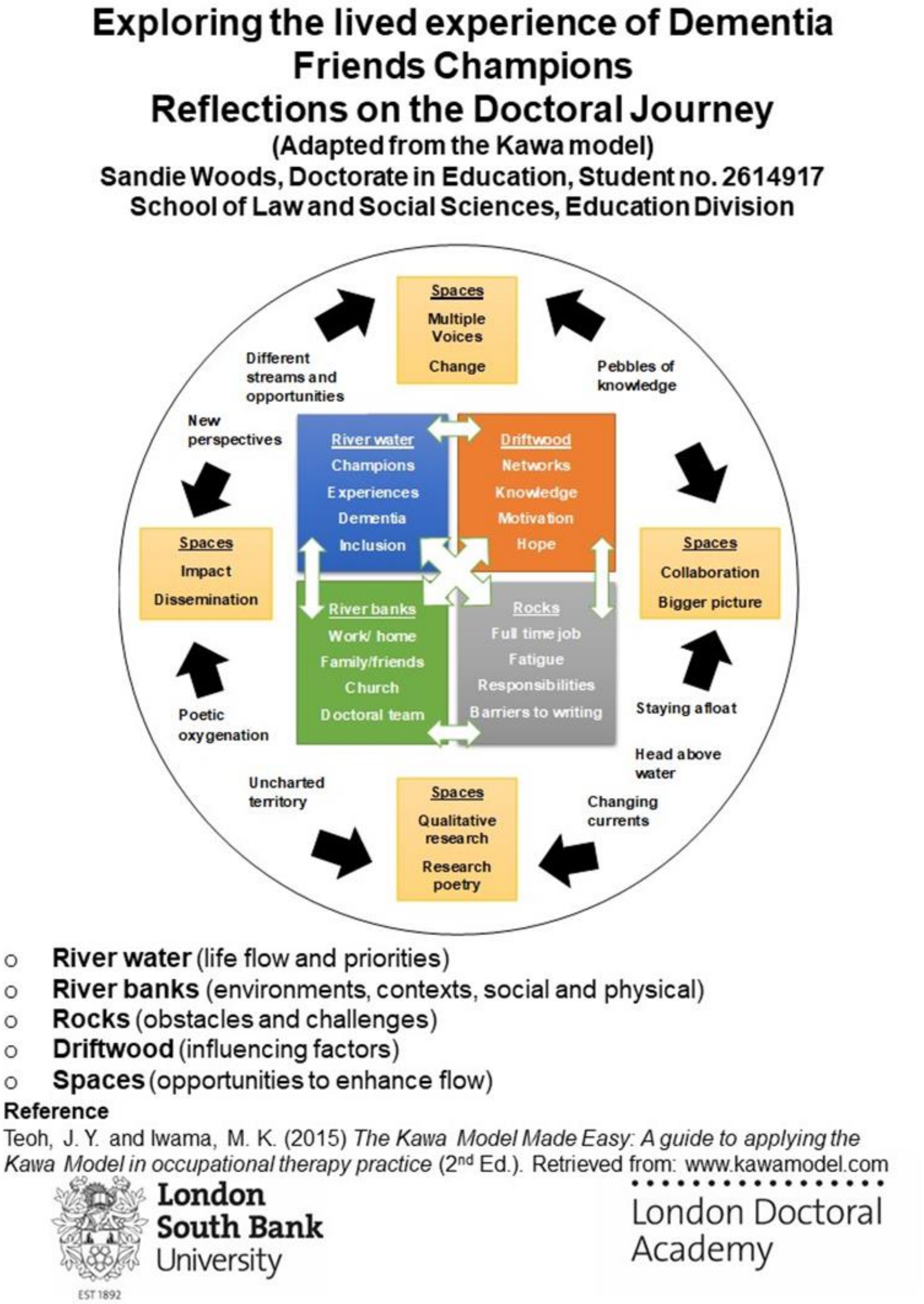
Kawa Concept	**Details (present and past)**
Water (life flow, priorities, past, present, and future)	• The experiences of dementia friends champions for the research. What, why and how. • Important role but very limited research. • Striving for a better future for people living with dementia and their carers. Dementia care, justice, inclusion, dignity, personhood.
River flow (streams, flowing into it, moving more powerfully)	• Increasing numbers of people living with dementia and a health priority. Action taking place across the world and a drive for change.
Rocks (obstacles and challenges)	• Time, full time job, workload, competing demands, tiredness. • Combining two approaches to present the research- academic and arts based created additional work. • Responsibilities as carer. • Fear of not completing in time.

	• Barriers to writing, feeling overwhelmed not knowing what to start on first. • Keeping my head above water
Riverbanks (environment, physical, social)	• Place of work- immersed in teaching, research, and academic environment. • Family and friends- support for health and well-being. • EdD supervisors- ongoing support. • EdD student group- on the journey together for over six years. • Interest from colleagues. • Spiritual life, church, keeping things in perspective, resilience and reflecting on meaning in life.
Driftwood (Beliefs, values, principles, personal resources, assets, skills, liabilities	• Networks and connections- contact with many organisations and people in the field of dementia and arts-based research. • Developing knowledge of qualitative research, research poetry, dementia research and a passion for them all. • Motivation, determination, commitment, hope, believing change will happen. • Employment providing financial stability and ability to pay for courses to develop skills.
Spaces (relationship between then all)	• Seeing the bigger picture. • Parts all coming together. • Impact of research- new knowledge. • Opportunity to make a difference • Academia and arts-based research • 3-minute thesis- synthesis/ essence of the research

Additional insights and perspectives	**Details (present and past)**
Finding different routes, areas of interest and unknown territories	**River flow:** • Rather than steering along the river on a tried and tested route I saw new streams, routes, and opportunities on the way. • Joining a collaborative poetics working party took me down a stream where I contributed to new and exciting developments but also delayed my progress and led to competing demands. • Taking a different route and incorporating two approaches to presenting the research involved exploring unknown territory and a world I had not previously encountered.
Going against the flow	**Rocks:** • Deciding how to integrate the research poetry into the thesis, trying different ways • Writing a research poetry book with commentary and incorporating the poetry into the findings chapter. • Producing poem cards and posters from the research
Kawa	**Details (future)**
Spaces: How to flow more powerfully Opportunities to enhance the flow	• Participatory research • Publish research and disseminate the poetry book • Conferences and forums • Promoting opportunities for arts-based research for students • Teaching arts-based research methods

	• Integrating more arts-based approaches into teaching • Develop the use of the Kawa model as a research method and engage with the network
Where the river meets the sea	• The end of one journey • The beginning of a new journey • Meeting others who have navigated the journey/ journeying together

10.2.4 Reflection example 4 (Kawa model)



Exploring the lived experience of Dementia Friends Champions
Reflections on the Doctoral Journey
(Adapted from the Kawa model)
Sandie Woods, Doctorate in Education, Student no. 2614917
School of Law and Social Sciences, Education Division

Spaces
Multiple Voices
Change

Pebbles of knowledge

Spaces
Collaboration
Bigger picture

Staying afloat

Head above water

Changing currents

Spaces
Qualitative research
Research poetry

Uncharted territory

Poetic oxygenation

Spaces
Impact
Dissemination

New perspectives

Different streams and opportunities

River water
Champions
Experiences
Dementia
Inclusion

Driftwood
Networks
Knowledge
Motivation
Hope

River banks
Work/ home
Family/friends
Church
Doctoral team

Rocks
Full time job
Fatigue
Responsibilities
Barriers to writing

- **River water** (life flow and priorities)
- **River banks** (environments, contexts, social and physical)
- **Rocks** (obstacles and challenges)
- **Driftwood** (influencing factors)
- **Spaces** (opportunities to enhance flow)

Reference

Teoh, J. Y. and Iwama, M. K. (2015) *The Kawa Model Made Easy: A guide to applying the Kawa Model in occupational therapy practice* (2nd Ed.). Retrieved from: www.kawamodel.com

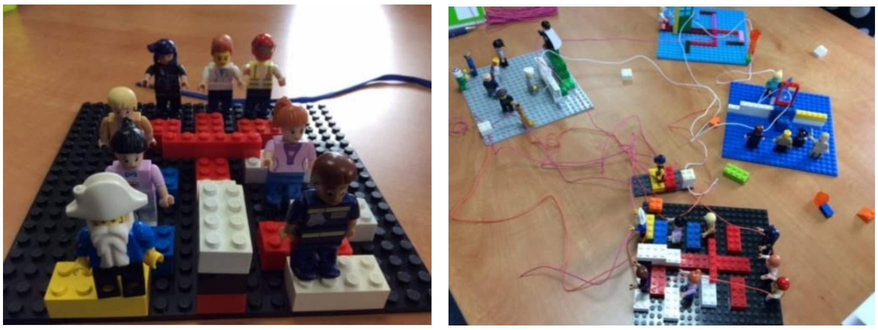
London South Bank University
EST 1892

London Doctoral Academy

10.2.5 Reflection example 5 (Lego bricks)

Title: Fostering wellbeing through creative reflective practice for PhD Students and Supervisors **Venue** SRHE: 14th March 2019

Facilitators: Nicole Brown (UCL Institute of Education), Jennifer Leigh & Jo Collins (University of Kent)



Attendees selected pieces of Lego and designed a representation of their doctoral journey. In small groups, they discussed similarities, differences, meanings, emotions and learning from experience. Then, they considered common patterns or threads in the doctoral journey, represented visually by joining the models together with string.

Observations

The workshop title and description showed it was an interactive day and involved creative approaches for students and supervisors. The group seemed familiar with the Lego bricks and figures and several attendees shared how they had used it in play as children. Some were eager to get to the table and begin the creative process, others showed less excitement at the opportunity for creativity. There were limitations due to the number and type of figures and set shapes and structures. It promoted reflection and a relaxed and informal way to share with others. It would be interesting to find out more about how it translated across cultures and ages and whether childhood familiarity would have an influence. Reading the research undertaken by Brown and Collins (2018) provided additional insights into how it enabled participants to engage creatively. Brown, N. and Collins, J. (2018) Using Lego to understand emotion work in doctoral education, *International Journal of Management and Applied Research*, 5(4), pp. 193-209. https://doi.org/10.18646/2056.54.18-014

10.2.6 Reflection example 6 - Personal statement: The doctoral journey using the metaphor of a puzzle

I use the metaphor of a jigsaw puzzle to describe my doctoral journey. The pieces were in the box, but the lid was missing that provided the complete picture. There were lots of shapes, each providing a small part of the picture, but I could not see what the final landscape would look like when I started.

Over time I put pieces together and it began to take shape. It was colourful, captured my interest, and was the biggest puzzle I have ever undertaken.

At times I put the pieces in the wrong place or tried to fit them together and they did not match. I had to go back, take them apart and take a fresh look to identify where they fitted. I worked on different parts of the puzzle rather than one section at a time which meant there were gaps with aspects of the picture missing.

I had supervisors and fellow students helping me with the puzzle and my husband always encouraging me to carry on and providing the solid base that stopped the pieces falling onto the floor. Everyone brought a fresh eye to the task, identified when they did not seem to fit or there was a mismatch, and made suggestions about how I should reconfigure it. As I continued the step by step progress the image became clearer. There were still some incomplete sections, but I started to feel I had an idea of what the finished picture would look like. I was eager to see the product.

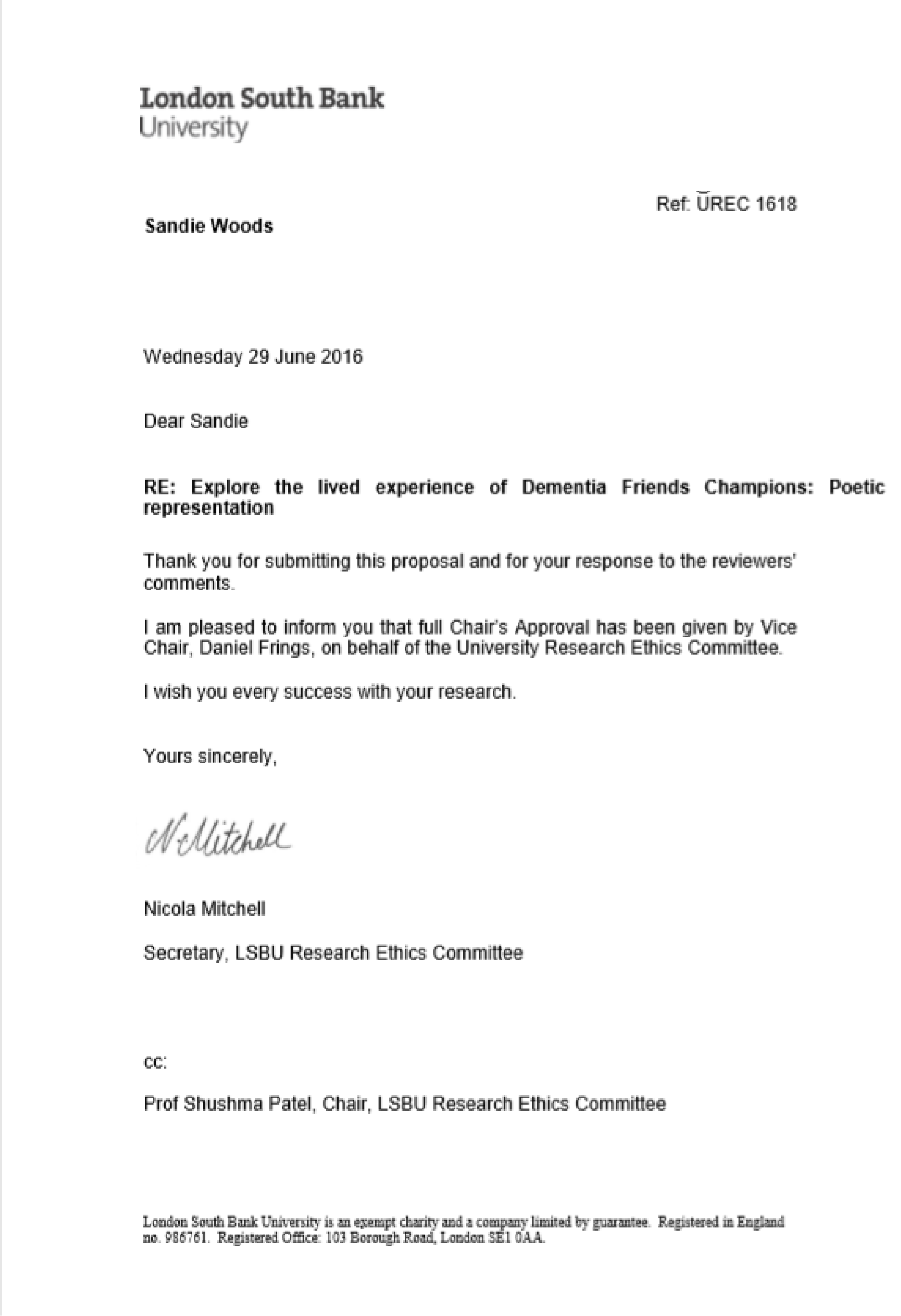
Constructing the puzzle required patient effort. There were times when lots of puzzle pieces were added and times when it sat there untouched. Every time I returned; I became aware of perspectives I had not noticed previously. No two pieces were the same and each part contributed to the overall aesthetics of the work.

I showed the puzzle to lots of people and discussed why I was doing it and how I had approached the task. I talked about how much I liked the landscape and what it meant to me. I also listened to many people who had completed similarly large puzzles and heard about the strategies they used.

It has taken a long time to finish the puzzle but as I place the final pieces, I recognise what has been created from so many small parts. Looking at the picture I notice it has been taken from a certain angle with a specific lens. Some images are larger in the foreground and some appear in the distance. I notice at the edges there are pieces of the landscape missing and some parts are a little blurred. I recognise that if the photograph on the puzzle box had been taken from a different angle, in another setting or at a different time, the final picture would have looked different. I can see what it has to offer, and I enjoy sharing it with others. There is a sense of satisfaction in seeing the results of the work and it was worth doing. I will come back to the main parts of the picture, but I will also look at the edges and corners of the puzzle to see what I did not notice the first time.

10.3 Forms and research participant engagement

10.3.1 Ethics approval letter



London South Bank
University

Ref: UREC 1618

Sandie Woods

Wednesday 29 June 2016

Dear Sandie

RE: Explore the lived experience of Dementia Friends Champions: Poetic representation

Thank you for submitting this proposal and for your response to the reviewers' comments.

I am pleased to inform you that full Chair's Approval has been given by Vice Chair, Daniel Frings, on behalf of the University Research Ethics Committee.

I wish you every success with your research.

Yours sincerely,

N Mitchell

Nicola Mitchell

Secretary, LSBU Research Ethics Committee

cc:

Prof Shushma Patel, Chair, LSBU Research Ethics Committee

10.3.2 Participant information sheet

Title: Explore the lived experience of dementia friends champions: Poetic representation

You are invited to participate in a research study to share your experiences of being a dementia friends champion. The research is being undertaking as part of a Doctorate in Education at London South Bank University. Please take the time to read the following information and get in contact if anything is not clear or you need additional information. Take time to decide whether or not you wish to participate.

What is the purpose of the research?

The aim is to explore the experiences of dementia friends champions who are delivering sessions with the goal of establishing dementia friendly communities.

Why have I been chosen?

You have been chosen because you are a dementia friends champion and have delivered at least three sessions to adults in London.

Do I have to take part?

It is up to you to decide whether or not to participate. If you do decide to take part, you will be provided with a participant information sheet and consent form at least two weeks before the interview. You will be asked to confirm that you meet the eligibility criteria of delivering at least three sessions to adults in London or South East. The consent form can be signed on the day of interview. The interview guide will also be made available to you before the interview. If you decide to take part, you can still withdraw until the transcribing of the interview has taken place and you have had the opportunity to see and confirm it is an accurate record of the interview.

What will happen if I take part?

If you agree to participate you will be invited to a one to one interview with the researcher, at a time and location that is convenient to you. This may be in a meeting room at your place of work, local vicinity, or at London South Bank University in a quiet and confidential space. The interview will be approximately one hour. With your permission the interview will be digitally recorded and transcribed. The transcript from the interview and poems produced will be made available to you.

What are the possible benefits of taking part?

It will provide an opportunity for you to share your experiences and insights from being a dementia friends champion and delivering Dementia Friends sessions.

What are the possible disadvantages of taking part?

It is not envisaged that there will be any disadvantages in taking part in the research. To ensure you feel comfortable with the information you choose to share it might be helpful to think about the experiences prior to the interview. You will also be provided with a copy of the interview guide. Should sharing any experiences trigger an emotional reaction the interview can be stopped, and support provided. The Alzheimer's Society also provide a National Dementia Helpline 0300 222 112. Further details can also be found on their website: https://www.alzheimers.org.uk/site/scripts/documents.php?categoryID=200365

Will information be kept confidential?

All information will be kept confidential and there will not be any reference to names or identifiable information. Each transcript will be anonymised and given a code and the poems produced will not identify individuals.

Data collected will be stored in a locked filing cabinet and on a password protected computer and kept within the timescale laid out by the university (10 years). The regulations can be found online at: http://www.lsbu.ac.uk/__data/assets/pdf_file/0018/36630/safeguarding-good-scientific-practice.pdf

What will happen to the results of the study?

Electronic copies of the report will be available for participants on request.

Who has reviewed the study?

The proposal has been reviewed and approved by the Research Committee at London South Bank University.

Contact for further information?

If you require any further information about the study please contact Sandie Woods, lead investigator. If you wish to raise any concerns, please contact the lead research supervisor Dr Nicola Martin. You may also contact the research ethics committee on ethics@LSBU.ac.uk

Thank you for reading the participant information sheet and considering taking part in the study

Lead Investigator: Sandie Woods Senior Lecturer Department of Allied Health Sciences Faculty of Health and Social Care	**Lead research supervisor:** Dr Nicola Martin. PhD Associate Professor Head of Research and Postgraduate Courses Department of Education London South Bank University

10.3.3 Consent form

Title of Investigation: Explore the lived experience of Dementia Friends Champions: poetic representation

- I have read the attached information sheet on the research in which I have been asked to participate and have been given a copy to keep.
- I have had the opportunity to discuss the details and ask questions about this information.
- The investigator has explained the nature and purpose of the research and I believe that I understand what is being proposed.
- I understand that my personal involvement and my particular data from this study will remain strictly confidential.
- I have been informed about what the data collected in this investigation will be used for, to whom it may be disclosed, and how long it will be retained.
- I have been informed that the interview will be approximately one hour and digitally recorded.
- I understand that I am free to withdraw from the study at any time, without giving a reason for withdrawing.
- I hereby fully and freely consent to participate in the study.

Participant's Name :(Block Capitals) ……………………………….
Participant's Signature: ……………………………….
Date: ……………………………….

As the Investigator responsible for this investigation I confirm that I have explained to the participant named above the nature and purpose of the research to be undertaken.

Investigator's Name: ………………………………….
Investigator's Signature: ………………………………….
Date: ………………………………….

10.3.4 Interview guide

Interview Guide

Can you tell me about why you became a dementia friend’s champion?

Can you share your experiences of being a dementia friends champion?

What was it like for you?

What did it mean to you?

What have been the benefits of delivering sessions?

What have been the challenges of delivering sessions?

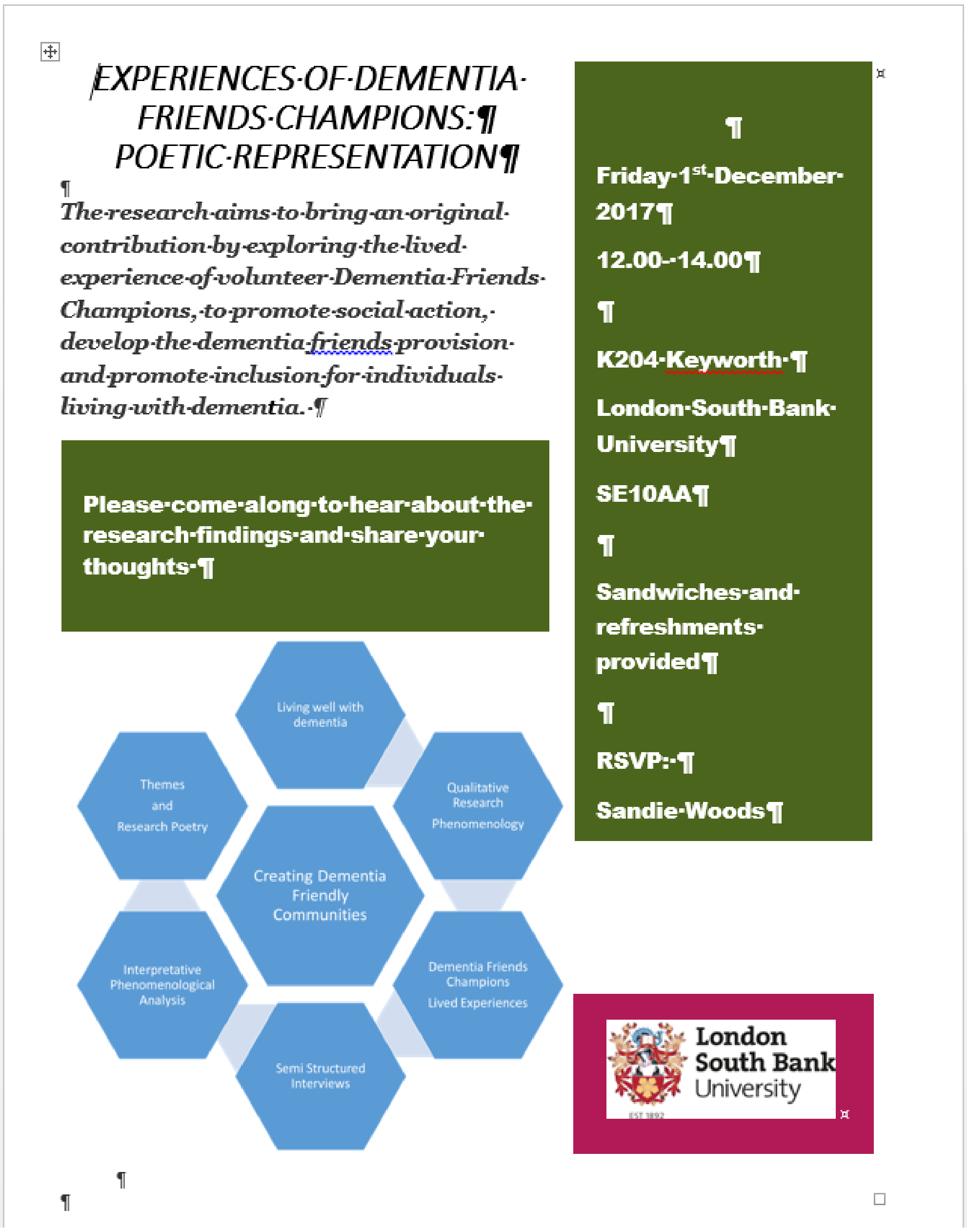
What have you learnt as a result of being a dementia friends champion?

Can you tell me about whether being a champion had an impact on your understanding or beliefs about dementia? Can you give some examples?

How do you think we can create dementia friendly communities?

Please feel free to share further thoughts and insights from your own experience

10.3.5 Flyer for meeting with research participants



EXPERIENCES OF DEMENTIA FRIENDS CHAMPIONS: POETIC REPRESENTATION

The research aims to bring an original contribution by exploring the lived experience of volunteer Dementia Friends Champions, to promote social action, develop the dementia friends provision and promote inclusion for individuals living with dementia.

Please come along to hear about the research findings and share your thoughts

Friday 1st December 2017

12.00 - 14.00

K204 Keyworth

London South Bank University

SE10AA

Sandwiches and refreshments provided

RSVP:

Sandie Woods

London South Bank University

10.3.6 Feedback from research participant engagement

Meeting with research participants, supervisors, and colleagues

1st December 2017

Feedback from participants

- Brilliant
- Poems you give us are so real
- Poems are very powerful and emotive
- Your simple poems are very effective
- Clear emphasis on finding out about the person's background, acknowledgement of them, their skills, and talents

Feedback from supervisors, researchers, academics

- Please deliver this session to the Critical Disabilities Research Group
- Poems are very emotive, and I can see how they would bring comfort to a lot of people
- Mind maps are a clear visual representation. Consider adding the use of colour for themes

Comments/ suggestions/ ideas for development

- Interesting how there are shared themes across the participants and some singular
- Diagrams are clear
- Themes are relevant and the posters are a good idea
- It would be helpful to write up to clarify how Dementia Friends works in the organisation (employer, employee, support)

10.4 Literature review

10.4.1 PEOT Inclusion and Exclusion Criteria

	Inclusion	Exclusion
P	Dementia champions, supporters Adults (18 and above)	Not a dementia champion, supporter Not including children
E	Undertaking any champion role to raise awareness and support people with dementia and their carers in any setting	Not undertaking a dementia champion role
O	Experience of being a champion	Not including experience
T	Qualitative, quantitative, or mixed method research study design. In English. Between the years 2000-2019	Not research. Excluding opinion piece, editorial, commentary, discussion, reflection. Not in English. Before the year 2000

10.4.2 Databases and grey literature

Databases	**Grey Literature**	**Other sources**
Amed	Authors of research papers and experts in the field e.g.Hayashi contacted	Alzheimer's Research UK and Alzheimer's Europe, Alzheimer's Research and Therapy
Cinahl	Conferences (Alzheimer's Champs, Alzheimer's UK)	Alzheimer's Society UK
Dementia Sage Premier	Alzheimer's Society Regional Officer London and South East contacted	Alzheimer's Disease International
Education Research complete	Email alerts, policy, research, and practice	Bradford University Dementia Research
Google scholar	Policy documents	British Medical Journal
Internurse	Reviewing reference lists	Dementia Action Alliance
Medline via Ebsco	EthOs PhD thesis online British Library	Department of Health
Psychinfo	ResearchGate	Dementia Research UK
Qualitative Health Research		Dementia Engagement and Empowerment Project (DEEP)
Sage Premier		Dementia Special Interest Groups
Scopus		Direct to specific journals

		Dementia magazines (Dementia Care)
		Higher Education Dementia Network (HEDN)
		Health Education England UCL Academic Health Science Partnership Dementia
		Mental Health Foundation
		National Institute for Health and Clinical Excellence
		Royal College of Nursing
		Royal College of Occupational Therapy
		Skills for Health and Skills for Care
		Social Care Institute for Excellence (SCIE)
		Society for Research in Higher Education (SRHE)
		World Health Organisation

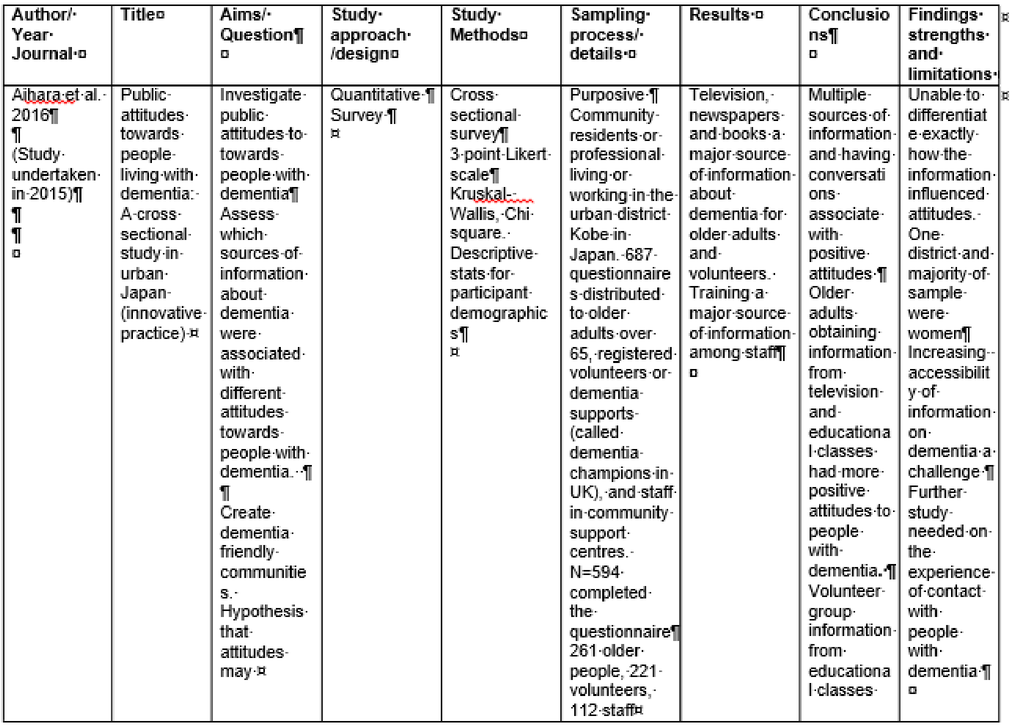
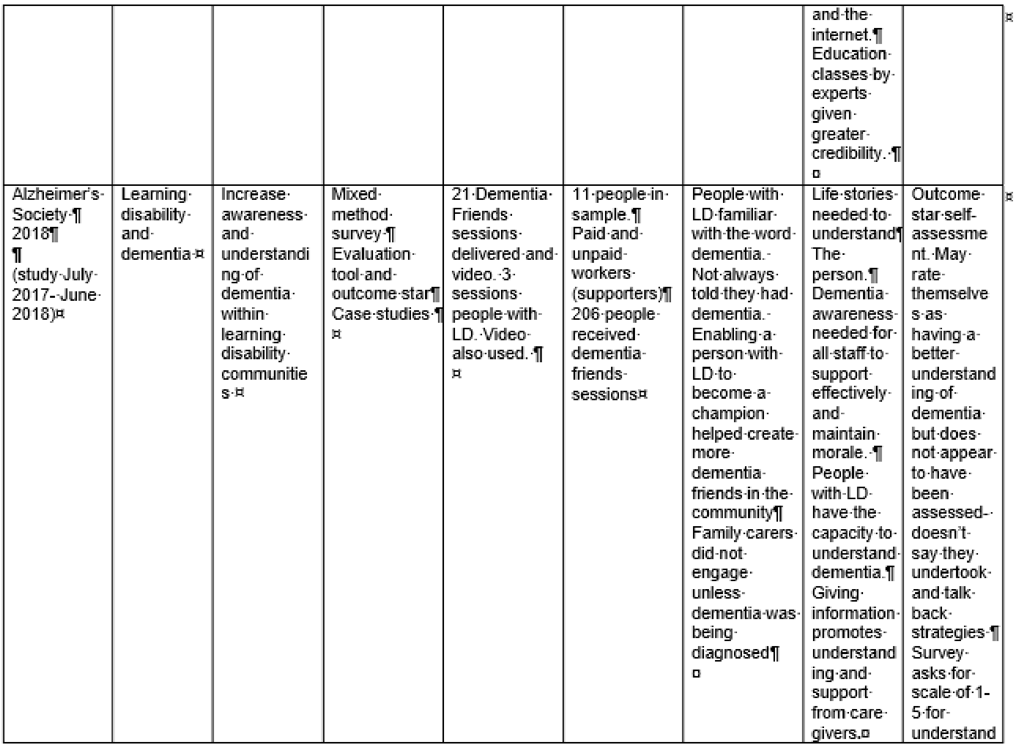
10.4.3 Narrative synthesis

- Identification of a theory
- Definition of a question
- Search for literature
- Appraisal of literature
- Textual description of the data
- Tabulation of the data
- Thematic analysis of the data
- Similarities in the data
- Differences in the data

10.4.4 Strengths, limitations, opportunities, and threats in being a dementia champion identified from the literature

Strengths	Weaknesses
• Increased knowledge and skills in dementia care • Improved communication skills • Improved patient care • Staff satisfaction • Seeing change within settings • Positive responses and engagement from the public and communities • Clear leadership • Motivated senior person	• Lack of control to bring about change • Change in staffing/ rotations • Different needs within different settings • Not always feeling supported • Lack of qualification or remuneration • Difficulty engaging people with dementia and carers
Opportunities	**Threats**
• Career development • Autonomy to act • Communities of practice • Diversity of approaches	• Sustainability • Time to undertake the role with competing demands • No clear understanding of the role • Lack of remuneration • Cost implications in delivering schemes and initiatives • Stakeholders engagement variable and changing • Curriculum demands • Focus on charity rather than state provision affecting equity across geographical areas

10.4.5 Data Extraction

Author/ Year Journal	Title	Aims/ Question	Study approach /design	Study Methods	Sampling process/ details	Results	Conclusions	Findings strengths and limitations
Aihara et al. 2016 (Study undertaken in 2015)	Public attitudes towards people living with dementia: A cross sectional study in urban Japan (innovative practice)	Investigate public attitudes to towards people with dementia Assess which sources of information about dementia were associated with different attitudes towards people with dementia. Create dementia friendly communities. Hypothesis that attitudes may	Quantitative Survey	Cross sectional survey 3 point Likert scale Kruskal- Wallis, Chi square. Descriptive stats for participant demographics	Purposive Community residents or professional living or working in the urban district Kobe in Japan. 687 questionnaires distributed to older adults over 65, registered volunteers or dementia supports (called dementia champions in UK), and staff in community support centres. N=594 completed the questionnaire 261 older people, 221 volunteers, 112 staff	Television, newspapers and books a major source of information about dementia for older adults and volunteers. Training a major source of information among staff	Multiple sources of information and having conversations associate with positive attitudes Older adults obtaining information from television and educational classes had more positive attitudes to people with dementia. Volunteer group information from educational classes and the internet. Education classes by experts given greater credibility.	Unable to differentiate exactly how the information influenced attitudes. One district and majority of sample were women Increasing accessibility of information on dementia a challenge Further study needed on the experience of contact with people with dementia
Alzheimer's Society 2018 (study July 2017- June 2018)	Learning disability and dementia	Increase awareness and understanding of dementia within learning disability communities	Mixed method survey Evaluation tool and outcome star Case studies	21 Dementia Friends sessions delivered and video. 3 sessions people with LD. Video also used.	11 people in sample. Paid and unpaid workers (supporters) 206 people received dementia friends sessions	People with LD familiar with the word dementia. Not always told they had dementia. Enabling a person with LD to become a champion helped create more dementia friends in the community Family carers did not engage unless dementia was being diagnosed	Life stories needed to understand The person. Dementia awareness needed for all staff to support effectively and maintain morale. People with LD have the capacity to understand dementia. Giving information promotes understanding and support from care givers.	Outcome star self-assessment. May rate themselves as having a better understanding of dementia but does not appear to have been assessed- doesn't say they undertook and talk back strategies Survey asks for scale of 1-5 for understand

								ing of dementia - confidence scale not answer yes or no to check knowledge 11 people out of the 206 for in depth work Case studies provide additional qualitative information
Banks el al. 2014 (study Oct 2011 - Feb 2012)	Enriching the care of patients with dementia in acute settings? The dementia champion programme in Scotland	Bring participants knowledge and skills to enhanced level Develop, deliver and evaluate a training programme to prepare NHS and Social Services dementia champions working in acute settings as change agents for practice. Distance travelled based on attitudes, achievement of learning and confidence	Mixed method Service evaluation. Self -reported evaluation Mixed method questionnaire prior to starting programme and at the end - 2 points in time.	Self -reported evaluation questionnaire prior to starting programme and at the end - 2 points in time.	100 health care professionals working in acute settings. 4 sites across Scotland between October 2011 and February 2012.	T test from questionnaire - positive response regarding person centred approaches. Positive response to time with people with dementia. Needs identified included suitable environment, education, identification of people with dementia, communication with people with dementia, involving relatives and carers, identifying and managing delirium.	Change agent - N=92 93% had or would change practice as a result of doing the course. Promoted the formation of a network of champions. Cost effective	Not all participants completed all parts of before and after. Identify that it could be transferred to other groups of staff and settings. Not possible to gauge impact on patient care Self-efficacy not included at the beginning so no baseline. Participants anonymous so not able to identify location or follow-up at later date
Bartlett, R. 2015	Visualising dementia activism: using the arts to communicate research findings	Use art to explore individual and collective strength of people to with dementia and enhance understanding of active citizenship. Alter perceptions about	Qualitative arts based approach (part 2 of research) Research communication project - 'No limits reimagining life with dementia'.	3 creative workshops about being active in their community. Artist designed 5 textile banners. Work exhibited. Visual scholarship. Transform research findings into artwork.	7 people participated in the follow up study - 4 men and 3 women and a social scientist, curator and installation artist. All those involved in the first study were invited to participate	Participants expressed themselves in a way that data collection tools could not. Art and image making mobilised emotions. Outputs by artist could people's imagination and attention,	Summary - art offers - fluid ways of knowing, multiple meanings, creative outlets, aesthetic vision, and multiple ways of experiencing the world. Cannot	Discussed recording the discussion during the arts based workshops

		dementia and ageing.		Touring exhibition textile banners, homemade protests placards and a documentary film.		transformative and new way of understanding. Space for the researcher, participants and viewers to discover something about themselves. Newness, new knowledge and insight in the space between research, art and the public. Took attention away from the research	offer- tethered knowledge, factual information, explanations, solutions or answers, certainties	
Brooke et al. 2017 Took place in 2015	Exploring the impact of dementia- friendly ward environments on the provision of care: A qualitative thematic analysis	Perceptions and experiences of the impact of the ward environments on the care nurses and health care assistants provide for patients.	Qualitative focus groups	10 focus group, 3 with HCA's, 2 qualified nurses and 5 with both groups- occurring naturally / not purposive selection for groups	Qualified nurses and health care assistants working in an acute NHS trust. Junior qualified nurses n=17 and health care assistants n=21 Purposive Recruited via flyers in staff rooms and monthly staff meetings	4 themes- changed environment, more options for person centred care, constant nurse presence, resistance to change. Mixed reactions from both groups- provided more options for the care of patients and closer proximity during the working day. Bay nursing- continued presence of staff. Dementia friendly wards increased contact with patients, increased person centred care and possible reduction in harm	The study was linked to training staff were receiving including 2 hour dementia awareness (tier 1) and tier 2 through simulation (4 hours observing and interacting with actors in different scenarios.	Limitation of the study was they did not have staff who had worked on the ward before and after the environment changes. Change management strategies may help with future uptake
Buckner et al, 2018	An evaluation tool for age friendly and dementia friendly communities	How an evaluation tool was pilot tested in dementia friendly communities (Sheffield)	Qualitative	Scoping conversations, documentary analysis, interviews and group discussions. 2 interviews with stakeholders	Steering groups and 2 interviews.	Strengths - Involvement of older people, service provision, collaboration, monitoring and evaluation. Tool adapted	Gaps in relation to LGBT and services for those newly diagnosed and their carers.	Pilot. Further research needed. Tool useful – 10 evidence input areas

				in dementia related roles Three steering group meetings. 5 month piloting exercise		to focus on dementia friendliness. Offered a range of services but		
Chalk and Page, 2014	Dementia RED (Respect, empathy dignity); Collaborating to build dementia supportive communities in North Wales - reporting on a pilot project (innovative practice)	Raise awareness of three words that the sub group regarded as paramount to care - RED Educate staff to recognise early dementia and how to support them Develop staff knowledge and skills about services	Qualitative	Project 1: Care information centre point - 5 weeks Jan - Feb 2013 Project 2: Primary care champions 8 - advocating for patients and promoting active citizenship Project 3: action plan, engagement between primary care and the community, links with local authorities, staff training, update and share knowledge, develop knowledge of range of dementia care in UK Project 4: Key ring - raise profile - person behind the dementia care Project 5: Road show - I day	I locality team in North Wales created dementia sub group. Range of initiatives to engage the community	Build dementia supportive communities. Raise awareness and awareness of services. Results unclear	Pilot project. Unclear what next, cost implications or Sustainability. Unclear how it was funded	Pilot with lots of different aspects. Unclear what was most effective or the long term implications
Crampton and Eley, 2013	Dementia-friendly communities: what the project "Creating a dementia friendly York" can tell us	What constitutes a dementia friendly community and how to achieve it Experience of people with dementia post diagnosis exploring their everyday lives an contact they had with agencies	Qualitative	Walk their patch' with people with dementia followed by a 'sounding board' event to share ideas	? number. Cross sectional operational with existing organisations group (health and social care, leisure and housing, police), people with dementia and family carers	Factors were physical environment, local facilities, support groups, support services, social networks and local groups. 4 cornerstone model-place, people, networks and resources developed.	What is good for people with dementia is good for all Increased awareness about dementia and talk about it Change negative stereotypes Provide training Encourage people	Linked to an earlier study. Recommend communities need knowledgeable input from people with dementia and family carers.

							with dementia to enjoy the city of York Grasp technology and involve people with dementia in planning	
Ebert, et al. (2019)	Effects of dementia knowledge and dementia fear on comfort with people with dementia: implications for dementia friendly communities	Effects of dementia knowledge and fear on social comfort (interacting with people with dementia).	Quantitative, multiple regression. Measures- personhood based knowledge, personal dementia fear measure and biomedical knowledge measure from different existing scales.	Online platform (Qualtrics)	Online platform and advertisements at senior centres and dementia support groups. 645 Wisconsin residents USA. All over 18 and residents of Wisconsin. 76% women and 50.9% had a relative or friend with dementia. Age range 18-86. Occupations – paid and unpaid not recorded.	People with biomedical knowledge benefitted most from having personhood knowledge. Unable to give causal link at this stage.	Community members and professionals should seek a balance between biomedical knowledge and personhood based knowledge to promote social comfort to benefit the promotion of dementia friendly communities	Occupation not captured and could be a proportion were working in health or social care influencing results. Some parts of Wisconsin have initiative in place- dementia café etc. Authors conclude the importance of creating communities that foster personhood-based knowledge
Ellison et al. 2014	Evaluating the impact of the Alzheimer Scotland Dementia Nurse Consultants/ Specialists and dementia champions in bringing about improvements to dementia care in acute general hospitals. Newcastle Upon Tyne: Blake Stevenson	Evaluating the impact of the Alzheimer Scotland Dementia Nurse Consultants/ Specialists and dementia champions in bringing about improvements to dementia care in acute general hospitals	Mixed method evaluation. Case study	interviews and focus groups, surveys, desk based research review of training	Purposive	Both roles raised the profile of dementia and supported improvements in care environments, identification of those with dementia in acute care, delivery of person centred care, involvement of carers, responses to stress and distress. Positive change in DC's attitudes and practice	Development of dementia champions as change agents	Small numbers of social services DC's can't compare Difficulty recruiting people living with dementia and carers Difference in number in baseline and final survey. Issues of sustainability – uncertainty about the ASN role, DC's not supported, no clear sense of leadership or direction leading to

								risk to ability and motivation to continue to influence change
Fossey et al. 2018	A qualitative analysis of trainer/ coach experiences of changing care home practice in the well- being and health in dementia randomised control trial	Experiences of Dementia trainer/ coaches engaged in cascade model of delivery change care home practice Perceptions, resources and support	Qualitative Inductive Thematic analysis Braun and Clarke	Focus group Part of a larger RCT	N=12 8 therapists and 4 supervisors HSC professionals dementia trainer coach and supervisors Purposive	Theme 1: skills in relationship building with two subthemes – trust and getting to know individual staff and care home. Theme 2: making use of tangible resources with two subthemes manual and supervision. Theme 3: being an agent for change and three subthemes- effective training methods, opportunity for dementia champions to reflect and therapists perceived rewards of the role.	Time needed to develop skills and confidence in care home staff Time issues for staff Manual was overwhelming for some needed to use carefully and introduce slowly Need to tailor to home and needs Supervision and support important Knowledge level different Emotional and practice challenges	Therapists and supervisors together may have affected ability to express views All paid staff no volunteers Delivered across 36 care homes Cultural awareness of different care homes needed Cost implications and sustainability to be undertaken
Heward et al. 2017 Study during 2013- 2014	Dementia- friendly communities: challenges and strategies for achieving stakeholder involvement	Experiences, strategies and challenges to achieve stakeholder involvement in dementia friendly communities. To inform and guide the creation of dementia friendly community initiatives	Qualitative research	14 interviews and a focus group DFC steering group members and 4 part time project workers employed to develop initiatives. Only project workers engaged in interviews and focus group. Secondary data provided through project worker progress forms, good news stories minutes of meetings, press	All project workers	Progress in each of the 7 localities against the criteria for dementia friendly communities identified by the Alzheimer's Society. Most progress in challenging stigma, accessible community activities, respectful and responsive businesses and services .	Challenges in establishing networks and including people representative of the local population, involving people living with dementia, and gaining commitment from organisations	Small study. Only project workers. Stakeholder engagement is unpredictable and changeable and reliance on the approach questions long term sustainability.

				releases , news reports Dementia action alliance plans and memory awareness scheme forms				
Mayne et al. (2014)	Experience and opinions on postgraduate dementia training in the UK: a survey of selected consultant geriatricians,	How they gained experience and their opinions on current training	Quantitative	Mixed method survey	Contacted 100 UK dementia champions from the British Geriatric Society	Themes Lack of formal and structured training Variability of training across geographical areas Inadequate training at undergraduate and post graduate training Inadequate time spent on dementia as a sub speciality Lack of collaboration between geriatric and psychiatric side of training	They recommended having specific modules or formal qualification, mandatory attachments in curriculum, more exposure at undergraduate level	Only a select group of geriatricians in the study with high levels of interest in dementia Authors suggest an interview based study may have provided a higher response rate
Mayrhofer et al. 2016	The role of dementia champion in dementia care: Its aspirations, development and training needs (innovative practice)	Elicit their role and training needs	Quantitative survey	(Bristol online survey) Undertaken in 2015 25 questions with mix of multiple choice, multiple answer, and text questions. 10 mins to complete	34 participants from potential 188 (18%) In professional roles and practitioners. Nurses, therapists, emergency staff, senior practitioners, managers and support staff. 27 in NHS Trusts , 6 in social care, one did not disclose	53% (18) one day of training, 26% (9) half a day, 4 short course without qualification, 3 course linked to an award, 3 no training Dementia awareness training useful but limited	Suggest specific skills training and education programmes that are formally recognised and clarification around expectations for the role	Linked to previous study in Hertfordshire UK Small numbers in specific location in England
Mayrhofer et al. 2014	Health care professionals, variety of job descriptions, multiple organisations, role of DC with other roles	Setting up a Dementia Champions Community of Practice (DEMCoP) in Hertfordshire. A county wide group with shared identity to identify and address dementia training and	Mixed method	survey and meeting face to face with groups	Whole population of those known as DC's via database in Hertfordshire	120 people attended symposium Only small group had DC as recognised title No common roles DCs resistant to registering as a member on the online system	Community of practice, bottom up approach Need organisational framework with resources to maintain opportunities Changing jobs and	Part of a bigger project Engagement varied for different parts of the project Very diverse groups that have evolved

		development needs for the health and social care workforce.				NHS trusts with dedicated posts and staff for dementia care On lie resources for students not staff Newsletter reliant on people to contribute	organisational changes affecting roles Competing priorities	
Phillipson et al, 2018 2nd survey Undertaken in 2016	Involvement of people with dementia in raising awareness and changing attitudes in a dementia friendly pilot project (Australia)	Increase community awareness and understanding of dementia and reduce stigma in Kiama/ Australia and surrounding areas	Quantitative Delivering information in wide range of formats to over 1000 community members	2 cross sectional mixed method surveys 2014 and 2016 2 validated tools Paper relates to second survey undertaken in 2016	Convenience Sampling 174 completed questionnaire	Reduced stigma and reduced negative images	Direct involvement of people living with dementia improved attitudes and reduced negative stereotypes Need to compare different approaches • Awareness raising and educational activities- positive attitudes and reduction in stigma Multiple communication channels- increasing availability of information	Wide range of interventions- unclear what aspects were beneficial to shape future provision. Assumed that having people living with dementia as spokespersons and educators had a positive effect but unclear what was most beneficial Convenience sample/ self-selecting those who were interested which could affect result No feedback from people living with dementia or carers after the events Convenience sample with more women than men Later study by Alzheimer's Australia found stigma and

								negative attitudes persisted. Self reporting does not necessarily equate with knowledge
Sheaff et al (2019)	Evaluating a dementia learning community : exploratory study and research implications	Evaluation of the logic model of a dementia learning community Did they improve quality of life indicators	Mixed method. Evaluation	Dementia champion trained care home staff in dementia awareness and change management with the aim of changing. work routines, improving quality of life and reducing demands on external services. Using plan, do , study, act (PDSA) approach	13 care homes with 10 controls in England during 2013-2015.	Resident's well-being improved in 50% of the care homes but not in the other half- got worse in some. Ambulance call out did and admissions did not improve. Training alone had more impact on care workers knowledge of dementia than on coping styles.	Changes are likely to come about from better knowledge of the residents and staff morale rather than knowledge or attitudes.	Good to see evaluations published where the expected changes had not been recognised . Further research needed

Wilkinson et al. 2016	Junior doctor dementia champions in a district general hospital (innovative practice)	Experiences of junior doctors being dementia champions in a dementia and delirium team in an acute hospital (DaD)	Junior doctors in acute hospitals in two hospital trusts Hospital trust A -1-Focus group- N=6, Hospital trust B- 20 completed questionnaires	Mixed method focus group and survey 2 different groups	Purposive	Gained knowledge and skills, understanding of their role in patient care and leadership and career development	Service improvement Skills, knowledge , confidence and transforming to "I must do something" to improve patient care	Small study. Those who completed survey did not have a champions group. Some in focus group had only been in role very short time and at the end of foundation year of training. Consider sustainability and change if ongoing change of staff. Interest and motivation affected by personal experience

10.4.6 Summary of papers using PEOT framework

Paper number	Reference
1	**Aihara, Y. Kato, H. Sugiyama, T. Ishi, K. and Goto, Y. (2016)** Public attitudes towards people living with dementia: A cross- sectional study in urban Japan (innovative practice), *Dementia*, 0 (0), 1-9

Population	594 residents and professionals from the urban region Kobe in Japan. 261 adults over 65, 221 volunteers and 112 staff.
Exposure	Attitudes towards people living with dementia. What source of information about dementia was associated with different attitudes towards people dementia in urban Japan?
Outcome	90% felt they could have a good relationship with person with dementia 50% wanting to keep it a secret and would be ashamed to have family member with dementia. Increasing access to information via variety of sources could lead to improved attitudes about dementia (TV, educational classes. Television, newspapers, magazines, and books major source of information for older adults and volunteers Training was a major source of information for staff.
Type of study	Quantitative, cross sectional survey.
Results	Fostering a dementia friendly community and increasing the accessibility of information on dementia is a challenge. Increasing access to information via variety of sources could lead to improved attitudes about dementia (TV, educational classes).

Paper number	**Reference**
2	**Alzheimer’s Society (2018)** Learning disability and dementia project evaluation

Population	People with a learning disability and their carers in Herefordshire 206 people received sessions. Dementia advisor worked 1:1 with 11 people. 5 case studies
Exposure	21 awareness sessions (Dementia Friends session) for paid and unpaid supporters 3 of the 16 sessions were delivered to people with a learning disability. Also ‘Supporting Derek’ video
Outcome	Increase awareness and understanding of dementia in the learning disability community Better prepare people living and working with dementia for the changes dementia brings Raise awareness of the trial and resources developed with the support of the Alzheimer’s Society
Type of study	Mixed method. All self-assessment Used outcome star (evaluation tool) to evaluate with carers and paid workers Before and after data capture form (mixed method survey) undertaken face to face to measure the impact on their understanding of how dementia can affect a person who has a learning disability Case study
Results	Without an understanding of dementia may not recognise decline and delay diagnosis People may not have equal access to information and support People with LD familiar with the word dementia. Not always told they had dementia. Enabling a person with LD to become a champion helped create more dementia friends in the community Family carers did not engage unless dementia was being diagnosed Beneficial: developing dementia friends champions who have a learning disability to co-facilitate awareness sessions and support their peers
Comments	Little detail about how the 11 who were selected Recommendations could have included a further study to identify whether people with an LD were becoming champions/ co- facilitating Facilitators and barriers included

	Facilitators- different organisations, LD partnership board and LD team, communication Barriers- time of year- summer holidays, fear, stigma, and lack of awareness reduced people coming forward No mechanism to link up champions in the community Limitations could have included the design- self assessment and self-perceptions Mix of paid and unpaid participants

Paper number	**Reference**
3	**Banks et al. (2014)** Enriching the care of patients with dementia in acute settings? The dementia champion programme in Scotland, *Dementia*, 13 (6), 717-736

Population	100 health care professionals working in acute settings. 4 sites across Scotland between October 2011 and February 2012.
Exposure	Blended learning programme. 5 study days, 0.5 day in community setting and e-learning. 3 web based. Completed the programme by submitting reports related to three work-based activities. Includes a supporting change workbook.
Outcome	Bring participants knowledge and skills to enhanced level Develop, deliver, and evaluate a training programme to prepare NHS and Social Services dementia champions working in acute settings as change agents for practice. Distance travelled based on attitudes, achievement of learning and confidence
Type of study	Mixed method service evaluation. Self -reported evaluation questionnaire prior to starting programme and at the end- 2 points in time. Qualitative and quantitative information
Results	T test from questionnaire- positive response regarding person centred approaches. Positive response to time with people with dementia.

	Needs identified included suitable environment, education, identification of people with dementia, communication with people with dementia, involving relatives and carers, identifying, and managing delirium. Change agent- N=92 93% had or would change practice because of doing the course. Promoted the formation of a network of champions. Cost effective
Comments	Not all participants completed all parts of before and after. Identify that it could be transferred to other groups of staff and settings. Not possible to gauge impact on patient care Self-efficacy not included at the beginning so no baseline Participants anonymous so not able to identify location or follow up at later date

Paper number	Reference
4	**Bartlett, R. (2015)** Visualising dementia activism: using the arts to communicate research findings, *Qualitative Research*, 15 (6), 755-768

Population	7 people participated in the follow up study- 4 men and 3 women and an installation artist. All involved in the first study invited to participate. First study had 16 people with dementia, (11 men and 5 women between 58 and 78 People with dementia activists are activists through artwork. From previous study in 2012
Exposure	3 creative workshops about being active in their community. Installation artist introduced to the primary research before the residency – part 2 of the project. Artist designed 5 textile banners. Work exhibited. Visual scholarship. Research communication project- ‘No limits reimagining life with dementia’. Transformation of research findings into artwork. Touring exhibition textile banners,

	homemade protests placards and a documentary film.
Outcome	Use art to explore individual and collective strength of people to with dementia and enhance understanding of active citizenship. Alter perceptions about dementia and ageing. Research study about campaigning practices of people living with dementia- changing how we see people with dementia. Rationale for the touring exhibition, how the exhibition was created and involved participants work, how visitors engaged.
Type of study	Qualitative arts-based approach
Results	Participants expressed themselves in a way that data collection tools could not. Art and image making mobilised emotions. Outputs by artist could people's imagination and attention, transformative and new way of understanding. Space for the researcher, participants, and viewers to discover something about themselves. Newness, new knowledge, and insight in the space between research, art and the public. Took attention away from the research. Author discussed development by recording the dialogue while the participants made the banners. Images not necessarily aligned to the original research. Images have agency and can extend understanding independently of the text. Closer relationship between participants. Summary- art offers- fluid ways of knowing, multiple meanings, creative outlets, aesthetic vision, multiple ways of experiencing the world. Cannot offer- tethered knowledge, factual information, explanations, solutions or answers, certainties
Comments	Seeing people with dementia as change agents Growing not dying Some concern that when arts are used the meaning may be distorted and important information may be lost. Alternative perspective that visual could bring a topic to life and convey more authentic understanding.

	Emotional learning on an even ground with scientific learning Exhibitions think and feel about topics in a new way Artists could be given detailed knowledge about the messages to be conveyed

Paper number	Reference
5	**Brooke et al. (2017**) Exploring the impact of dementia- friendly ward environments on the provision of care: A qualitative thematic analysis, *Dementia*, 18 (2), 685- 700

Population	Qualified nurses and health care assistants working in an acute NHS trust. Junior qualified nurses n=17 and health care assistants n=21
Exposure	10 focus group, 3 with HCAs, 2 qualified nurses and 5 with both groups- occurring naturally / not purposive selection for groups
Outcome	Perceptions and experiences of the impact of the ward environments on the care nurses and health care assistants provide for patients.
Type of study	Qualitative, focus groups
Results	4 themes- changed environment, more options for person centred care, constant nurse presence, resistance to change. Mixed reactions from both groups- provided more options for the care of patients and closer proximity during the working day. Bay nursing- continued presence of staff. Dementia friendly wards increased contact with patients, increased person-centred care and possible reduction in harm. Change management strategies could improve staff uptake.
Comments	The study was linked to training staff were receiving including 2-hour dementia awareness (tier 1) and tier 2 through simulation (4 hours observing and interacting with actors in different scenarios.

	Limitation of the study was they did not have staff who had worked on the ward before and after the environment changes

Paper number	Reference
6	**Buckner et al. (2018)** An evaluation tool for age-friendly and dementia friendly communities, *Working with Older People*, 22 (1), 48-58

Population	Sheffield UK stakeholder steering group
Exposure	Scoping conversations, documentary analysis, interviews, and group discussions. 2 interviews with stakeholders in dementia related roles Three steering group meetings. 5-month piloting exercise
Outcome	Evaluation of a tool to measure dementia friendly communities
Type of study	Qualitative, across 10 input areas identified in the tool- political support, leadership and guidance, financial and human resources, involvement of people affected by dementia, priorities based on needs assessment, application of existing frameworks for assessing dementia friendliness, provision, interventions rooted in evidence, co-ordination, collaboration and interlinkages, monitoring and evaluation.
Results	Strengths - Involvement of older people, service provision, collaboration, monitoring, and evaluation Tool adapted to focus on dementia friendliness. Offered a range of services but gaps in relation to LGBT and services for those newly diagnosed and their carers.
Comments	Recommendations include pooling of resources and collecting evidence of how people living with dementia have shaped the dementia friendly community initiative Small preliminary research pilot study.

Paper number	Reference
7	**Chalk, A. and Page, S. (2014**) Dementia RED (Respect, Empathy, Dignity); Collaborating to build dementia supportive communities in North Wales- reporting on a pilot project, *Dementia*, 15 (2), 257-262

Population	1 locality team in North Wales, North Denbighshire- deprivation and elderly population. Began meeting in 2011.Dementia subgroup formed
Exposure	5 projects Project 1: Care information centre point- 5 weeks Jan- Feb 2013 Project 2: Primary care champions 8- advocating for patients and promoting active citizenship Project 3: action plan, engagement between primary care and the community, links with local authorities, staff training, update, and share knowledge, develop knowledge of range of dementia care in UK Project 4: Key ring- raise profile- person behind the dementia care Project 5: Road show- I day
Outcome	Raise awareness of three words that the subgroup regarded as paramount to care- RED Build a dementia supportive environment through working collaboratively with partners to raise awareness of dementia by Educating staff to recognise signs of dementia and support them Develop staff knowledge of local services
Type of study	Qualitative.
Results	Citizenship model. Limited information about what was most successful
Comments	Based on a biopsychosocial model (Engel, 1977) Pilot project- limited information about sustainability, cost, or long-term impact. Raising awareness but need feedback from those who engaged or what next

Paper number	Reference
8	**Crampton, J and Eley, R. (2013**) Dementia- friendly communities: what the project “Creating a dementia friendly York” can tell us, *Working with Older People*, 17 (2), 49-57

Population	Cross sectional operational with existing organisations group (health and social care, leisure and housing, police), people with dementia and family carers
Exposure	‘Walk their patch’ with people with dementia followed by a ‘sounding board’ event to share ideas
Outcome	What constitutes a dementia friendly community and how to achieve it. Experience of people with dementia post diagnosis exploring their everyday lives an contact they had with agencies
Type of study	Qualitative, walk observe and listen and group
Results	Model to use to create dementia friendly communities. Factors were physical environment, local facilities, support groups, support services, social networks, and local groups. 4 cornerstone model-place, people, networks, and resources developed. What is good for people with dementia is good for all Increased awareness about dementia and talk about it Change negative stereotypes Provide training Encourage people with dementia to enjoy the city of York Grasp technology and involve people with dementia in planning
Comments	Linked to an earlier study in 2012. Dementia without walls. Recommendation that communities need knowledgeable input from people with dementia and family carers.

Paper number	Reference
9	**Ebert et al. (2019)** Effects of dementia knowledge and dementia fear on comfort with people having dementia: implications for people with dementia: implications for dementia friendly communities, Dementia 0 (0) 1-13

Population	645 Wisconsin residents USA. All over 18 and residents of Wisconsin. 76% women and 50.9% had a relative or friend with dementia. Age range 18-86. Occupations – paid and unpaid not recorded.
Exposure	Online platform and advertisements at senior centres and dementia support groups.
Outcome	Effects of dementia knowledge and fear on social comfort (interacting with people with dementia).
Type of study	Quantitative, multiple regression. Measures- personhood based knowledge, personal dementia fear measure and biomedical knowledge measure from different existing scales.
Results	People with biomedical knowledge benefitted most from having personhood knowledge. Unable to give causal link at this stage.
Comments	Community members and professionals should seek a balance between biomedical knowledge and personhood-based knowledge to promote social comfort to benefit the promotion of dementia friendly communities. Occupation not captured and could be a proportion were working in health or social care influencing results. Some parts of Wisconsin have initiative in place- dementia café etc. Authors conclude the importance of creating communities that foster personhood-based knowledge.

Paper number	Reference
10	**Ellison et al. (2014)** *Evaluating the impact of the Alzheimer Scotland Dementia Nurse Consultants/ Specialists and dementia champions in bringing about improvements to dementia care in acute general hospitals*. Newcastle Upon Tyne: Blake Stevenson

Population	N=12 baseline interviews with stakeholders N=11 Baseline interviews with DNS and follow up N=154 DCs baseline survey N=108 follow up survey N=30 telephone interviews with DCs N=6 interviews with people with dementia and carers N=34 Ds case study interviews and focus groups N=28 interviews and focus groups with colleagues, line managers and stakeholders. 205 (64%) of a possible 321 DCs responded to at least one survey, only 57 responded to baseline and final survey. Smaller number of Social Services DCs
Exposure	Impact evaluation of the experiences and outcomes of dementia champions in practice after the completion of a DC programme and experiences and outcomes of ASNs in practice, how the two work together to achieve improvements in dementia care Desk based research, baseline and follow up qualitative telephone interviews and each ASN, baseline and follow up interviews with key stakeholders, consultation and evaluation with the steering group, members of the Scottish dementia working group (SDWG), in depth interviews with 30 dementia champions. Baseline and follow up online surveys with DCs from cohort 1, 2, 3, consultation with a small number of people with dementia and carers, intensive case study research in 4 health care boards areas, consultation with stakeholders ASNs, DCs colleagues and managers.

Outcome	Evaluate the impact of Alzheimer Scotland Dementia Nurse consultant/ specialists in bringing about improvements in the care of people with dementia in acute hospital settings. Evaluate the introduction of dementia champions across health and social care organisations in bringing about improvements in the care of people with dementia in acute hospital settings. Explore the inter relationships between Alzheimer Scotland Dementia Nurse Consultants and the dementia champions in bringing about improvements. Explore how the introduction of social services DCs has impacted on the wider initiative and Identify barriers/ enablers to change in progressing the impact of these roles Evaluating the impact of the Alzheimer Scotland Dementia Nurse Consultants/ Specialists and dementia champions in bringing about improvements to dementia care in acute general hospitals
Type of study	Mixed method evaluation. Case study interviews and focus groups, surveys, desk-based research review of training
Results	Both roles raised the profile of dementia and supported improvements in care environments, identification of those with dementia in acute care, delivery of person-centred care, involvement of carers, responses to stress and distress. Positive change in DCs attitudes and practice
Comments	Development of dementia champions as change agents Small numbers of social services DCs cannot compare Difficulty recruiting people living with dementia and carers Difference in number in baseline and final survey. Issues of sustainability –uncertainty about the ASN role, DCs not supported, no clear sense of leadership

	or direction leading to risk to ability and motivation to continue to influence change.

Paper number	**Reference**
11	**Fossey et al. (2018)** A qualitative analysis of trainer/ coach experiences of changing care home practice in the well- being and health in dementia randomised control trial, Dementia 0 (0), 1-6.

Population	N= 8 therapists and 4 supervisors (mental health, occupational therapy, nursing, and psychology) and supervisors engaged in individual and group supervision. All with over a year experience in dementia care Health and social care professionals employed in the role of trainer/ coach to support care home staff to implement psychosocial intervention for residents living with dementia. Cascade model leaders are trained, given resources, and supported to lead dementia practice. 36 care homes involved. Different grades of staff involved.
Exposure	Experiences of dementia trainers/ coaches engaged in a cascade model of delivery to implement psychosocial intervention Reflected on their perceptions of the resources and support required
Outcome	Identify the factors pertinent to the role in the context of the cascade model of training.
Type of study	Qualitative, focus group, part of a larger randomised control trial (WHELD). Inductive thematic analysis, Braun and Clarke
Results	3 themes. Theme 1: skills in relationship building with two subthemes – trust and getting to know individual staff and care home. Theme 2: making use of tangible resources with two subthemes manual and supervision. Theme 3: being an agent for change and three subthemes- effective training methods, opportunity for dementia champions to reflect and therapists perceived rewards of the role.
Comments	Paid health care professionals (therapists) doing training

	Needed time to build confidence, develop skills in using the resources and training to understand and make use of the manual. The resources could appear daunting and there were literacy issues for some staff. Needed to be responsive to different learning styles. Role modelling was important. Staff had the opportunity to personalise what they used rather than keeping to the format. Workload and time pressures affected engagement and time was needed to bring about change. Supervision was important away from the workplace to express themselves. There was a noticeable change in communication picked up by relatives and visitors. Trainers needed cultural awareness of the care homes and time for change. Did not mention a follow up in a year to see whether change has taken place or long-term effectiveness which could be affected by changes in staff across the homes.

Paper number	Reference
12	**Heward et al. (2017)** Dementia- friendly communities: challenges and strategies for achieving stakeholder involvement, *Health and Social Care in the Community*, 25 (3), 858-867

Population	7 dementia friendly communities/ localities. 14 interviews and a focus group. 4 part time project workers employed to develop initiatives. Only the project workers engaged in the interviews and focus groups. South of England Data from 2013-2014- 12 months. Secondary data provided through project worker progress forms, good news stories minutes of meetings, press releases, news reports Dementia action alliance plans and memory awareness scheme forms
Exposure	Dementia friendly communities stakeholder engagement
Outcome	Experiences, strategies, and challenges to achieve stakeholder involvement in dementia friendly communities. To inform and guide the creation of dementia friendly community initiatives

Type of study	Qualitative, interviews and focus group, secondary data, content analysis
Results	Progress in each of the 7 localities against the criteria for dementia friendly communities identified by the Alzheimer's Society. Most progress in challenging stigma, accessible community activities, respectful and responsive businesses, and services. Challenges in establishing networks and including people representative of the local population, involving people living with dementia, and gaining commitment from organisations.
Comments	Small study with project workers. Limited information about the role. Stakeholder engagement is unpredictable and changeable and reliance on the approach questions long term sustainability.

Paper number	Reference
13	**Mayne et al. (2014)** Experience and opinions on postgraduate dementia training in the UK: a survey of selected consultant geriatricians, *Age and Ageing*, 43, 263-266

Population	55 geriatricians known as dementia champions from the British Geriatric Society Dementia and Similar Disorders Special Interest Group (100 contacted)
Exposure	Elicit their role, experiences, and opinions on current training in dementia within geriatric medicine
Outcome	How they gained experience and their opinions on current training
Type of study	Survey questionnaire
Results	Themes Lack of formal and structured training Variability of training across geographical areas Inadequate training at undergraduate and post graduate training

	Inadequate time spent on dementia as a sub speciality Lack of collaboration between geriatric and psychiatric side of training 56% reported experience was via a clinical attachment with old age psychiatry and 47% regarded themselves as self-taught. Felt that current training was inadequate with need for more structure and time spent on attachments, less variation across areas, more training at undergraduate level and in other specialities and better collaboration in psychiatry
Comments	They recommended having specific modules or formal qualification, mandatory attachments in curriculum, more exposure at undergraduate level Only a select group of geriatricians in the study with high levels of interest in dementia Authors suggest an interview-based study may have provided a higher response rate

Paper number	Reference
14	**Mayrhofer et al. (2016**) The role of dementia champion in dementia care: It's aspirations, development and training needs (innovative practice), *Dementia* 15 (5), 1306-1312

Population	34 participants from potential 188 (18%) In professional roles and practitioners. Nurses, therapists, emergency staff, senior practitioners, managers, and support staff. 27 in NHS Trusts, 6 in social care, one did not disclose
Exposure	Elicit their role and training needs
Outcome	Preparation and dementia specific education and training dementia champions received Roles and whether they were formally recognised What the role entailed and if they were reflected in job description

	Clinical contexts they worked in Perceptions of adequacy and applicability of dementia education and training and associated training needs to inform the conceptualisation and development of the role
Type of study	Quantitative survey (Bristol online survey) Undertaken in 2015 25 questions with mix of multiple choice, multiple answer, and text questions. 10 mins to complete
Results	53% (18) one day of training, 26% (9) half a day, 4 short courses without qualification, 3 course linked to an award, 3 no training Dementia awareness training useful but limited Suggest specific skills training and education programmes that are formally recognised and clarification around expectations for the role
Comments	Linked to previous study in Hertfordshire UK Change agent a key term used for role Dementia champion defined as someone with excellent skills and knowledge in care of someone with dementia, advocate, source of information and support for co- workers, self-motivated, role model, leadership qualities, communication skills and change agent. Lack of formal endorsement for role, qualification, or remuneration

Paper number	**Reference**
15	**Mayrhofer et al. (2015**) Establishing a community of practice for dementia champions (innovative practice), Dementia, 14 (2), 259-266

Population	Health care professionals, variety of job descriptions, multiple organisations, role of DC with other roles
Exposure	Dementia champions symposium (120 health care professionals, on-line site, bi- monthly newsletter (sent to 180 individuals, face to face meeting with local DC groups,

Outcome	Setting up a Dementia Champions Community of Practice (DEMCoP) in Hertfordshire. A county wide group with shared identity to identify and address dementia training and development needs for the health and social care workforce.
Type of study	Mixed method survey and meeting with groups
Results	120 people attended symposium Only small group had DC as recognised title No common roles DCs resistant to registering as a member on the online system NHS trusts with dedicated posts and staff for dementia care On lie resources for students not staff Newsletter reliant on people to contribute Changing jobs and organisational changes affecting roles Competing priorities HSC professionals provide insight into practice
Comments	Community of practice, bottom up approach Need organisational framework with resources to maintain opportunities

Paper number	Reference
16	**Phillipson et al. (2018)** Involvement of people with dementia in raising awareness and changing attitudes in a dementia friendly community pilot project, *Dementia*, 0 (0), 1-16

Population	174 Members of the Kiama community in Australia completed a survey
Exposure	Education and awareness raising activities. Presentations, discussions, educational events, blogs

Outcome	Promote understanding of the lived experience of dementia and reduce stigma associated with dementia.
Type of study	Mixed method survey 34 item questionnaire. Knowledge, attitudes, and experiences of people living with dementia. Initial survey Oct- Dec 2014 Paper and online 2nd survey- March- June 2016 this study Part of the community based participatory action research group (CBPAR) Chi square, descriptive stats, t tests, qualitative responses thematically codes.
Results	Attitudes: Positive attitude and perceptions to people with dementia in both surveys. Reported good knowledge of dementia Identified issues with communicating with people with dementia and lack of understanding about the environment in both surveys Scenario- said they would feel depressed if they had a diagnosis, felt they would not be taken seriously and unable to do things (stigma)
Comments	The full content of what was included not described. Unclear what aspects were the most beneficial. Self-assessment of knowledge about dementia but not assessed if good knowledge or accurate understanding Wide range of interventions- unclear what aspects were beneficial to shape future provision. Assumed that having people living with dementia as spokespersons and educators had a positive effect but unclear what was most beneficial Convenience sample/ self-selecting those who were interested which could affect result No feedback from people living with dementia or carers after the events Convenience sample with more women than men Later study by Alzheimer’s Australia found stigma and negative attitudes persisted.

Paper number	Reference
17	**Sheaff et al. (2018)** Evaluating a dementia learning community: exploratory study and research implications, *BMC Health Services Research*, 18 (83), 1-13

Population	13 dementia champions in each dementia learning community (DLC) care home delivering training to promote changes in staff attitudes and knowledge. Compared with 10 controls. NHS trust in England. All 23 homes were privately owned. Random allocation to intervention and control group.
Exposure	Dementia champion trained care home staff in dementia awareness and change management with the aim of changing work routines, improving quality of life and reducing demands on external services. Using plan, do, study, act (PDSA) approach
Outcome	Evaluation of the logic model of a dementia learning community Did they improve quality of life indicators
Type of study	Mixed method. Evaluation comparing 13 care homes with 10 controls in England during 2013-2015.
Results	Residents' well-being improved in 50% of the care homes but not in the other half- got worse in some. Ambulance call out did and admissions did not improve. Training alone had more impact on care workers knowledge of dementia than on coping styles.
Comments	Dementia champions are trained in dementia awareness- 8 hour multi module training programme including nature of dementia, communicating with people with dementia, influence of the environment upon dementia care, person centred care planning, end of life care, mental capacity act, dealing with challenging behaviour, and creating and managing organisational change. A vast amount to cover in an 8-hour multi module training programme. Learning facilitators support the champions through visits, newsletter, conference, web-based forums. This was

	considered the first step before moving onto a DLC logic model where the champions identify a care home and implement the PDSA cycle. Changes are likely to come about from better knowledge of the resident and staff morale rather than knowledge or attitudes. Further research needed. Good to see evaluations published where the expected changes had not been recognised.

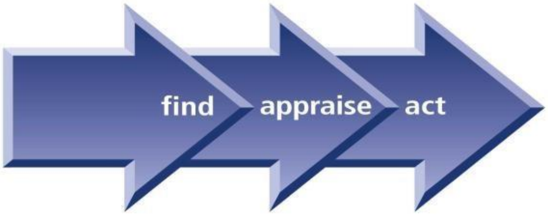
Paper number	Reference
18	**Wilkinson et al. (2016)** Junior doctor dementia champions in a district general hospital (innovative practice), *Dementia*, 15 (2), 263-272

Population	Junior doctors in acute hospitals in two hospital trusts Hospital trust A 1-Focus group- N=6 ,4 champions for 11 months, 1 for 7 months and 1 for four months (end of their first foundation year). Hospital trust B- 20 completed questionnaires
Exposure	Experiences of junior doctors being dementia champions in a dementia and delirium team in an acute hospital (DaD)
Outcome	What influenced the junior doctors to become dementia champions? What impact did being a dementia champion have on junior doctors
Type of study	Mixed method design. Qualitative study drawing on qualitative- focus group information and quantitative survey with second group of doctors. Semi structured format. Questionnaire mixed method with multi-choice and open-ended questions
Results	3 themes: Prior experiences-empathy for people with dementia affected by personal experience of relative Peer involvement- group coming together and peer led resulted in increased interest. They gained access to management meetings and were able to lead on quality improvement and change in discharge summaries. Recognition and empowered

	Desire for knowledge gain- felt that they did not have the knowledge to care for patients with dementia and gained skills. Gained knowledge and skills, understanding of their role in patient care and leadership and career development
Comments	Noted that several national strategies were being launched at the time. Dual diagnosis meant it was appropriate in all areas of practice One focus group at end of first year of training. Some in role very short time. Trust B – questionnaire- did not have a dementia champion scheme Confidence in talking to patients, carers, relatives, MDT and finding out more about the person Transformative- threshold concept of caring about to caring for. Trust A had programme- I must do something Trust B did not have programme- something must be done Changes in standards of care. Key point was having a motivated senior doctor who trust and allows juniors to make changes in the way care delivered. Gaining additional information early on saved time and money in the long term Title does not fully reflect the study as the questionnaire was answered by a group that did not have a dementia champion scheme

10.4.7 CASP Completed quality appraisal form (qualitative)

CRITICAL APPRAISAL SKILLS PROGRAMME
Making sense of evidence about clinical effectiveness



10 questions to help you make sense of qualitative research

These questions consider the following:

Are the results of the review valid?

What are the results?

Will the results help locally?

A number of italicised prompts are given after each question. These are designed to remind you why the question is important. There will not be time in the small groups to answer them all in detail!

Screening Questions

1. Was there a clear statement of the aims of the research? *Consider:* • *What the goal of the research was* • *Why is it important* • *Its relevance*	**Yes** Experiences, strategies, and challenges to achieve stakeholder involvement in dementia friendly communities. To inform and guide the creation of dementia friendly community initiatives

2. Is a qualitative methodology appropriate? *Consider:* ☐ *If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants*	**Yes** Qualitative methodology to explore experiences about stakeholder engagement. Exploring ways to achieve stakeholder engagement to promote dementia friendly communities.

Detailed questions

3. Was the research design appropriate to address the aims of the research? *Consider:* ☐ *If the researcher has justified the research design (e.g. have they discussed how they decided which method to use)?*	**Yes** 14 interviews and a focus group DFC steering group members and 4 part time project workers employed to develop initiatives. Only project workers engaged in interviews and focus group. Secondary data provided through project worker progress forms, good news stories minutes of meetings, press
4. Was the recruitment strategy appropriate to the aims of the research? *Consider:* • *If the researcher has explained how the participants were selected* • *If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study* • *If there are any discussions around recruitment (e.g. why some people chose not to take part)*	**Partly** Purposive. Whole population of project workers invited to take part from the seven localities. Did not involve people with dementia or carers.

5. **Were the data collected in a way that addressed the research issue?** *Consider:* • *If the setting for data collection was justified* • *If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)* • *If the researcher has justified the methods chosen* • *If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews were conducted, or did they use a topic guide)?* • *If methods were modified during the study. If so, has the researcher explained how and why?* • *If the form of data is clear (e.g. tape recordings, video material, notes etc.)* • *If the researcher has discussed saturation of data*	**Yes** Incorporated a range of methods 14 interviews and a focus group DFC steering group members and 4 part time project workers employed to develop initiatives. Only project workers engaged in interviews and focus group. Secondary data provided through project worker progress forms, good news stories minutes of meetings, press releases, news reports Dementia action alliance plans and memory awareness scheme forms
6. Has the relationship between researcher and participants been adequately considered? *Consider*: • *If the researcher critically examined their own role, potential bias, and influence during:* o *Formulation of the research questions* o *Data collection, including sample recruitment and choice of location* • *How the researcher responded to events during the study and whether they considered the implications of any changes in the research design*	**Partly** There were four members of the research team. One from a university in the south of England (Bournemouth) where parts of the study was located. 2 were PhD students and one was a researcher from Scotland.

7. Have ethical issues been taken into consideration? *Consider:* • *If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained* • *If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)* • *If approval has been sought from the ethics committee*	**Yes** Ethics approval received from the lead researcher's university (Bournemouth). Participant information sheets provided and consent forms. Rigor is discussed in relation to follow up questions.

8. Was the data analysis sufficiently rigorous? *Consider:* • *If there is an in-depth description of the analysis process* • *If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data?* • *Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process* • *If sufficient data are presented to support the findings* • *To what extent contradictory data are taken into account* • *Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation*	**Yes** One researcher independently analysed the data and scrutinised by all researchers until consensus achieved. Content analysis.

9. Is there a clear statement of findings? *Consider:* • *If the findings are explicit* • *If there is adequate discussion of the evidence both for and against the researcher's arguments* • *If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)* • *If the findings are discussed in relation to the original research question*	**Yes** Progress in each of the 7 localities against the criteria for dementia friendly communities identified by the Alzheimer's Society. Most progress in challenging stigma, accessible community activities, respectful and responsive businesses, and services. Challenges in establishing networks and including people representative of the local population, involving people living with dementia, and gaining commitment from organisations.
10. How valuable is the research? *Consider:* • *If the researcher discusses the contribution the study makes to existing knowledge or understanding e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature?* • *If they identify new areas where research is necessary* • *If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used*	**Yes** Paper suggests the insights into the experiences of those who are developing dementia friendly initiatives is key to informing researchers, policy makers and others working to develop dementia friendly communities. Need to find ways to engage stakeholders for long term sustainability of Dementia friendly communities to enhance quality of life for people with dementia. Limitations identified- small study and findings could vary in different localities. Identified that it was difficult to recruit people with dementia, carers and businesses in the research and they were therefore not included in the study. Highlights the Dementia Engagement and Empowerment Project (DEEP) user movement in the UK that could be influential in later studies

10.4.8 CASP Completed quality appraisal form (quantitative)

CEBMa
center for
Evidence-Based Management

Mayrhofer, A. Goodman, C. and Smeeton, N. (2016) The role of dementia champions in dementia care: Its aspirations, development, and training needs (innovative practice), *Dementia*, 15 (5) 1306-1312

Appraisal questions	**Yes**	**Can't tell**	**No**
1. *Did the study address a clearly focused question / issue?* **Dementia champions views on their role and associated training needs**	✓		
2. *Is the research method (study design) appropriate for answering the research question?* **Partly**. **A survey does allow for in depth discussions about views or training needs. What is included is dictated by the questions included in the survey. However, this was part of a bigger study in England and the survey included a range of multiple choice, multiple answer and text questions. It states it could be completed in 10 minutes highlighting it will only capture views in a brief and succinct way. Bristol online survey (BOS) used regularly for surveys**	✓		
3. *Is the method of selection of the subjects (employees, teams, divisions, organizations) clearly described?* **Emailing survey link to all 224 on the dementia champion database**	✓		
4. *Could the way the sample was obtained introduce (selection) bias?* **No. Survey link was emailed to all the dementia champions on Dementia Champion Community of Practice (DEMCoP) in East of England.**			✓
5. *Was the sample of subjects representative with regard to the population to which the findings will be referred?* **Dementia**	✓		

champions known through the community of practice			
6. Was the sample size based on pre-study considerations of statistical power? **Not discussed. Small numbers that responded identified as a limitation. 34 responded out of 224 dementia champions contacted. 1 person not eligible- not a champion**			✓
7. Was a satisfactory response rate achieved? **Limited 18%**			✓
8. Are the measurements (questionnaires) likely to be valid and reliable? **Incorporated a mixed survey design with multi choice, multi answer and text responses**	✓		
9. Was the statistical significance assessed? ***No descriptive statistics with numbers/ percentages.***			✓
10. Are confidence intervals given for the main results? ***No***			✓
11. Could there be confounding factors that haven't been accounted for? **No.** ***But all part of a consortium***			✓
12. Can the results be applied to your organization? **Provides insight into the roles, aspirations, development, and training needs. It includes practitioners, senior practitioners and managers across health and social care in acute trusts, community trusts and social care**	✓		

Adapted from Crombie, *The Pocket Guide to Critical Appraisal*; the critical appraisal approach used by the Oxford Centre for Evidence Medicine, checklists of the Dutch Cochrane Centre, BMJ editor's checklists and the checklists of the EPPI Centre.

https://www.cebma.org/wp-content/uploads/Critical-Appraisal-Questions-for-a-Survey.pdf
https://www.cebma.org/resources-and-tools/what-is-critical-appraisal/

10.4.9 Review of the literature using key words, Boolean terms and truncation

P	E	O	T
Dementia Friends Champion	Role of dementia champion	Experience/ Lived experience	Qualitative research
Dementia champion	Supporter	Social inclusion	Quantitative research
Dementia supporter	Action	Dementia friendly/ Dementia friendly community	Mixed method research
Cognitive champion		Impact	Arts based research
		Change agent	Service evaluation

10.5 Methodology

10.5.1 Table showing superordinate themes, subordinate themes, and phenomenological coding

Superordinate theme	**Subordinate theme**	**Phenomenological Coding** Line by line analysis- claims, understandings, and objects of concern (events, relationships, values, what matters to the participant)
Theme 1: Being a champion	Proud to be a volunteer	• Badge • Motivation • Passionate • Proud • Not paid • Satisfaction • Connection • Valued • Empowered • Inspiring • Social action
Theme 1: Being a champion	Understanding in a new way	• Making sense • Answers • Mirroring own experiences • Validating • Looking back • Still learning
Theme 1: Being a champion	Making a difference	• Positive messages • Knowledge • Information • Attitudes • Behaviour • Beliefs • Myths- devilish • Understanding • Blown away • Managing better • Raising money • Messages • Communities • Letters and emails • More equipped • Talked about • Out of the shadows

Theme 1: Being a champion	Emotional connection	• Emotional memories • Humbling • Kind at heart • Reassurance • Hope • Upsetting • Shock • Sadness • Pity • In their shoes • Devastating • Concern • Emotional intelligence • Relationship • Stories shared • Striking a chord • Making an impression
Theme 1: Being a champion	Resilience	• Anger • Own experiences • Challenging self and others • Negative perceptions • Stereotypes • Misconceptions • Self-motivated
Theme 2: Knowledge and understanding in communities	Limited knowledge in public	• Making sense of situations • Mirroring experiences • Clear messages • People needing more information • Knowledge gap • Light bulb moments • Practical ideas • Something to learn • Us and them • Distancing • Embedding awareness • Bottom up approach • Linchpin

Theme 2: Knowledge and understanding in communities	Fear of dementia	• People attending sessions expressing fear of diagnosis • Will stop them seeking help • Will be treated badly • Carers fearing loved ones will forget them • No fear expressed by champions for themselves
Theme 2: Knowledge and understanding in communities	Carers seeking support	• Connecting with carers • Sharing stories • Champions and carers shared experiences • Engaging on an emotional level • Looking for answers • Humbled • Empathy • Affected by carers struggles • Emotional insight into carers mental health • Carers challenging champions messages • Carers expressing living in hell not living well • Young people’s experiences • Under the radar
Theme 2: Knowledge and understanding in communities	Stigma	• People attending sharing diagnosis • African culture- evil spirits, devilish problem • Challenging myths and stereotypes • Us and them • Segregated • Bringing them into the fold • Embedding awareness • Counter stigma a driving force • Media • Stamp someone with label

Theme 3: Experiences and insights	Personal experience and motivation	• Making sense • New understandings • Finding answers • Someone to talk to • Motivating force • Enlightened • Own experiences-an upper hand • Close to me • Challenging own beliefs and perceptions • Questioning • Reflecting back • What could have been different
Theme 3: Experiences and insights	Storytelling and sharing	• Recalling and recounting stories • Constructing stories in new light • Sharing and relating through stories • Learning and connecting through stories • Analogies • Seeing change • Planting a seed
Theme 3: Experiences and insights	Personal challenges	• Dissonance • End of life • Reliving experiences • Struggles and conflict • New understandings • Constructing experiences differently
Theme 3: Experiences and insights	Changed	• A better side of me • Understanding differently • Looking back • Emotional memory • New knowledge and insights • Emotionally affected

Theme 4: Dementia friendly communities	Communities that care	• Kind at heart • Life a rush • Making a difference • Community focussed approach • Big society • Flavour of the month • Charities • Positive relationship • Us and them or inclusion • This is us • Awareness like a seed • Counter stigma
Theme 4: Dementia friendly communities	Workplace challenges	• Challenging misconceptions • People wanting a platform to complain • Attitudes and relevance • Relating to the setting and audience • Time and money • Go to them • Networking • Access
Theme 4: Dementia friendly communities	Sustainability	• Young people • Education • Momentum • Keeping it on the agenda • Taking information through their lives • Change the future
Theme 4: Dementia friendly communities	Promoting understanding and action	• Understanding more important that action • Keep the action part • Word of mouth • Networking • Connections • Media • Self advertising

Larkin, M. and Thompson, A. (2012) Interpretative phenomenological analysis. In: Thompson, A. and Harper, D. (eds) *Qualitative research methods in mental health and psychotherapy: a guide for students and practitioners*. Oxford: John Wiley and Sons. pp. 99-116 https://doi.org/10.1002/9781119973249

10.5.2 Superordinate theme 2: Knowledge and understanding in communities - Subordinate theme - Carers seeking support

Transcript	Exploratory comments
I did actually have an e-mail from somebody afterwards you know basically thanking me and just saying that you know the examples mirrored her examples and she, you know was interested in finding out much more (P1, 128-131)	Carers reflecting on their own experiences mirrored in the sessions. Contact and connection with champions
But also, there has been a lot of mutual support as you know people's journeys have gone through different stages and it has worked extremely well. But we are sort of under the radar, we are not an official carers group that has been set up by one of the health and social care organisations. But we sort of learned of people. (P2, 691-694)	Carers connecting for mutual support. Champions insight into the needs of carers from their own experiences- ‘under the radar’ not noticed
I perhaps had not anticipated quite how much people were just sort of desperate for support, you know there was one man in particular who was trying to support either his mum or his mother-in-law and really struggling (P3,150-152)	Carers attending sessions look for support and guidance and struggling to manage. Champions recognising their plight and challenges faced that were beyond the scope of dementia friends
..one person actually also came up to me and said I may not be able to stay for the whole session, I've got something personal going on with someone with dementia, a family member and I may find this too upsetting to stay and I said of course that's absolutely, you know up to you how long you stay and think she did go halfway through (P3, 372-376)	The examples resonating with carers lived situations. Champions expressing empathy and concern Champions listening and recognising the impact on carers
Yesterday a lady come up to me and she was talking about her mother who had had dementia and passed away but actually what she was really talking about was her own mental health and about how	Telling and sharing stories that had an emotional impact.

she couldn't get support (P4, 341-344)	
..I realised that there was two sisters and mother because the mother actually took me to one side and sort of said thank you, thank you for your understanding. But they were all very upset (P6, 424-426)	Champions listening and trying to provide support. Remembering the emotion of the time and how he felt
I think it's been very humbling, that people are willing to share their personal experiences of perhaps someone in their family and willingly share that in a classroom setting so it has been very humbling (P7, 271-274)	Champions feeling humbled at the trust put in them. People coming to sessions and sharing their personal stories and experiences. Engaging on an emotional level
I've had people say to me yeah you say living well with dementia you know it is a living hell coping with somebody with dementia (P8, 356-358)	Champions facing the challenges of delivering a key message faced with people who had faced or were facing great difficulty. Champions thinking about how to respond and returning to their own beliefs and experiences
know a lot of the people have had their experiences with dementia which is interesting that they still come along (P8, 403-405)	Challenging assumptions that people with experience of dementia would not come but they did
Especially with carers because they are quite isolated aren't they… (P8, 510)	Champions engaging with people attending and engaging on an emotional level
I did the one for the Scouts the young people I was really surprised the amount of people who had had experience in some way or another (P10, 216-217)	Young people sharing their stories and experiences with champions- relative with dementia. Connection and engagement with people attending sessions

10.5.3 Superordinate theme 3: Personal challenges - Subordinate theme - Personal challenges experienced

Transcript	Exploratory comments
it's very difficult when somebody with dementia reaches the severe cognitive stage (P2, 70-71)	Challenges at the end of life stage of dementia. Bringing to the fore an experience many years ago
He was absolutely fixed in the foetal position …….and I think he lived for three weeks And that made short such an impression on me (P2, 177-180)	Returning to experiences that left an emotional mark- over forty years ago. Challenges at the end of life
..I think there are aspects of living with dementia that are actually quite bleak, both in terms of the condition itself but also the care that is available and I think that creates a kind of like, you know, it is a kind of a conflict because it is possible to live well with dementia but it is not totally possible to live well with dementia. There are times and stages that either people or not cared for very well or that actually can be very, very difficult (P5, 159-164)	Reflecting on the key message that you can live well with dementia. End of life with dementia expressed as 'bleak'. Conflict of delivering the message when returning to own experiences
I'm happy to go with that theme about living well with dementia. There is a part of me that does agree with some people that actually it is a bit of a living hell for people you know but I equally think that if you have more information about anything, whatever it is, be it cancer, MS, Parkinson's, whatever, if you have more understanding and more information it can help you actually deal with it (P8, 429-443)	Described the challenges of two family members with dementia. Used the term 'living hell' but did not identify a conflict with the message about living well with dementia. Information helpful to manage the situation better
I think it's important to talk about it in a way that doesn't negate the difficulties (P10, 284-285)	Shared the difficulties but did not suggest changing the wording about living well but talking about it in a sensitive way

I can see how it can be a struggle but I think to only focus on the negative then misses all those many, many thousands of people who do have aspects of their life that are still positive (P10, 295-297)	Seeing the struggles but not just focussing on the negatives
..even if somebody was dying with Dementia you could deal with it better if you educated all the people around them as to what was going on and even the person who was dying if they were still compos mentis enough you could educate them about this is what is happening to you. So living with Dementia well, if it was me, I would probably change it to a word like ‘dealing’ with Dementia well (P11,309-314)	Emphasising the importance of providing information but conflict with ‘living well’ when reflecting on own experiences. ‘Dealing’ with dementia well. Returning to own experience of end of life care
I think the hardest key message is that it's possible to live with Dementia, alright, people can live well with Dementia because whenever I've said that even from my own personal experiences, my mother wasn't living well with Dementia (P11, 303-305)	Conflict and dissonance in delivering the message influenced by personal lived experience

10.5.4 Superordinate theme 3: Experience and insights - Subordinate theme - Changed

Transcript	Exploratory comments
I think it was validated, stuff I kind of, you know suspected it was happening but you just kind of think yeah that makes perfect sense (P1, 99-100)	Giving answers, making sense of what was happening to her aunt
It's altered my knowledge. My belief and views (P2, 588)	Increasing knowledge, belief, and views about dementia- linked to how memories may be lost but feelings last
…it's given me information that I've been able to take out into my day-to-day workings which has been really helpful (P4, 491-492)	Information that results in changing his day to day practice
I found a better side for myself. Let me relate this please (P6, 465)	Becoming a better person Emphasised in the interview how his attitude had changed. Emotional as he recognised and reflected on his previous ways of thinking and behaviour
I now have a greater understanding of Dementia (P6, 492-493)	Change in his own understanding as well as delivering a message to others
ordinary human beings with a story with a life history that can with support live a normal life but they need to have that understanding and you need to be patient with people and I don't think we are a very patient society really. So I have learned to be much more patient and slow down really (P7, 285-288)	Learning to slow down and being more patient. Seeing the person not the dementia
I would like to think that we have all got a bit more of an insight (P8, 453-454)	Understanding differently
..suppose I would just like people to appreciate that we are all the same,	

we are all human beings and I would like people to just be open minded enough to not buy into all the ways that people get segregated you know (P11, 717-719)	Reflecting on how people may be marginalised because of dementia.

10.5.5 Superordinate theme 2: Knowledge and understanding in communities - Subordinate theme - Fear of dementia

Transcript	Exploratory comments
A friend of mine ... phoned me when her husband was out because her husband obviously has developed Alzheimer's disease….., he went up afterwards and the question was about euthanasia. So, she has got that fear. (P2, 621-633)	Friends sharing their fears about dementia
People are terrified that you know their loved ones are going to forget who they are (P4, 326-327)	Fear expressed by carers Fear they will be forgotten
…I think there is a fear, the fear kind of stops people seeking help or fear of you know having a relative that is diagnosed with dementia so I think to reduce that fear I think that would make a big difference for people with dementia (P5, 179-181)	Fear that stops people seeking help Fear that a relative will be diagnosed
..So while I think this can do quite a bit to change attitudes, that fear of dementia remains when people are still treated really badly at the end stages and when they really, when the care kind of falls apart (P5, 270-272)	Fear of being treated badly
my mum was petrified of then getting Alzheimer's or Dementia…… ..I think just knowing her anxiety makes you then think well it's going to happen to one of us at some stages isn't it (P9, 115-123)	Fear from seeing the effects on a family member No champions expressed fears for themselves. The shared stories of the people they knew and met. Others confided in them

10.5.6 Superordinate theme 3: Experiences and insights - Subordinate theme - Personal experiences of dementia and motivations

Transcript	Exploratory comments
My Aunt had died just before I did the dementia friends training ….she had vascular dementia so you know I think a lot of the stuff I could, you know I could relate to but the training actually gave me some answers as well (P1, 87-90)	Being a champion giving answers and making sense of own experiences
…I often say, forget everything else just remember this, emotional memories last and I've got a personal illustration of that you see. But I mean I think it's something I didn't know when I was caring for X and I can look back now on things (P2, 331-334)	Focussing on emotions and not memory. Seeing things differently- looking back
I don't know. I think if I'm absolutely honest, what it has done has made me reflect on how I was with X and wish I'd been a bit better. I think that's what it has done. It has made me think of things that I could have done better but then I was doing the best I could at the time. (P2, 588-593)	Reflecting on experiences. Understanding more and seeing things differently
A friend of mine phoned me when her husband was out because her husband obviously has developed Alzheimer's disease….., he went up afterwards and the question was about euthanasia. So, she has got that fear (P2, 621-633)	Friends looking for support and guidance- connection
X was diagnosed he was 57 so I was 55, 56. And the one thing I wanted more than anything else was to talk to someone of my own age where it was their husband and not their parent and I didn't seem able to do that at the time. (P2, 654-657)	Early onset dementia Wanting someone to talk to who understands
…I am a carer, you know, I don't present in that way but I can relate	Calling on own experience to help others

back to certain things that have happened to me that people might ask you more in the dementia awareness sessions (P4, 189- 190)	
I look back and I think the sort of first three years of my caring and I don't live with my love one, my dad and I support her, so I wasn't a 24/7 carer but I can look back and think you know, goodness I didn't handle that very well, or we didn't handle this very well (P4, 597-599)	New understandings and insights. Reflecting on own experience and confronting the challenges of what could have been different
…my dad had dementia and it was around the same time as I did the dementia training but he I think he was diagnosed way before that but I think he passed away around about the same time so I had the kind of personal experience of being a carer as well (P5, 40-43)	Personal experiences of caring. Deeper understanding of dementia
…I think the personal experience gave me a completely different perspective in terms of the challenges for every day caring and being, and for someone with dementia to be part of society and remain part of society (P5, 46-48)	Different perspectives. Challenges of caring and feeling part of the community
…I think people who do have a relative or work in the field that have come across people with dementia have a slightly different perspective (P5, 60-62)	Different perspectives when you have experienced it. A connection with others. Understanding in a different way
The only experience I have of dementia, one occurred during my working time at the leisure centre. There was an elderly gentleman who used to come to the gym a very nice guy, one of life's gentlemen (P6, 98-100)	Not having personal experience but through work
X is developing Dementia. And his decline was very rapid (P6, 108)	Telling the story, seeing a change, and being emotionally affected

The only other experience I directly have of Dementia is and I find this one quite upsetting…… And suddenly I recognised her and the shock,…. my initial response was shock, sadness, perhaps even pity and in the few moments of her relating her experience…. I have suddenly gone the other way but I use that relationship (daughter), that relating as an example of it's possible to live well with Dementia (P6, 112-139)	Being shocked at own feelings. Questioning own perceptions, beliefs, and responses. Seeing things differently
I had a Grandmother who obviously had dementia and although I'm going back sort of 35, 40 years probably so 40 years ago it wasn't very well known, the treatments were very different, they were quite horrific and looking back yes she had dementia and it was quite progressive quite quickly and it was quite horrible to see that and to see my mum as her daughter trying to cope with that. So I feel much more enlightened now (P7, 45-50)	Recalling something from over forty years ago-impact of seeing her mum trying to cope. Feeling ‘enlightened’. A different level of understanding Recalling the events and telling the stories that had meaning Stories passed on and shared
We got a diagnosis of Alzheimer's…..she knew obviously there was something wrong but to her he was just irritating her by keep repeating everything and being difficult and I think gradually it became a problem, she would go off to the hairdressers and he would be halfway up the road, you know looking for her because he had forgotten (P8,108-112)	A personal point of view-insights from two family members with dementia
So yeah from a personal point of view and now my mother-in-law has got vascular dementia (P8, 133-137)	Insights from personal experience
I would like to think that we have all got a bit more of an insight (P8, 453-454)	Grandma had dementia. Participant 9 remembers the impact on her mum- petrified

my mum was petrified of then getting Alzheimer's or Dementia…….. I think just knowing her anxiety makes you then think well it's going to happen to one of us at some stages isn't it (P9, 115-123)	How her mum felt stayed with the participant
my partner's Aunt has recently over the last few months died of Dementia, she had Dementia quite a number of years (P10, 77-78)	Every champion new someone with dementia but not expressed in an emotional way like those with experiences of providing care
…it is close to me because my mother suffered from Dementia and I never knew how to deal with it to be quite honest (P11, 35-36)	Close to me- did not know how to deal with it
..my motivation for that was a deeply wanted to understand a little bit more about what had caused the death of my mum. I probably didn't really, what's the word, formulise that in my mind but I think that was one of my motivations, this is what took my mum away (P11, 57-61)	Only just recognising how his mother's death was his motivation
I don't think I would have done if I had not been caring for my loved one because it would have been probably a little bit too far removed from really the work that I was doing which was around, particularly around physical impairment rather than sort of any mental capacity (P2, 178-182).	Being a carer a motivating force
…if you have got a foundation built on the fact that that is something you have experienced; it gives you an upper hand (P11, 349-351)	Experience giving you the upper hand- a different way of knowing

10.5.7 Superordinate theme 1: Being a champion - Subordinate theme - Proud to be a volunteer

Transcript	Exploratory comments
I think again, it gives you confidence, it is something to be passionate about, it is fun, it is something that makes you feel good about what you are doing and the information you are imparting. It can be challenging, it can be scary but the more you do it, the easier it gets is probably the wrong term but I think the more you do it the more you enjoy it because you feel more confident in presenting (P4, 748-752)	Being passionate about what you do and sense of satisfaction Highlighting communication and presentation skills Gaining confidence with experience
most people who wear the badge will wear the badge because they feel slightly more empowered (P4, 700-701)	The badge a symbol of commitment. Representing a cause and feeling empowered
..I think satisfaction in being able to kind of like make a difference and I think maybe keeping people interested and they might go off and become a dementia champion as well so that kind of as the second one. And the third one would be a 'hope', so kind of like the sort of hope for change (P5 291-294)	Giving and receiving- personal satisfaction. Not just delivering a message but encouraging others to go off and become champions
I will wear my badge, you know. Very often I will be more patient in the supermarket queue that sort of thing (P6, 338-339)	The badge as a symbol for others but also as a reminder for him and altering his behaviour
When it's a personal passion it's going to be much more solid than if it's something that has been either imposed are taken on board at the end (P6, 661-663)	Personal passion and decision to volunteer. Not something imposed by others
humbling, emotional, and I feel very proud to be involved in the movement really, because it is a social action movement and so I will proudly wear my badge and I proudly tell people about it and I feel	Emotional connection Social action movement The badge giving a sense of pride and feeling humbled. Described as lucky to be involved

very lucky to have been, to have found out about it and to have actively got involved with it really (P7, 276-279)	Positive
It's been enjoyable. I'm glad because I am a volunteer and I do stress that I'm a volunteer because depending on where you are obviously I especially do when I'm in places of work. They haven't paid me to come, you know that I am a volunteer. Yeah and I have had fun and we have had laughs (P8, 582-585)	Stressing the importance of being a volunteer. Demonstrating commitment and belief in what she is doing Positive experience
…tend to wear my badge because I think if nothing else even if it is subliminal, someone will be sitting across a train, look at my badge and think oh why do I know that name or equally they will know that name. I've had a couple of occasions where I have had people give me a thumbs up and say I'm a champion you know, well done sort of thing and I think okay, cool (P11, 466-470)	Badge symbolic Champion to the cause Doing something important and worthwhile Feeling valued

10.5.8 Superordinate theme 1: Being a champion - Subordinate theme - Resilience

Transcript	Exploratory comments
Sometimes people come up to me afterwards wanting to talk and I personally find it difficult to obey the rule of, you know, I'm not the person, I will direct you to so and so because I often have the answers. So, I do find that one very difficult because you want to help, you know (P2, 295-298)	Not keeping to the rules. Wanting to help and share what she knows Engaging and having a relationship with people attending not just delivering key messages Emotional intelligence
…there were two or three people with dementia in the audience. That was hard because you are getting to that stage of, you know with a terminal illness etc and you are thinking how I deal with this. That was tough. (P4, 225-227)	Emotionally aware and affected by the plight of others. Finding it difficult. Reflecting on own experiences
Yesterday a lady come up to me and she was talking about her mother who had had dementia and passed away but actually what she was really talking about was her own mental health and about how she couldn't get support (P4, 341-344)	Seeing beyond the words to the meaning. Aware of impact on carers. Listening and showing compassion
So yesterday I mean actually yesterday was a really good example of some of these, yesterday was a bit of a challenge because there were a couple of people there that were very clear about dementia is this because it was that for their immediate family. Everyone is aggressive, they all get violent. Actually, no they don't, well they did for me so therefore they must for everybody (P4, 411-416)	A challenge. Reflecting on how to manage negative perceptions and stereotypes Challenging misconceptions and managing conflict
The only other experience I directly have of Dementia is and I find this one quite upsetting…… And suddenly I recognised her and the shock,…. my initial response was	Being upset and recalling events much later. Being affected not by other perceptions but recognising own perceptions about living

shock, sadness, perhaps even pity and in the few moments of her relating her experience…. I have suddenly gone the other way but I use that relationship (daughter), that relating as an example of it's possible to live well with Dementia (P6 112-139) but people come up to me afterwards and tearful and say gosh you have really opened my eyes and my mind to something that I haven't really thought about for a while (P7, 101-103)	with dementia and being personally challenged by beliefs Listening and responding as people attending the sessions start to see things in a new light. Opening heart and mind

10.5.9 Superordinate theme 4: Dementia friendly communities - Subordinate theme - Sustainability

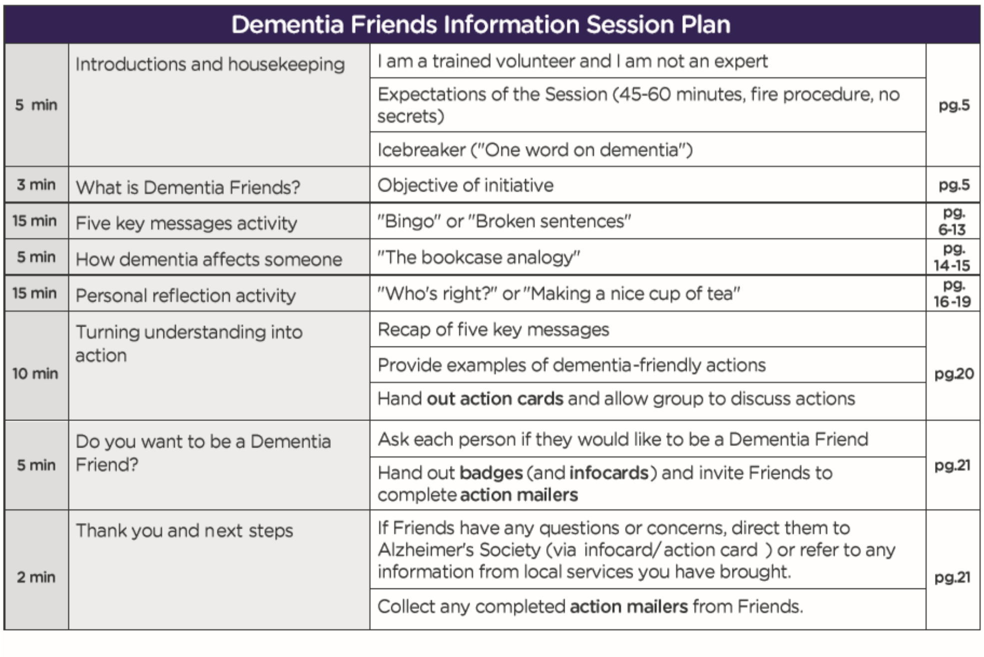
Transcript	Exploratory comments
I think that we should be educating children and young people about dementia so that they take that information right the way through their lives, you see. (P2, 773-775)	Educating young people Preparing for the future
I think there is an issue around how do we keep the momentum going because dementia is flavour of the month at the moment. How do we keep that going? My worry is that if we are not careful at some point something else will take over and that sounds terribly awful but... (P4, 679-682)	Keeping the momentum going
My view I'm sure and I know you feel the same way most of us do, we have got to work more with children (P5, 858-859)	Raising awareness in young people
Yes it's like changing the world now for youngsters (P5, 858-861)	Educating young people
..it can grow from the bottom up and also when I say low of course I mean young people because they are the future anyway (P6, 652-653)	Schools and young people Raising awareness and creating change for the future
I think in schools really is a massive thing because actually if we begin to embed this into the thinking of, you know teenagers particularly I think, then you know you have got a whole generation growing up with that kind of awareness and that kind of way of thinking (P10, 431-434)	Young people The future generation
…all children should be kind of having that kind of input really at young teenage, I would say something like 13 or something when they are beginning to kind of you know think about some of those things (P10, 444-446)	Part of the curriculum Preparing for the future

….it's a little bit like they say that there is no such thing as bad press, right because if you are talking about a subject whether you are talking about it negatively or positively you are talking about it (P11,460-462)	The importance of the media in getting people to talk about dementia. Keeping it on the agenda

10.6 Alzheimer’s Society DF resources (consent given)

(Permission to include resources provided by the Alzheimer’s Society London and South East Regional Office)

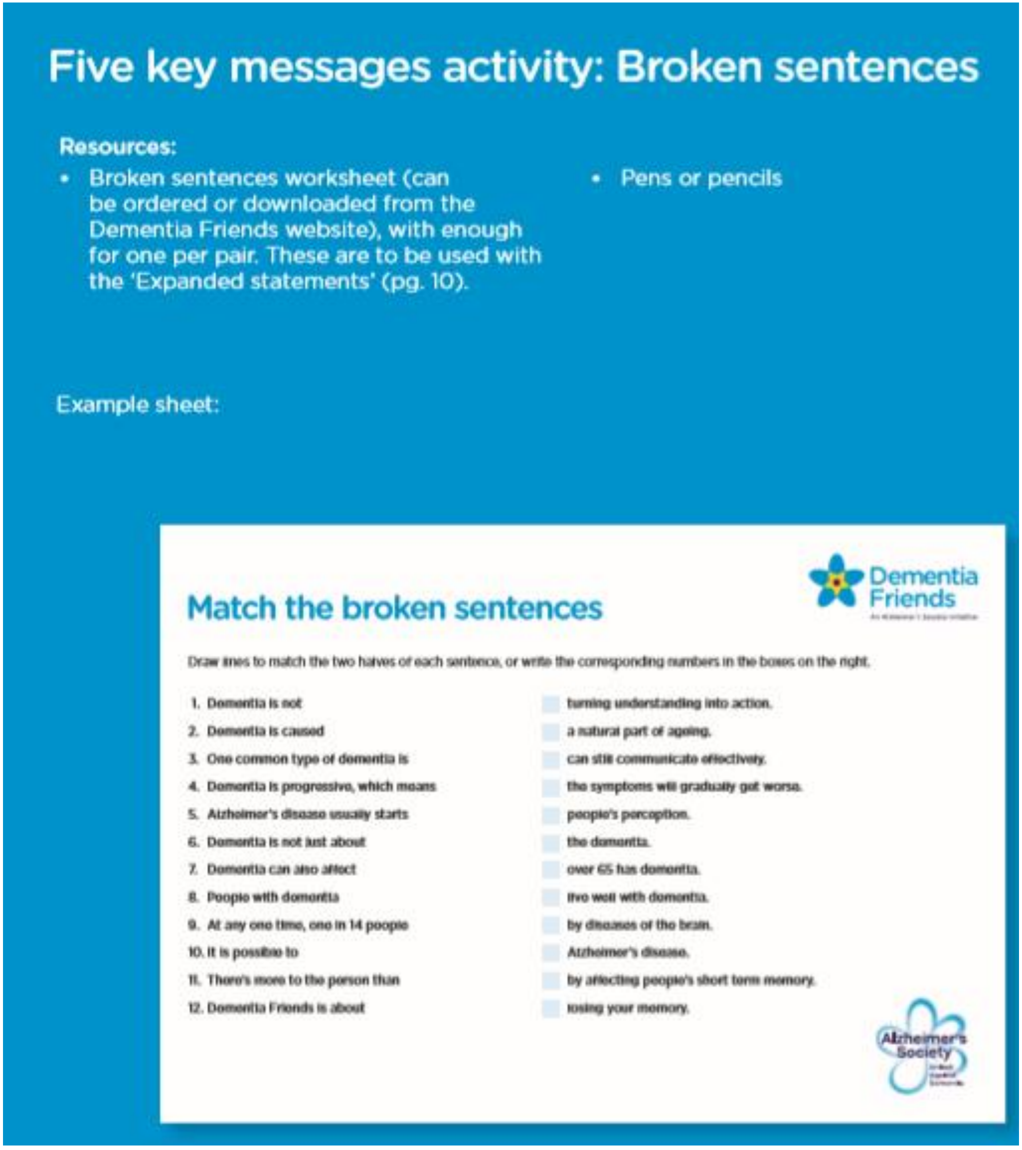
10.6.1 Session plan



Dementia Friends Information Session Plan

5 min	Introductions and housekeeping	I am a trained volunteer and I am not an expert	pg.5
		Expectations of the Session (45-60 minutes, fire procedure, no secrets)	
		Icebreaker ("One word on dementia")	
3 min	What is Dementia Friends?	Objective of initiative	pg.5
15 min	Five key messages activity	"Bingo" or "Broken sentences"	pg. 6-13
5 min	How dementia affects someone	"The bookcase analogy"	pg. 14-15
15 min	Personal reflection activity	"Who's right?" or "Making a nice cup of tea"	pg. 16-19
10 min	Turning understanding into action	Recap of five key messages	pg.20
		Provide examples of dementia-friendly actions	
		Hand **out action cards** and allow group to discuss actions	
5 min	Do you want to be a Dementia Friend?	Ask each person if they would like to be a Dementia Friend	pg.21
		Hand out **badges** (and **infocards**) and invite Friends to complete **action mailers**	
2 min	Thank you and next steps	If Friends have any questions or concerns, direct them to Alzheimer's Society (via infocard/action card) or refer to any information from local services you have brought.	pg.21
		Collect any completed **action mailers** from Friends.	

10.6.2 Key messages activity: Broken sentences



Five key messages activity: Broken sentences

Resources:

- Broken sentences worksheet (can be ordered or downloaded from the Dementia Friends website), with enough for one per pair. These are to be used with the 'Expanded statements' (pg. 10).
- Pens or pencils

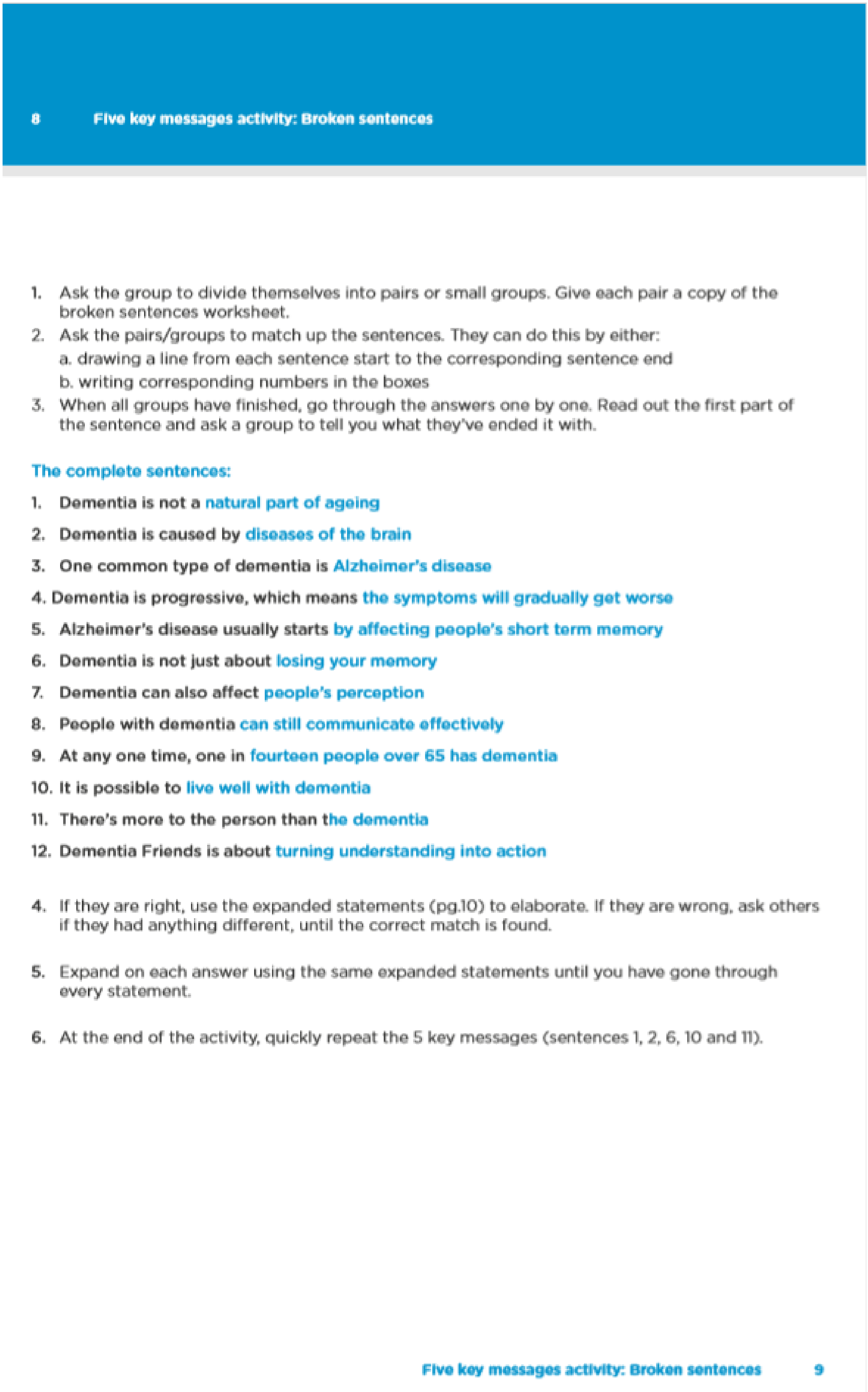
Example sheet:

Match the broken sentences

Draw lines to match the two halves of each sentence, or write the corresponding numbers in the boxes on the right.

1. Dementia is not
2. Dementia is caused
3. One common type of dementia is
4. Dementia is progressive, which means
5. Alzheimer's disease usually starts
6. Dementia is not just about
7. Dementia can also affect
8. People with dementia
9. At any one time, one in 14 people
10. It is possible to
11. There's more to the person than
12. Dementia Friends is about

☐ turning understanding into action.
☐ a natural part of ageing.
☐ can still communicate effectively.
☐ the symptoms will gradually get worse.
☐ people's perception.
☐ the dementia.
☐ over 65 has dementia.
☐ live well with dementia.
☐ by diseases of the brain.
☐ Alzheimer's disease.
☐ by affecting people's short term memory.
☐ losing your memory.



1. Ask the group to divide themselves into pairs or small groups. Give each pair a copy of the broken sentences worksheet.
2. Ask the pairs/groups to match up the sentences. They can do this by either:
   a. drawing a line from each sentence start to the corresponding sentence end
   b. writing corresponding numbers in the boxes
3. When all groups have finished, go through the answers one by one. Read out the first part of the sentence and ask a group to tell you what they've ended it with.

The complete sentences:

1. **Dementia is not a** natural part of ageing
2. **Dementia is caused by** diseases of the brain
3. **One common type of dementia is** Alzheimer's disease
4. **Dementia is progressive, which means** the symptoms will gradually get worse
5. **Alzheimer's disease usually starts** by affecting people's short term memory
6. **Dementia is not just about** losing your memory
7. **Dementia can also affect** people's perception
8. **People with dementia** can still communicate effectively
9. **At any one time, one in** fourteen people over 65 has dementia
10. **It is possible to** live well with dementia
11. **There's more to the person than** the dementia
12. **Dementia Friends is about** turning understanding into action

4. If they are right, use the expanded statements (pg.10) to elaborate. If they are wrong, ask others if they had anything different, until the correct match is found.

5. Expand on each answer using the same expanded statements until you have gone through every statement.

6. At the end of the activity, quickly repeat the 5 key messages (sentences 1, 2, 6, 10 and 11).

10.6.3 Key messages activity: Bingo

Five key messages activity: Bingo

Resources:

- A mix of different Bingo sheets (can be ordered or downloaded from the Dementia Friends website) with enough for one per person, per pair or per group. These are to be used with the 'Expanded statements'
- Pens or pencils

Example sheet:

Dementia Friends
An Alzheimer's Society initiative

B	I	N	G	O
losing your memory	more	diseases		Alzheimer's
communicate	action	live well		progressive
	perception	ageing	short term memory	fourteen

My action: ____________________

1. Explain to the group that you are going to read out statements about dementia, each with a missing word. They should find the missing word on their bingo sheet and circle it – but they should not say it out loud. The first person to get a horizontal row of four should shout "line!" The blue boxes can count towards your line. It's not a test, we won't ask you to read out your answers, so don't be afraid to shout 'line'!
2. Begin reading out the sentences below, but do not read out the missing word:

1. Dementia is not a natural part of ______.	ageing
2. Dementia is caused by ______ of the brain.	diseases
3. One common type of dementia is ______ disease.	Alzheimer's
4. Dementia is ______, which means the symptoms will gradually get worse.	progressive
5. Alzheimer's disease usually starts by affecting people's ______.	short term memory
6. Dementia is not just about ______.	losing your memory
7. Dementia can also affect people's ______.	perception
8. People with dementia can still ______ effectively.	communicate
9. At any one time, one in ______ people over 65 has dementia.	fourteen
10. It is possible to ______ with dementia.	live well
11. There's ______ to the person than the dementia.	more
12. Dementia Friends is about turning understanding into ______.	action

3. When someone shouts out "line!", have a round of applause for the first winner!

4. Repeat the statements you've gone through so far but ask the group for the missing word each time. Using the expanded statements (pg.10), elaborate on each statement to generate discussion.

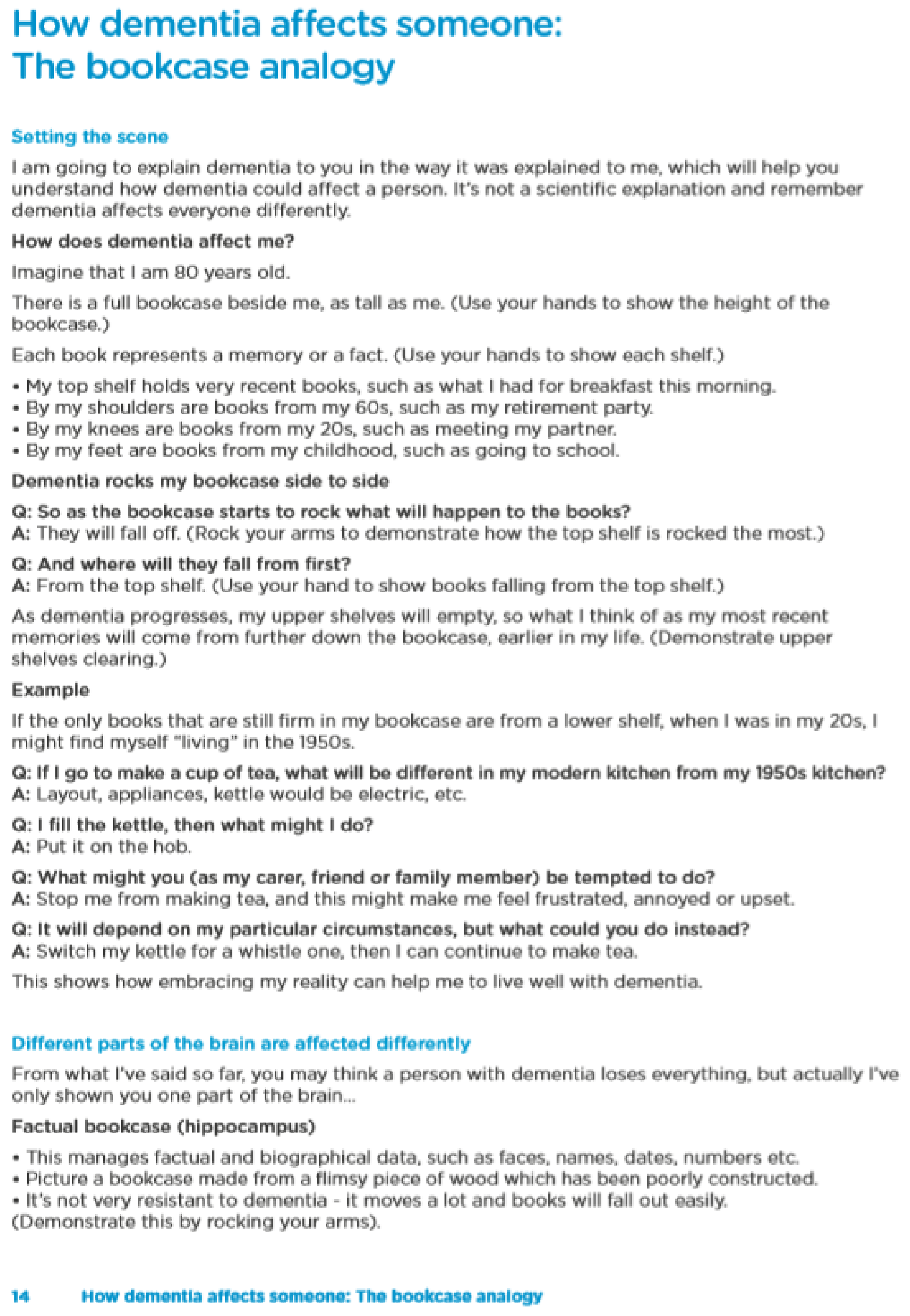
5. Explain to the group that you are going to continue the game and to win they must now circle all the words on their bingo sheet.

6. Continue reading out the statements above until you have a winner (everyone wins!).

7. Expand upon remaining statements, as per instruction 4.

8. At the end of the activity, quickly repeat the 5 key messages (sentences 1, 2, 6, 10 and 11).

10.6.4 How dementia affects someone: The bookcase analogy



How dementia affects someone: The bookcase analogy

Setting the scene

I am going to explain dementia to you in the way it was explained to me, which will help you understand how dementia could affect a person. It's not a scientific explanation and remember dementia affects everyone differently.

How does dementia affect me?

Imagine that I am 80 years old.

There is a full bookcase beside me, as tall as me. (Use your hands to show the height of the bookcase.)

Each book represents a memory or a fact. (Use your hands to show each shelf.)

- My top shelf holds very recent books, such as what I had for breakfast this morning.
- By my shoulders are books from my 60s, such as my retirement party.
- By my knees are books from my 20s, such as meeting my partner.
- By my feet are books from my childhood, such as going to school.

Dementia rocks my bookcase side to side

Q: So as the bookcase starts to rock what will happen to the books?
A: They will fall off. (Rock your arms to demonstrate how the top shelf is rocked the most.)

Q: And where will they fall from first?
A: From the top shelf. (Use your hand to show books falling from the top shelf.)

As dementia progresses, my upper shelves will empty, so what I think of as my most recent memories will come from further down the bookcase, earlier in my life. (Demonstrate upper shelves clearing.)

Example

If the only books that are still firm in my bookcase are from a lower shelf, when I was in my 20s, I might find myself "living" in the 1950s.

Q: If I go to make a cup of tea, what will be different in my modern kitchen from my 1950s kitchen?
A: Layout, appliances, kettle would be electric, etc.

Q: I fill the kettle, then what might I do?
A: Put it on the hob.

Q: What might you (as my carer, friend or family member) be tempted to do?
A: Stop me from making tea, and this might make me feel frustrated, annoyed or upset.

Q: It will depend on my particular circumstances, but what could you do instead?
A: Switch my kettle for a whistle one, then I can continue to make tea.

This shows how embracing my reality can help me to live well with dementia.

Different parts of the brain are affected differently

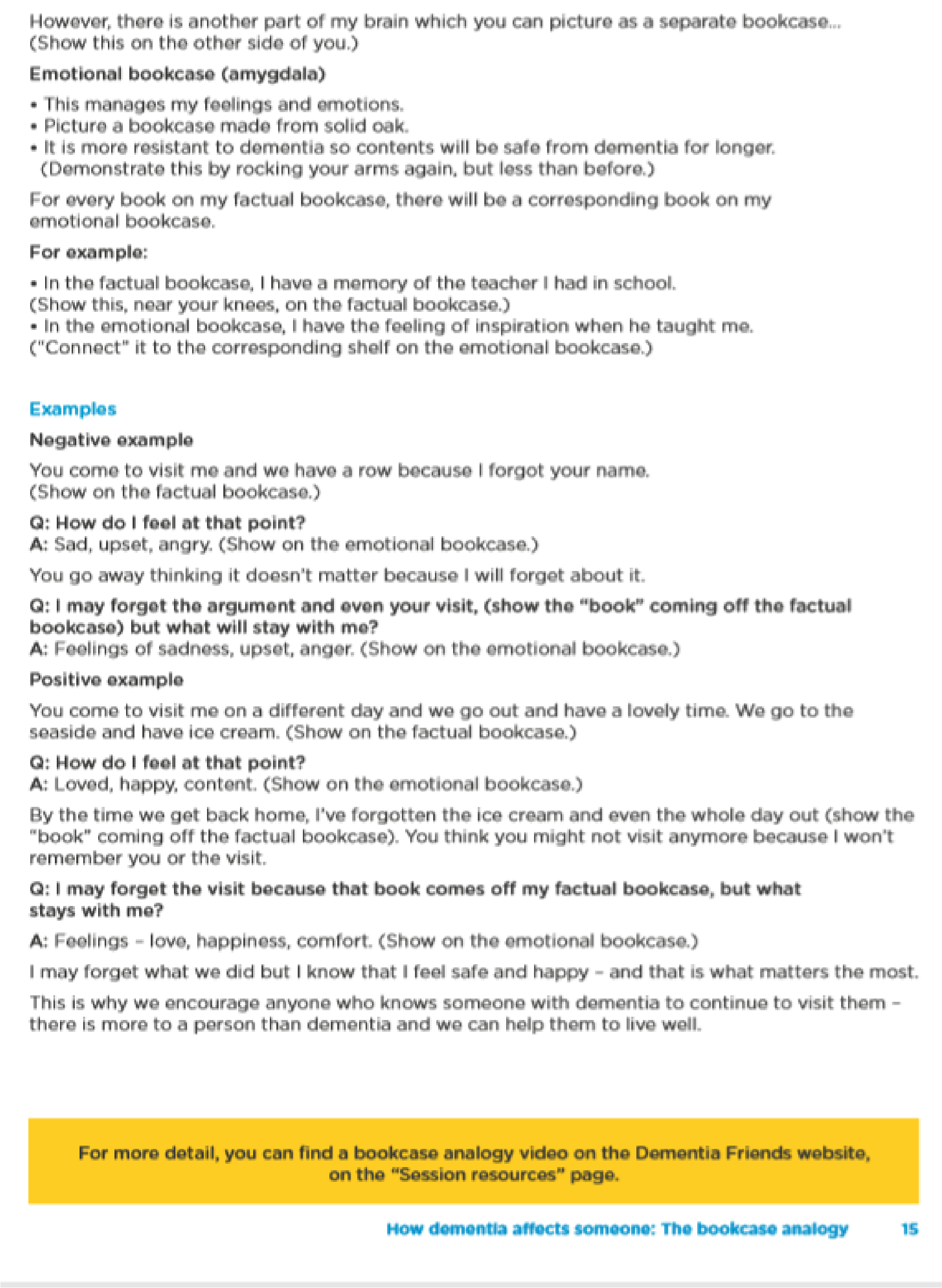
From what I've said so far, you may think a person with dementia loses everything, but actually I've only shown you one part of the brain...

Factual bookcase (hippocampus)

- This manages factual and biographical data, such as faces, names, dates, numbers etc.
- Picture a bookcase made from a flimsy piece of wood which has been poorly constructed.
- It's not very resistant to dementia - it moves a lot and books will fall out easily.

(Demonstrate this by rocking your arms).

14 How dementia affects someone: The bookcase analogy



However, there is another part of my brain which you can picture as a separate bookcase...
(Show this on the other side of you.)

Emotional bookcase (amygdala)

- This manages my feelings and emotions.
- Picture a bookcase made from solid oak.
- It is more resistant to dementia so contents will be safe from dementia for longer. (Demonstrate this by rocking your arms again, but less than before.)

For every book on my factual bookcase, there will be a corresponding book on my emotional bookcase.

For example:

- In the factual bookcase, I have a memory of the teacher I had in school.
(Show this, near your knees, on the factual bookcase.)
- In the emotional bookcase, I have the feeling of inspiration when he taught me.
("Connect" it to the corresponding shelf on the emotional bookcase.)

Examples

Negative example

You come to visit me and we have a row because I forgot your name.
(Show on the factual bookcase.)

Q: How do I feel at that point?
A: Sad, upset, angry. (Show on the emotional bookcase.)

You go away thinking it doesn't matter because I will forget about it.

Q: I may forget the argument and even your visit, (show the "book" coming off the factual bookcase) but what will stay with me?
A: Feelings of sadness, upset, anger. (Show on the emotional bookcase.)

Positive example

You come to visit me on a different day and we go out and have a lovely time. We go to the seaside and have ice cream. (Show on the factual bookcase.)

Q: How do I feel at that point?
A: Loved, happy, content. (Show on the emotional bookcase.)

By the time we get back home, I've forgotten the ice cream and even the whole day out (show the "book" coming off the factual bookcase). You think you might not visit anymore because I won't remember you or the visit.

Q: I may forget the visit because that book comes off my factual bookcase, but what stays with me?

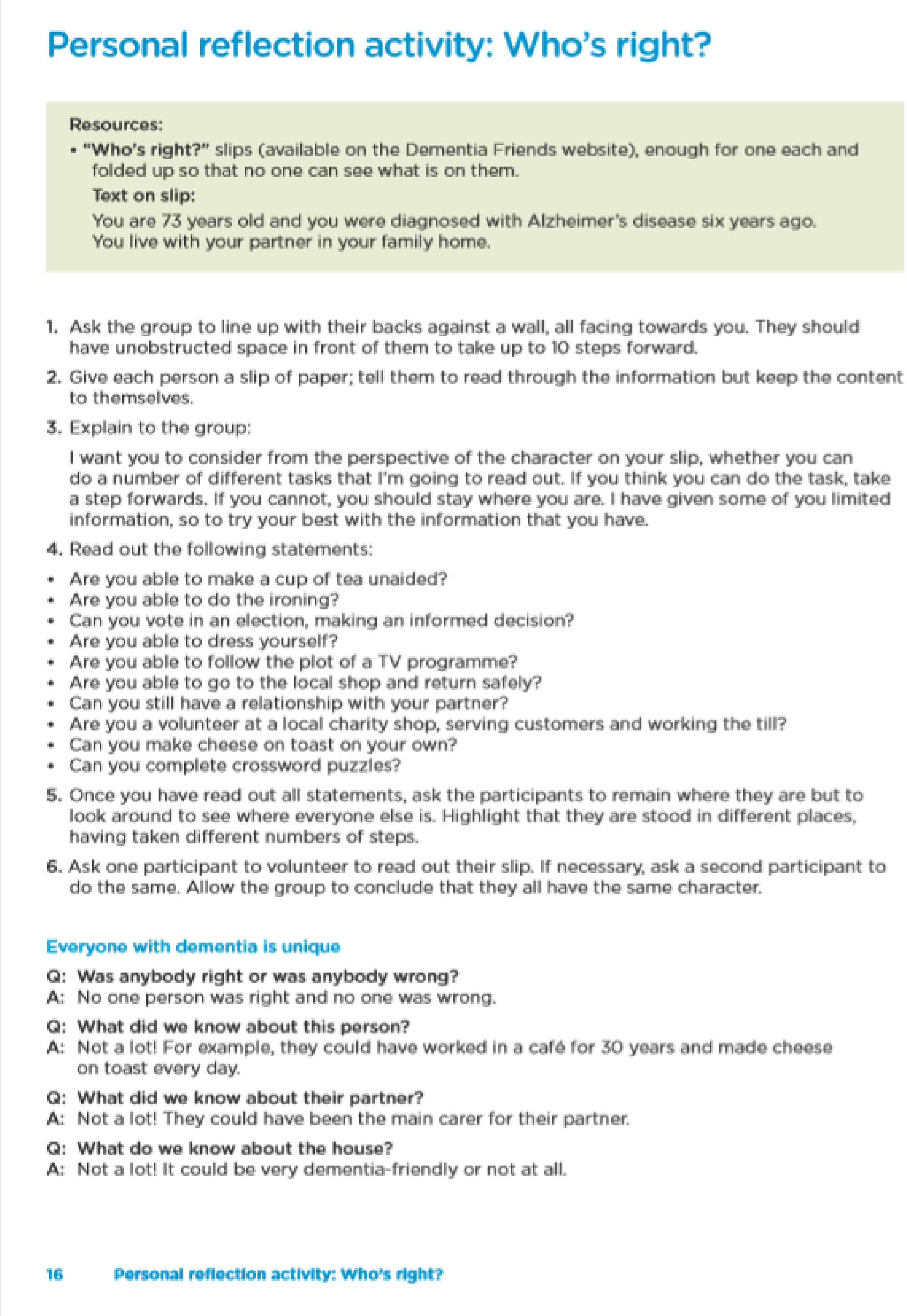
A: Feelings – love, happiness, comfort. (Show on the emotional bookcase.)

I may forget what we did but I know that I feel safe and happy – and that is what matters the most.

This is why we encourage anyone who knows someone with dementia to continue to visit them – there is more to a person than dementia and we can help them to live well.

For more detail, you can find a bookcase analogy video on the Dementia Friends website, on the "Session resources" page.

10.6.5 Personal reflection activity: Who is right?



Personal reflection activity: Who's right?

Resources:

- **"Who's right?"** slips (available on the Dementia Friends website), enough for one each and folded up so that no one can see what is on them.

  Text on slip:

  You are 73 years old and you were diagnosed with Alzheimer's disease six years ago. You live with your partner in your family home.

1. Ask the group to line up with their backs against a wall, all facing towards you. They should have unobstructed space in front of them to take up to 10 steps forward.
2. Give each person a slip of paper; tell them to read through the information but keep the content to themselves.
3. Explain to the group:

   I want you to consider from the perspective of the character on your slip, whether you can do a number of different tasks that I'm going to read out. If you think you can do the task, take a step forwards. If you cannot, you should stay where you are. I have given some of you limited information, so to try your best with the information that you have.
4. Read out the following statements:

- Are you able to make a cup of tea unaided?
- Are you able to do the ironing?
- Can you vote in an election, making an informed decision?
- Are you able to dress yourself?
- Are you able to follow the plot of a TV programme?
- Are you able to go to the local shop and return safely?
- Can you still have a relationship with your partner?
- Are you a volunteer at a local charity shop, serving customers and working the till?
- Can you make cheese on toast on your own?
- Can you complete crossword puzzles?

5. Once you have read out all statements, ask the participants to remain where they are but to look around to see where everyone else is. Highlight that they are stood in different places, having taken different numbers of steps.
6. Ask one participant to volunteer to read out their slip. If necessary, ask a second participant to do the same. Allow the group to conclude that they all have the same character.

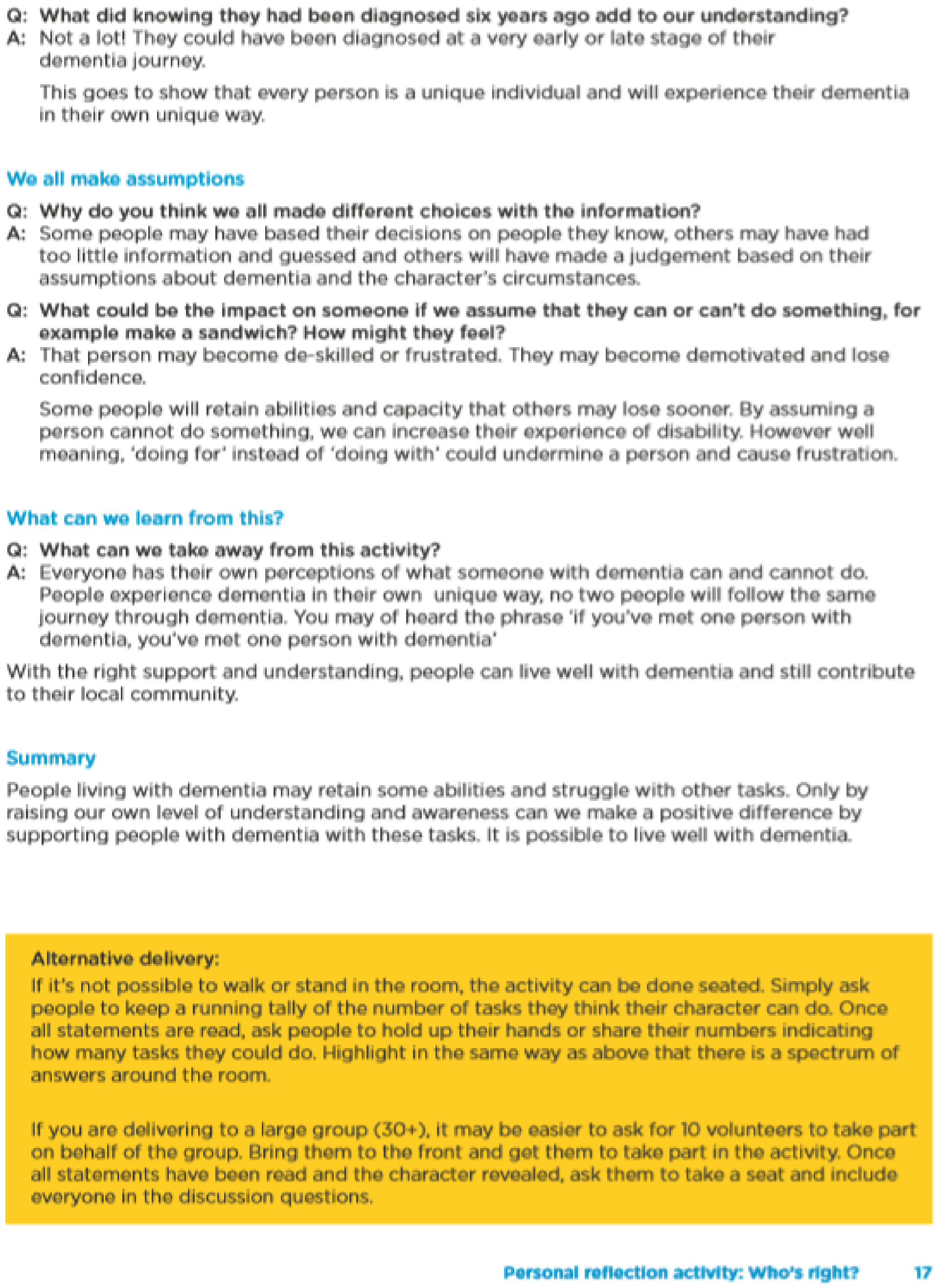
Everyone with dementia is unique

Q: Was anybody right or was anybody wrong?
A: No one person was right and no one was wrong.

Q: What did we know about this person?
A: Not a lot! For example, they could have worked in a café for 30 years and made cheese on toast every day.

Q: What did we know about their partner?
A: Not a lot! They could have been the main carer for their partner.

Q: What do we know about the house?
A: Not a lot! It could be very dementia-friendly or not at all.



Q: What did knowing they had been diagnosed six years ago add to our understanding?
A: Not a lot! They could have been diagnosed at a very early or late stage of their dementia journey.

This goes to show that every person is a unique individual and will experience their dementia in their own unique way.

We all make assumptions

Q: Why do you think we all made different choices with the information?
A: Some people may have based their decisions on people they know, others may have had too little information and guessed and others will have made a judgement based on their assumptions about dementia and the character's circumstances.

Q: What could be the impact on someone if we assume that they can or can't do something, for example make a sandwich? How might they feel?
A: That person may become de-skilled or frustrated. They may become demotivated and lose confidence.

Some people will retain abilities and capacity that others may lose sooner. By assuming a person cannot do something, we can increase their experience of disability. However well meaning, 'doing for' instead of 'doing with' could undermine a person and cause frustration.

What can we learn from this?

Q: What can we take away from this activity?
A: Everyone has their own perceptions of what someone with dementia can and cannot do. People experience dementia in their own unique way, no two people will follow the same journey through dementia. You may of heard the phrase 'if you've met one person with dementia, you've met one person with dementia'

With the right support and understanding, people can live well with dementia and still contribute to their local community.

Summary

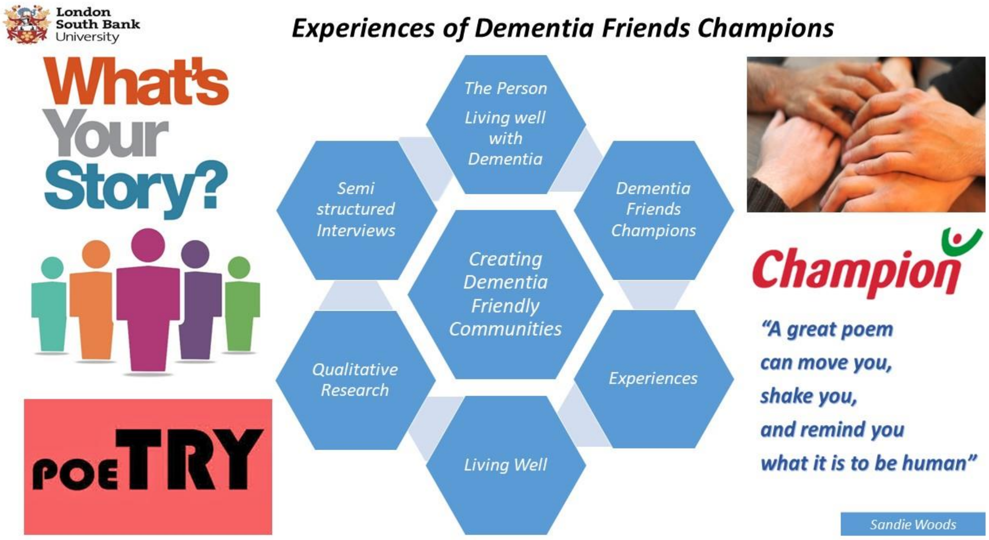
People living with dementia may retain some abilities and struggle with other tasks. Only by raising our own level of understanding and awareness can we make a positive difference by supporting people with dementia with these tasks. It is possible to live well with dementia.

Alternative delivery:
If it's not possible to walk or stand in the room, the activity can be done seated. Simply ask people to keep a running tally of the number of tasks they think their character can do. Once all statements are read, ask people to hold up their hands or share their numbers indicating how many tasks they could do. Highlight in the same way as above that there is a spectrum of answers around the room.

If you are delivering to a large group (30+), it may be easier to ask for 10 volunteers to take part on behalf of the group. Bring them to the front and get them to take part in the activity. Once all statements have been read and the character revealed, ask them to take a seat and include everyone in the discussion questions.

10.7 Conference Posters

10.7.1 Conference poster presentation 1



London South Bank University

Experiences of Dementia Friends Champions

What's Your Story?

poeTRY

The Person Living well with Dementia

Dementia Friends Champions

Experiences

Living Well

Qualitative Research

Semi structured Interviews

Creating Dementia Friendly Communities

Champion

"A great poem
can move you,
shake you,
and remind you
what it is to be human"

Sandie Woods

10.7.2 Conference poster presentation 2

London South Bank University

Explore the lived experience of Dementia Friends Champions: Poetic representation

The research aims to bring an original contribution by exploring the lived experience of volunteer Dementia Friends Champions, to promote social action, develop the dementia friends provision and promote inclusion for individuals living with dementia.

poeTRY

"A great poem
can move you,
shake you,
and remind you
what it is to be human"
(unknown author)

There are 850,000 people with Dementia in the UK, with numbers set to rise to over 1 million by 2025. This will soar to 2 million by 2051 (Alzheimer's Research UK, 2017)

Champion

Dementia Friends Champions (DFC's) are volunteers who deliver information sessions about the impact of dementia with the aim of turning understanding into action (Alzheimer's Society, 2017).

What's Your Story?

More broadly we want a society where the public thinks and feels differently about dementia, where there is less fear, stigma and discrimination; and more understanding (Department of Health, 2015)

Into her past

The present was gone
Drawing me into her past
When she was a teenager
I became her neighbour
In a little village
In the west of Ireland
Sandie Woods

Patience

You don't need to fear
Be patient, listen and care
She has dementia
Sandie Woods

As memories fall away

Just remember this
As memories fall away
What he feels will stay
Sandie Woods

Sandie Woods

References

Alzheimer's Research UK (2017) *Dementia Statistics.* https://www.dementiastatistics.org/statistics-about-dementia/

Alzheimer's Society (2017) *What is a dementia friends champion?* https://www.dementiafriends.org.uk/WEBArticle?page=what-is-a-champion#.WS6j3sa1vIU

Department of Health (2015) *Prime Ministers challenge on dementia 2020.* London: The Stationery Office

10.7.3 Research summer school poster

London
South Bank
University

Explore the lived experience of Dementia Friends Champions: Poetic representation

The research aims to bring an original contribution by exploring the lived experience of volunteer Dementia Friends Champions, to promote social action, develop the dementia friends provision and promote inclusion for individuals living with dementia.

Sandie Woods, London South Bank University,

DeMEntia

The word 'dementia' describes a set of symptoms that may include memory loss and difficulties with thinking, problem-solving or language *(Dementia Friends, 2017)*

There are 850,000 people with Dementia in the UK, with numbers set to rise to over 1 million by 2025. This will soar to 2 million by 2051 *(Alzheimer's Research UK, 2017)*

Eleven Dementia Friends Champions
Qualitative research
Semi-structured interviews
Themes and meanings
Research poetry

Champion

Dementia Friends Champions (DFC's) are volunteers who deliver information sessions about the impact of dementia with the aim of turning understanding into action *(Alzheimer's Society, 2017).*

Lived Experience of Dementia Friends Champions
- Knowledge and understanding
  - People attending had limited knowledge about dementia
  - Fear of dementia
  - Carers seeking support
  - Stigma
- Delivering sessions
  - Storytelling and sharing
  - Effectiveness of resources
  - Multitude of settings
  - Present and future needs
- Experiences and insights
  - Personal experience of dementia
  - Challenges to living well
  - End of life care
  - Changed by the experience
  - Emotional impact
- Being a champion
  - Volunteering
  - Proud
  - Making a difference
  - Encouragement
  - Reflection
  - Enjoyment
  - Support from the region
- Dementia friendly communities
  - Communities that care
  - Influence from the top
  - Challenges of the workplace
  - Future generations
  - Understanding and action

Otherness

Living well or living in hell
It up to you
To act
Let's end the silence
The stigma, the fear
No longer otherness but us
Sandie Woods

Quote: The whole idea of a Dementia Champion giving a session is it is a human being portraying his or her concern for another human being (participant 11, line 567-568)

Into her past

The present was gone
Drawing me into her past
When she was a teenager
I became her neighbour
In a little village
In the west of Ireland
Sandie Woods

As memories fall away

Just remember this
As memories fall away
What he feels will stay
Sandie Woods

Quote: I often say, forget everything else just remember this, emotional memories last and I've got a personal illustration of that you see. But I mean I think it's something I didn't know when I was caring for X and I can look back now on things (participant 2, line 331-334)

Quote: She was at that stage where she couldn't place somebody in the present, so she was bringing them way back into her past (participant 1, line 87-91)

Patience

You don't need to fear
Be patient, listen and care
She has dementia
Sandie Woods

Quote: I think there is a fear, the fear kind of stops people seeking help or fear of you know having a relative that is diagnosed with dementia so I think to reduce that fear I think that would make a big difference for people with dementia (participant 5, line 179-181)

References

Alzheimer's Research UK (2017) *Dementia Statistics.* https://www.dementiastatistics.org/statistics-about-dementia/

Alzheimer's Society (2017) *What is a dementia friends champion?* https://www.dementiafriends.org.uk/WEBArticle?page=what-is-a-champion#.WS6j3sa1viU

Dementia Friends (2017) https://www.dementiafriends.org.uk/WEBArticle?page=what-is-dementia#.Wv28YH8h3IU

10.8 Readers emails about the influence of research poetry

Feedback from article in OT News March 2018
21st March 2018 Hi Sandie I hope that you are well and that all is good at XXX Congratulations on your article for OT News – poetry is so powerful, and this is a really interesting area. Thanks so much for getting this published. Best wishes
21st March 2018 Hi Sandie Hope you don't mind a random email as I was interested to read your piece in the OT news. I'm also interested in the arts for reflection. I did a module of an MA once that used writing fiction and reading it together in a group to discuss themes around practise. It was enlightening and enjoyable process. I wanted to just share that and say I will be looking into some of the people that you mention and trying out the poetry. I wondered if there were any online forums for this process. Working in a group was really beneficial. Kind regards and thanks for sharing your knowledge and experience
29th March 2018 Dear Sandie, I read your article and excellent poems in OT News and felt compelled to write to thank and congratulate you. I have extended my journey from OT to CBT Therapist to Mindfulness, EMDR and ACT practitioner and I often use poetry in therapy and in training. I also write myself as a form of cathartic expression. I find it invaluable. I am looking to publish in this, my 60th year. Thank you for the references which I will follow. Prendergast was my mother's maiden name and I am choosing to see that as a sign from the universe rather than a popular Irish surname! I loved your poems. Haiku is a challenge and I so agree it focuses the mind on essential messages. Many thanks and if you ever think of running a workshop and are looking for participants or collaborators, please look me up! Warm wishes,

10.9 Examples of settings where Dementia Friends sessions were delivered

Businesses
Charities
Care homes
Community centres
Day centres
Faith organisations
Family and friends
Further education colleges
Fire services,
Government office
GP practices
Leisure centres
Libraries
Local government
Health services
Higher education
Hospitals and hospices
Housing services
Pharmacies
Places of worship
Police services
Primary care groups
Security services
Shopping centres
Sports facilities
Voluntary organisations
Women’s guild
Youth groups.